



# NHPCO Pediatric Facts and Figures

## 2023 EDITION

*Published June 2023*



# Table of Contents

Please see the **Data Sources Section** at the end of this report for details on the data sources used within this publication.

<b>Section 1: Introduction</b>	<b>1</b>	■ Private Insurance	11
■ About this Report	1	■ TRICARE	11
■ What is hospice care?	1	■ Other Mechanisms	12
■ What is palliative care?	2		
■ What is concurrent care?	3	<b>Section 5: Who Provides Care?</b>	<b>13</b>
■ How does pediatric care differ from adult care?	3	■ How many hospices are operational?	13
■ Transitions of Care	4	■ How many pediatric palliative care serves are operational?	13
■ Location of Care	4	■ What is the pediatric hospice service size?	14
■ Levels of Care	4	■ Who are the providers?	15
■ Volunteer Services	5		
■ Bereavement Services	5	<b>Section 6: What Services are Provided?</b>	<b>16</b>
		■ What types of services are provided?	16
<b>Section 2: Who Receives Pediatric Hospice and Palliative Care?</b>	<b>6</b>	■ What alternate therapies are provided?	16
■ What are the characteristics of patients who received hospice care?	6		
■ What age groups are served?	6	<b>Section 7: What are the Barriers and Facilitators to Care?</b>	<b>17</b>
■ What conditions are most commonly referred to hospice and palliative care?	7	■ Barriers	17
■ Where are patients referred from?	8	■ Facilitators	18
		■ What can we do to address barriers and facilitators?	18
<b>Section 3: Where are Services Provided and Accessible?</b>	<b>9</b>		
■ Location of Care	9	<b>References</b>	<b>19</b>
		<b>Data &amp; Methodology</b>	<b>22</b>
<b>Section 4: How is Care Reimbursed?</b>	<b>10</b>	<b>Acknowledgment</b>	<b>22</b>
■ How Much Does Pediatric Hospice and Palliative Care Cost?	10		
■ Who Pays for Pediatric Hospice and Palliative Care?	10		
■ Medicaid and CHIP	10		





# Section 1: Introduction

## About this Report

NHPCO Pediatric Facts and Figures provides an overview of pediatric hospice and palliative care in the United States. This overview provides specific information on:

- Pediatric hospice and palliative care patient characteristics
- Location and access to care
- Care reimbursement
- Provider characteristics
- Barrier and facilitators to care
- Specialty issues for kids
- Gaps in services

Pediatric palliative and hospice care (PP/HC) focuses on enhancing quality of life for the child and family, preventing and minimizing suffering, optimizing function, and providing opportunities for personal and spiritual growth. Pediatric care includes perinatal period, infancy, childhood, adolescence, and young adulthood.

## Definitions:<sup>1</sup>

**Perinatal:** before birth

**Neonatal:** birth to 1 month

**Infancy:** 1 month to one year of age

**Childhood:** age 1 to 12

**Adolescence:** ages 13 to 17

**Young adulthood:** age 18 years and over

*In this report, the term "living with a serious illness" is applied to define complex, chronic, and critical conditions which meet qualifying definitions for palliative and hospice care support.*

## What is hospice care?

According to the National Consensus Project for Quality Palliative Care,<sup>2</sup> "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." Considered the model for quality

## Introduction (continued)

compassionate care for people facing the last months of living with a serious illness, hospice provides care and support tailored to the patient's needs and wishes. Support is provided to the patient's family as well.

Hospice focuses on caring, not curing. In most cases, care is provided in the patient's private residence, but may also be provided in freestanding hospice facilities, hospitals, nursing homes, or other long-term care facilities. Hospice services are available to patients living with a serious illness with a six-month prognosis. 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.

For children, hospice is usually covered by Medicaid or private insurance. In most states, eligibility criteria require a six-month prognosis. Although adults must forego any curative or life-extending treatment when electing hospice, children are eligible for concurrent care.

### What is palliative care?

The World Health Organization defines palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with serious illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual."<sup>3</sup> The National Hospice and Palliative Care Organization defines palliative care as, "palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering."<sup>4</sup> Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice." Palliative care can be provided concurrently with life-prolonging care, curative care, or as the focus of care.

The National Consensus Project for Quality Palliative Care,<sup>4</sup> and NHPCO lists the following as precepts of palliative care:

- Appropriate at any stage in a serious illness, and it is beneficial when provided along with treatments of curative or life-prolonging intent
- 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

### Core Commitments of PP/HC

The American Academy of Pediatrics released a policy statement on PP/HC in 2013 that still holds today.<sup>6</sup>

1. Being patient-centered and family engaged
2. Respecting and partnering with patients and families
3. Pursuing care that is high quality, readily accessible, and equitable
4. Providing care across the age spectrum and life span, integrated into the continuum of care
5. Ensuring that all clinicians can provide basic palliative care and consult PP/HC specialists in a timely manner
6. Improving care through research and quality improvement efforts



## Introduction (continued)

### What is concurrent care?

"The primary goal of concurrent hospice care is enabling pediatric patients with life expectancies of six months or less to transition more smoothly to care focused on comfort and quality of life."<sup>5</sup> The Patient Protection and Affordable Care Act (ACA) entitled children enrolled in Medicaid or Children's Health Insurance Program (CHIP) and living with a serious illness to continue to receive curative or palliative treatment along with hospice care, avoiding the impossible choice between life-prolonging and hospice care.

Prior to the ACA, both children and adults had to have (1) a six-month prognosis and (2) forego any life-prolonging or curative treatments to enroll in hospice. With concurrent care, pediatric patients must still meet the six-month prognosis, but they no longer must choose care that may extend their life and hospice.<sup>5</sup> Current care treatments are any therapies, medications, equipment, or modalities related to the serious illness related to the child's serious health condition.

### How does pediatric care differ from adult care?

Children with palliative and hospice needs range in age from prenatal to young adult. In most states, the Medicaid definition of children is prenatal to 21 years. With the innovations in medical technology and treatments, many children with serious and complex medical conditions are living much longer than expected. Additionally, as noted in the NHPCO's Facts and Figures Pediatric Palliative & Hospice Care in America,<sup>7</sup> "some adults over the age of 21 are still considered part of this population because they have conditions monitored by pediatric subspecialists or have developmental and/or physical challenges that are better served by pediatricians."

Differences between pediatric and adult care can be from several different perspectives, including:

- Types of diagnoses
- Trajectories of illness
- Funding mechanisms
- Educational needs
- Ethical concerns
- Communication strategies
- Staffing management
- Care Coordination<sup>8,9</sup>
- Circle of Care include definition of family, community, degree of impact
- Lack of autonomy for hospice agency
- Prognostic uncertainty
- Complexity of collaboration with child's broader medical team<sup>8,9</sup>

The differences between adult and pediatric care are significant and can be challenging. The size of a child's community is much greater, conditions can be much more complex and often providers have not cared for anyone with a similar pediatric condition. Although the number of children with life-limiting conditions is increasing, the number of children who could benefit from PP/HC remains low. This may mean PP/HC providers may only serve one to five children per year in certain areas, while others may have a census in the hundreds.

# Introduction (continued)

PP/HC teams must be able to care for children with a wide range of diagnoses and often, unknown disease trajectories. With the advent of concurrent care, children's care differs from adult care in the ability to continue curative care while enrolled in hospice.

## Transitions of Care

Transitions is defined as "the process or a period of changing from one state or condition to another."<sup>10</sup> In pediatrics, this can mean changes due to the following:

- Maturation, such as prenatal, neonatal, early childhood, school age, adolescent, to young adult
- Changes in care providers such as inpatient, outpatient, pediatric to adult
- Differences in healthcare and payment systems
- Legal complexities as the child becomes a legal adult

Transitioning from pediatric to adult providers can be challenging and stressful. As mentioned above, many of these children are living much longer than they have in the past, often with medical conditions and complexities adult providers have never dealt with. Adding to this, children often have been living with these conditions since birth, have been with their providers for years if not decades, and have strong relationships with their providers. Transitioning to adult providers can engender a sense of loss and fear of the unknown.

## Location of Care

For both palliative and hospice, care can be provided wherever the patient and family call home. This can include:

- Private residence
- Group home
- Foster home
- Long-term or sub-acute care facility
- Respite facility
- Acute care facility

## Levels of Care

Hospice patients may require differing intensities of care during the course of their illness. While hospice patients may be admitted at any level of care, changes in their status may require a change in their level of care.

The Medicare Hospice Benefit affords patients four levels of care to meet their clinical needs: Routine Home Care, Continuous Home Care, Inpatient Respite Care, and General Inpatient Care. Payment for each covers all aspects of the patient's care related to terminal illness, including all services delivered by the interdisciplinary team, medication, medical equipment, and supplies.

- **Routine Home Care (RHC)** is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.
- **Continuous Home Care (CHC)** is care provided for between eight and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services, and intended to maintain the terminally ill patient at home during a pain or symptom crisis.
- **Inpatient Respite Care (IRC)** is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long-term care facility with enough 24-hour nursing personnel present.
- **General Inpatient Care (GIP)** is provided for pain control or other acute symptom management and is not feasible to be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility with a registered nursing available 24 hours a day to provide direct patient care.

Although most pediatric hospice care is funded through Medicaid and some private insurances, most will follow the Medicare/





## Introduction (continued)

Medicaid guidelines.<sup>5</sup> However, each state's guidelines and regulations pertaining to palliative and hospice care for children may be different.

### Volunteer Services

The U.S. hospice movement was founded by volunteers who continue to play an important and valuable role in hospice care and operations. Although pediatric programs generally do not require volunteers as adult programs do, many pediatric palliative and hospice providers rely on volunteer services to provide additional services and experiences for their patients and families. Volunteers add additional support either directly to the patient and family or indirectly allowing the care team to spend more time with their patients and their families.

Hospice volunteers provide service in three general areas:

- Spending time with patients and families (direct support)
- Providing clerical and other services that support patient care and clinical services (clinical support)
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a board of directors (general support)

### Bereavement Services

Counseling or grief support for the patient and family is an essential part of hospice care. After the patient's death, bereavement support is offered to families. These services can take a variety of forms including telephone calls, visits, written materials about grieving, phone or video calls, and support groups. Individual counseling may be offered by the hospice, or the hospice may make a referral to a community resource.

Some hospices also provide bereavement services to the community as a whole, in addition to supporting patients and their families. In PP/HC, bereavement support may start with anticipatory guidance from the time of diagnosis to after death bereavement support for the family. Many pediatric providers do not limit bereavement support but allow families to access supportive services whenever needed.

*\*See appendix for details on methodology and data sources, including cited references within the report.*

# Section 2: Who Receives Pediatric Hospice and Palliative Care?

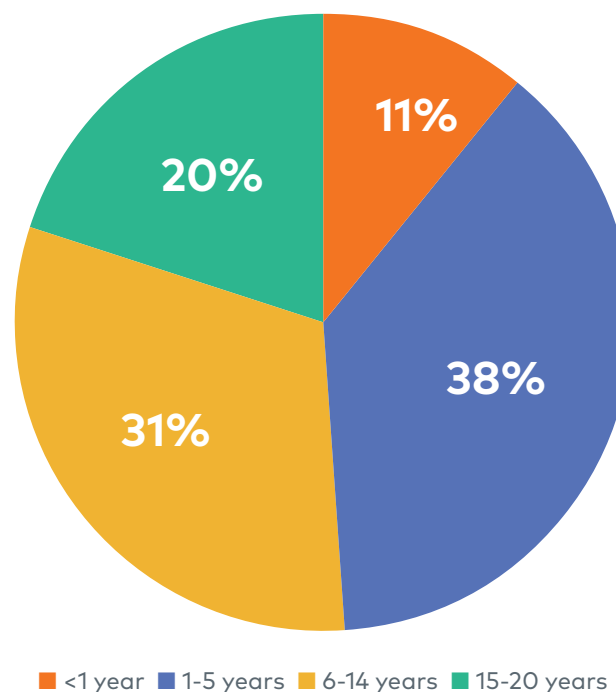
## What are the characteristics of patients who received hospice care?

National data regarding demographics such as gender, race, and ethnicity are incomplete and warrant further characterization. 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.<sup>10</sup> Furthermore, children and young adults often have shorter lengths of stay in hospice compared to adults. Length of admission is related to multiple factors including prognostic uncertainty, continued ability to pursue life prolonging, and continued access to curative interventions.

## What age groups are served?

Pediatric hospice and palliative care serves a broad variety of ages. Children and young adults who have met eligibility criteria have benefitted 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. It is important to note that at the age of 21, individuals are no longer entitled to concurrent care hospice as the Patient Protection and Affordable Care Act (ACA) mandates this for those under the age of 21 with Medicaid or Children's Health Insurance Program (CHIP).

Figure 1: Percent of pediatric hospice and palliative care providers caring for each age group





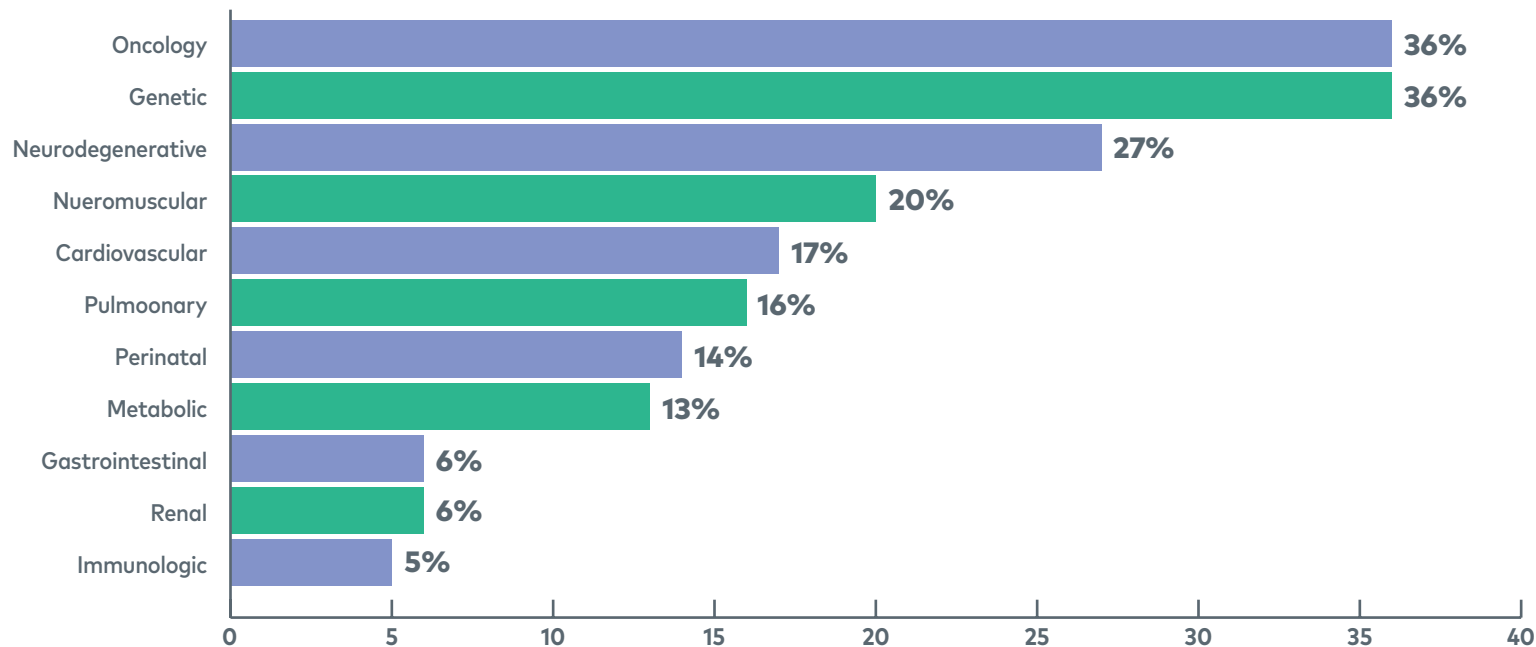
# Who Receives Pediatric Hospice and Palliative Care? (continued)

## What conditions are most commonly referred to hospice and palliative care?

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.<sup>5,12</sup> 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 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.<sup>13,14</sup>

Prior to the ACA, continuation of life sustaining interventions was a barrier to pediatric enrollment in hospice, especially for CMC. With implementation of the ACA requirement, 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 is less defined. 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.<sup>15</sup>

**Figure 2: Pediatric conditions commonly referred to pediatric hospice and palliative care.**



# Who Receives Pediatric Hospice and Palliative Care? (continued)

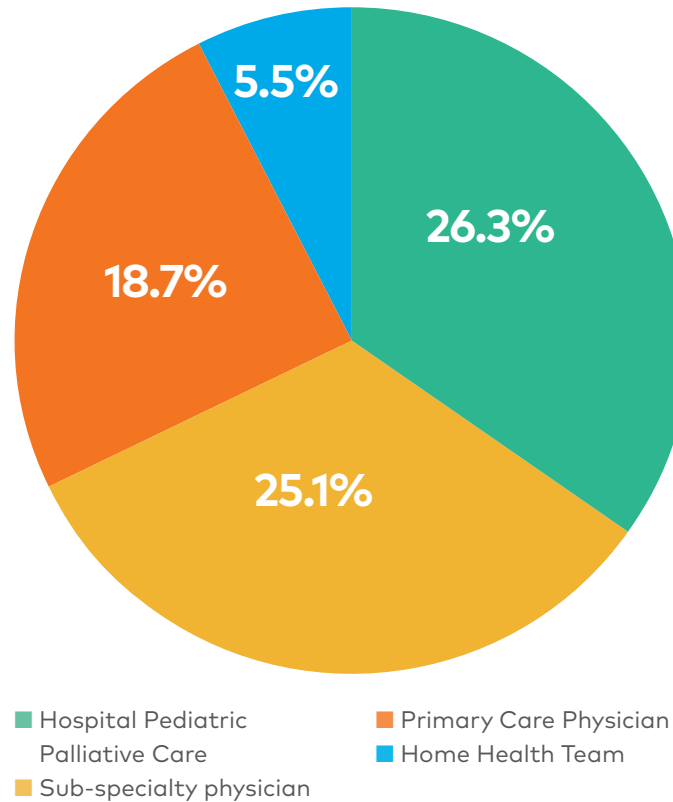
## Where are patients referred from?

Common referral sources include consultative pediatric palliative care teams, sub-specialty clinics, and other clinicians who see children with serious life limiting conditions. Referrals are commonly placed upon discharge from the acute or ambulatory settings. Specific data on clinical context of source of referral are poorly characterized. One study looking at inpatient PPC showed 45% of patients seen by the inpatient pediatric palliative care in one year were referred to home based palliative care or hospice.<sup>16</sup>

Based on the 2020 NHPCO Pediatric Needs Assessment:

- 6.3% of referrals came from a hospital pediatric palliative care team
- 25.1% of referrals come from a sub-specialty physician
- 18.7% of referrals come from a primary care physician
- 5.5% of referrals come from a home health team

Figure 3: Breakdown of referral sources



# Section 3: Where are Services Provided and Accessible?

## Location of Care

Pediatric hospice and palliative care are provided throughout the U.S. with variation by type of care (home based hospice, home based palliative, inpatient based hospice, inpatient palliative care) and the type of county (non-metropolitan, metropolitan).

- Pediatric home based hospice care was provided in 895 counties (430 non-metro, 465 metro)
- Pediatric home based palliative care was provided in 591 counties (243 non-metro, 348 metro)
- Pediatric inpatient based hospice care was provided in 670 counties (352 non-metro, 318 metro)
- Pediatric inpatient based palliative care was provided in 580 counties (312 non-metro, 268 metro)
- Pediatric home based hospice care was provided in 21.8% of non-metro counties v. 39.8% of metro counties
- Pediatric home based palliative care was provided in 12.3% of non-metro counties v. 29.8% of metro counties
- Pediatric inpatient based hospice care was provided in 17.8% of non-metro counties v. 27.2% of metro counties
- Pediatric inpatient based palliative care was provided in 15.8% of non-metro counties v. 23.0% of metro counties

Based on the 2020 NHPCO Pediatric Needs Assessment, a large majority of counties do not have access to any of these pediatric services with 71.5% of counties without access to home based hospice care, 81.2% without home based palliative care, 78.7% without inpatient-based hospice care, and 81.5% inpatient based palliative care.

Figure 4: Counties with pediatrics home services in the United States

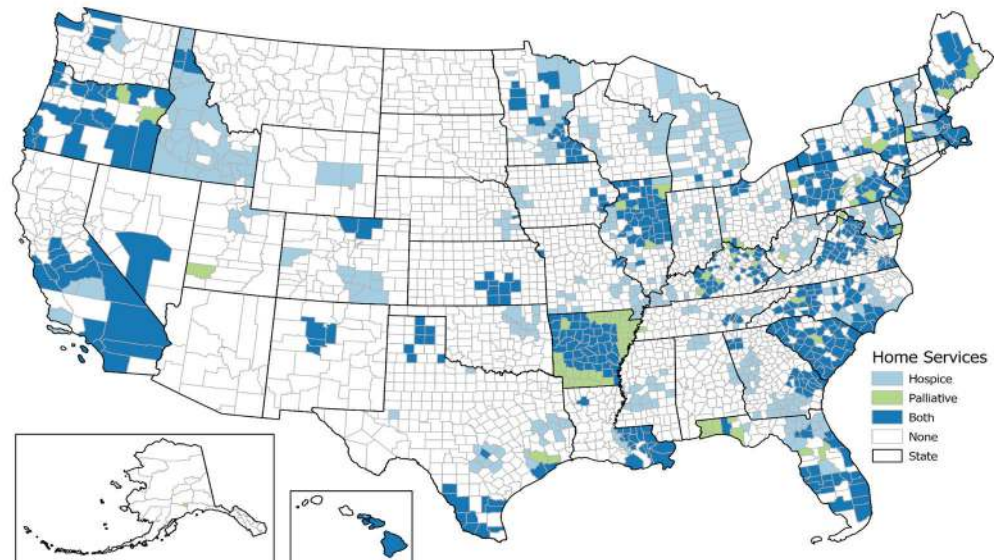


Figure 5: Location of care by county type (count)

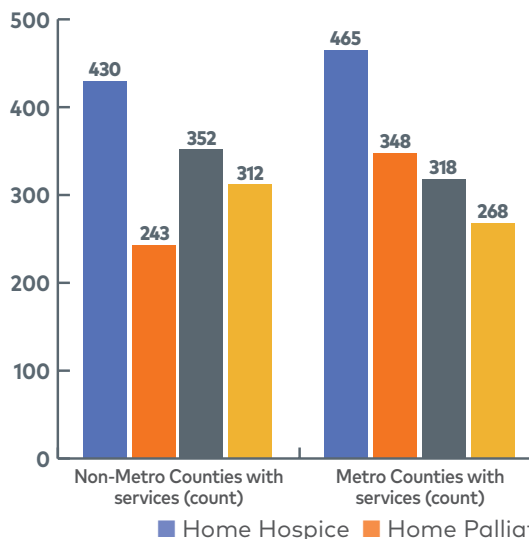
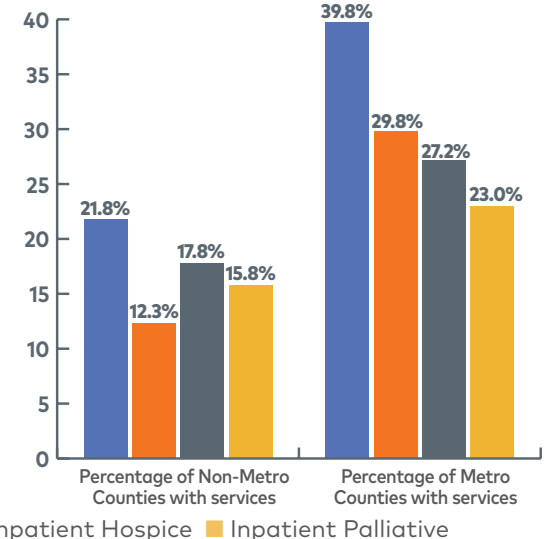


Figure 6: Location of care by county type (percentage)



Source: NHPCO Needs Assessment. \*Metropolitan areas are based on the Office of Management and Budget (OMB) delineation as of February 2013.

# Section 4: How is Care Reimbursed?

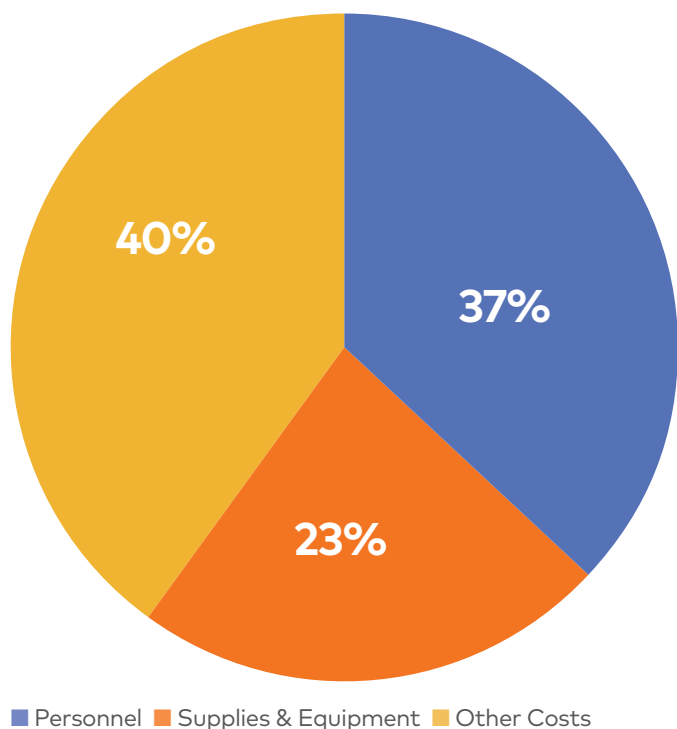
## How Much Does Pediatric Hospice and Palliative Care Cost?

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.<sup>17</sup>

Hospice and palliative care costs vary<sup>18,19</sup>

- Pediatric hospice care: \$54,540 per year
- Pediatric concurrent hospice care: \$76,452 per year
- Pediatric palliative care \$121,111 per year

**Figure 7: Distribution of pediatric hospice costs per day<sup>20,21</sup>**



## 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.<sup>22, 27</sup>

### 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).<sup>28</sup>

**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.<sup>29</sup>

**Concurrent Care.** The Concurrent Care for Children benefit is available for all eligible Medicaid and CHIP beneficiaries (i.e., under 21 years old with six months to live 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.

**Palliative Care.** Inpatient and community-based pediatric palliative care payment is limited under state Medicaid and CHIP plans.



# How is Care Reimbursed? (continued)

## Private Insurance

Less than half of children are covered by private insurance.<sup>12,24</sup> The most common plan types are Preferred Provider Organizations (PPO) (49%) and Point of Service Plans (POS) (37%).<sup>12</sup>

**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. Aetna is the exception.<sup>25</sup> Concurrent hospice care is paid by private insurance companies on a case-by-case basis.

**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.<sup>26</sup>

**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.<sup>26, 27</sup> 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 pediatric palliative care services.

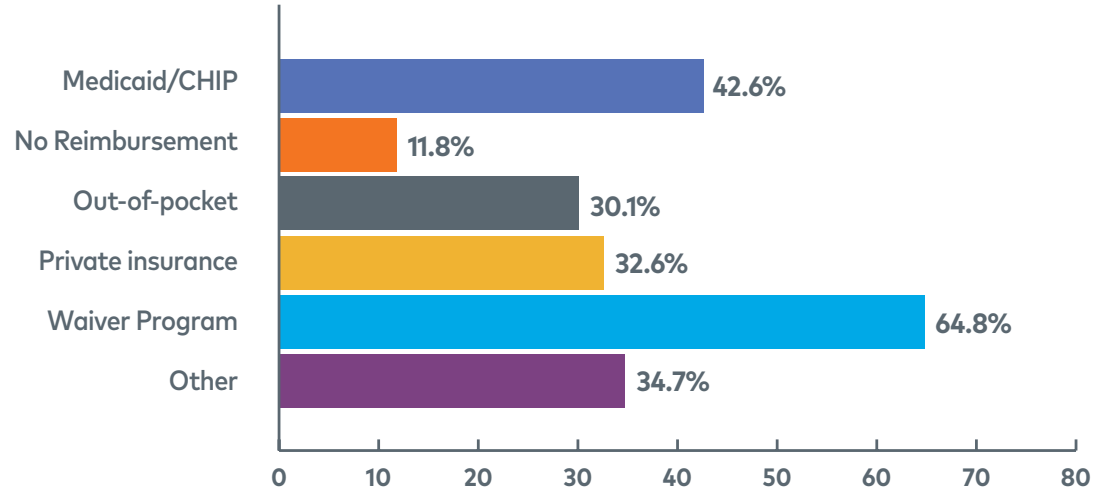
# How is Care Reimbursed? (continued)

## Other Mechanisms

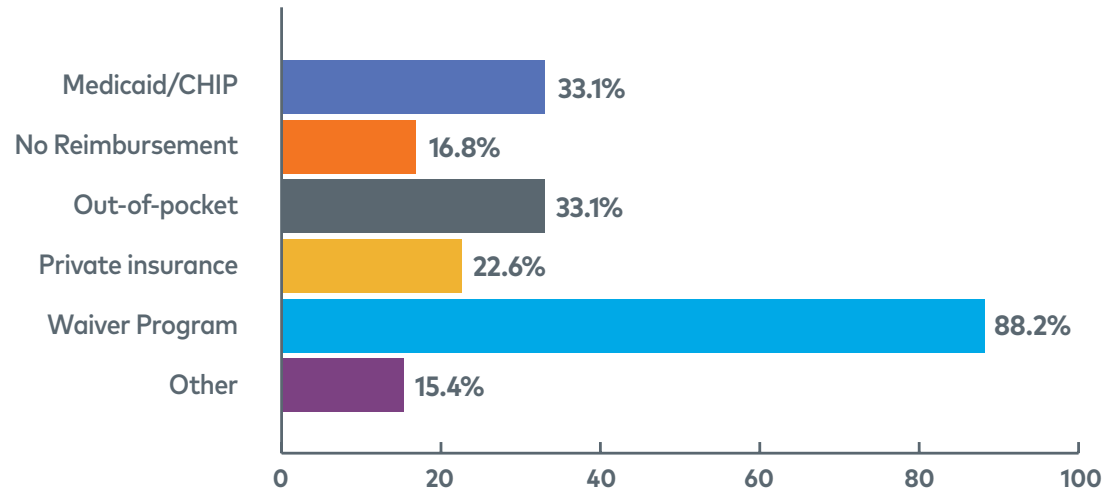
Other organizational, Federal, and State mechanisms are used to pay for pediatric hospice, concurrent, and palliative care, this includes<sup>14, 18, 20, 30</sup>

- Philanthropic support (e.g., donations, gifts, write-offs)
- 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

**Figure 8: Common sources of reimbursement for pediatric hospice care**



**Figure 9: Common sources of reimbursement for pediatric palliative care**



# Section 5: Who Provides Care?

## How many hospices are operational?

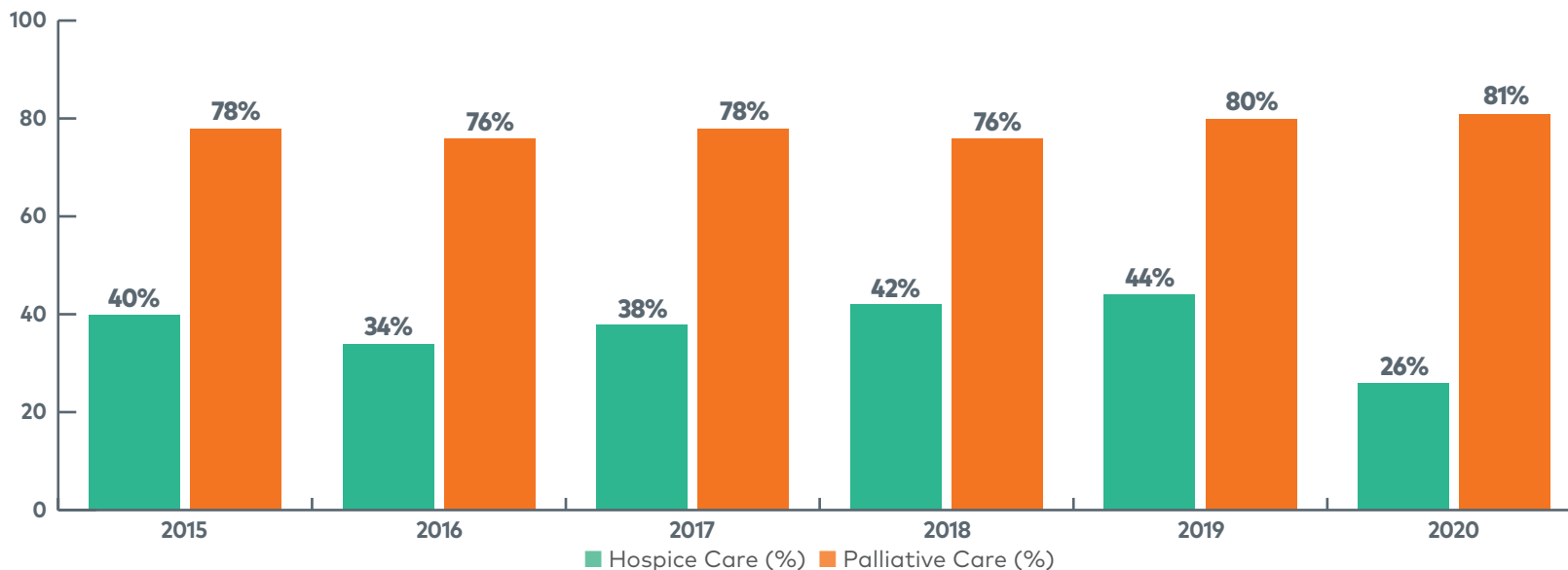
Utilization of hospice care by children has increased over the past decade in the U.S., most notably from 2014-2015.<sup>31</sup> Even with this increase, over half of children's hospitals listed within the Children's Hospital Association registry in 2020 reported not having access to hospice services for children (n=82/148, 55%).<sup>32</sup> It is estimated less than 30% of children eligible to receive hospice services in the U.S. receive hospice services, and those who do obtain services receive hospice care primarily through adult-focused hospice organizations.<sup>33,34</sup> Families most often rely on adult-trained hospice teams in urban and suburban areas.<sup>35,36</sup>

In 2020, pediatric services provided by organizations include home-based pediatric hospice (57%), home-based palliative care (31%), inpatient pediatric hospice (23%), and inpatient pediatric palliative care (14%).

## How many pediatric palliative care services are operational?

Of 148 children's hospitals in the 2020 Children's Hospital Association registry, 119 (80%) reported having a pediatric palliative care program (PPC).<sup>32</sup> Larger, academically-affiliated, higher acuity, free-standing children's hospitals were more likely to report the presence of a PPC program.<sup>32</sup> PPC program expansion and reach plateaued from 2015 to 2020 with minimal program growth.<sup>31,35</sup> Only a quarter of the pediatric oncology centers in the U.S. offer pediatric patients referrals to community-based palliative care.<sup>36</sup>

**Figure 10: Percentage of free-standing children's hospitals in the United States with access to services.**



**Figure 10.** The percentage of survey respondents from free-standing children's hospitals in the United States reporting access to palliative care service enrollment (orange) or hospice service enrollment (green). The survey was completed annually between 2015 to 2020 (n=147 in 2015, 150 in 2016, 155 in 2017, 159 in 2018, 151 in 2019, and 149 in 2020) with response rate 69%. All fifty states and the District of Columbia were represented in the annual survey responses. Note that fewer than half of all free-standing children's hospitals in the United States depict access to a hospice enrollment for children being discharged from the hospital. The palliative service representation is inclusive of the sub-specialty palliative care team present at the children's hospital and/or community-based.

# Who Provides Care? (continued)

## What is the pediatric hospice service size?

Based on the 2020 NHPCO Pediatric Needs Assessment, the daily census for a pediatric palliative and hospice care were small:

- Daily average hospice censuses – 4.6 patients (median 2)
- Daily average palliative censuses – 12.7 patients
- Annual average hospice census – 16.5 patients (median 6)
- Annual average palliative census – 36 patients

Average length of services (days) - Hospice service duration for children and adolescents was reported as median 90 days (average 146.6 days). Median pediatric palliative care service duration was reported at 0 days (average 215.1 days).

Figure 11: Pediatric hospice and palliative care service size

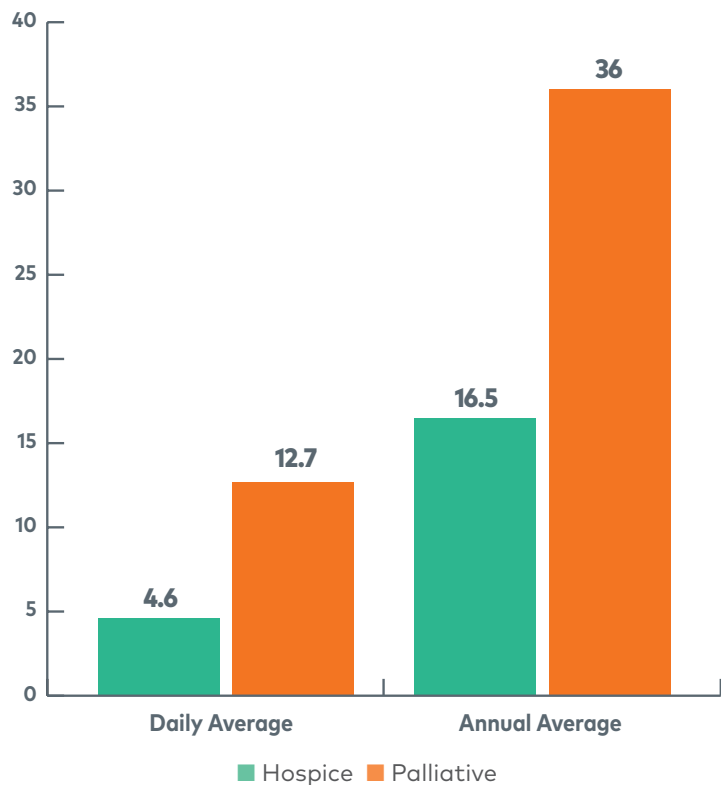
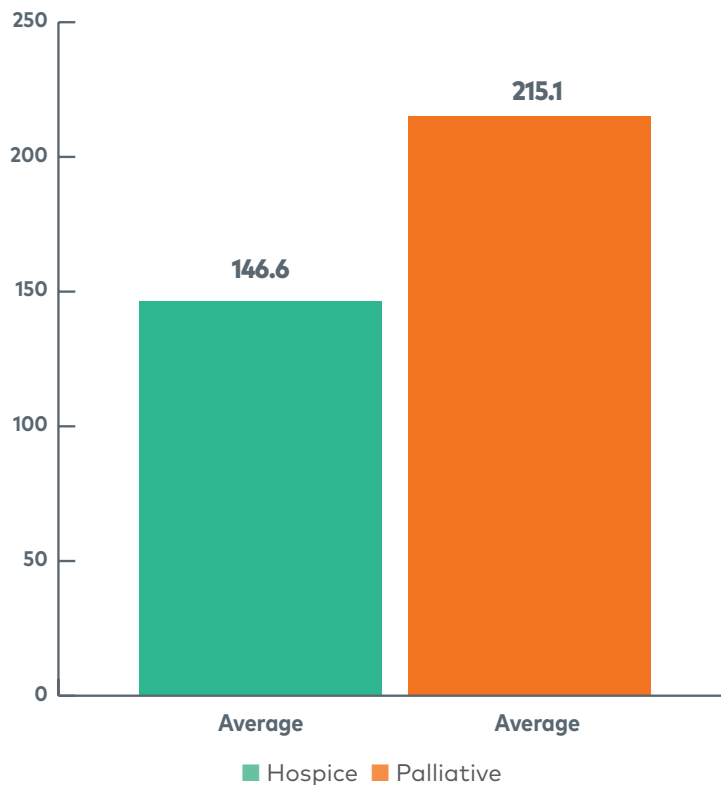


Figure 12: Length of services





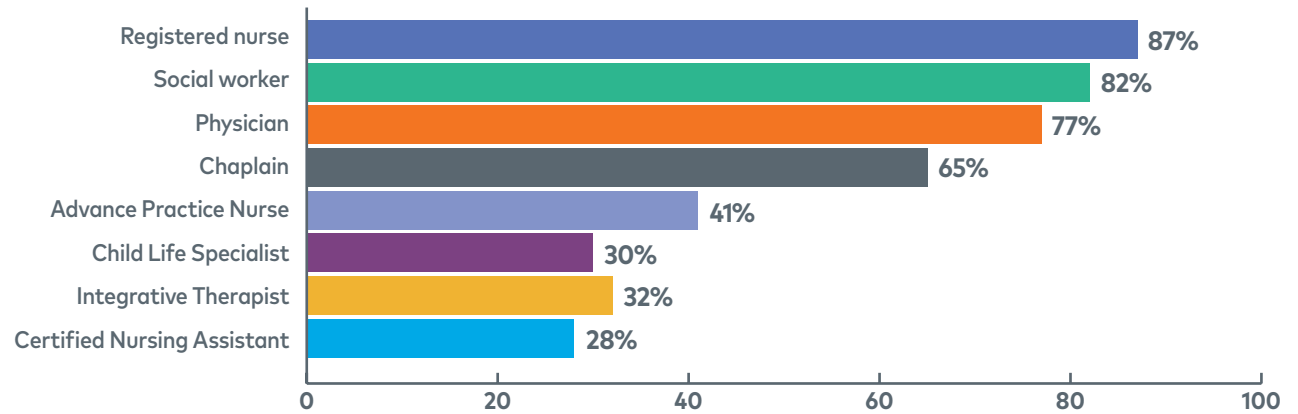
# Who Provides Care? (continued)

## Who are the providers?

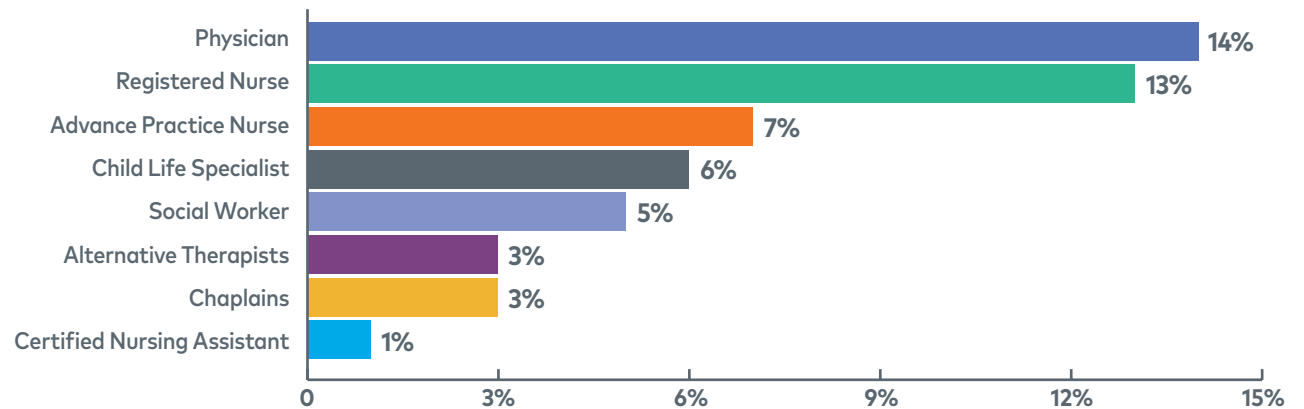
Less than half (48%) of organizations who responded to the 2020 Needs Assessment have a dedicated pediatric team. For those 118 responding organizations with staff dedicated to pediatrics, the team consists of a registered nurse (87%), social worker (82%), physician (77%), chaplain (65%), advance practice nurse (41%), child life specialist (30%), integrative therapist (32%), and certified nursing assistant (28%). To staff pediatric-specific teams, almost half (46%) of responding organizations contract out roles.

There is a wide-spread shortage of trained, pediatric palliative and hospice healthcare professionals.<sup>37</sup> Among team members on adult hospice staff with certifications in pediatrics include: physicians (14%), registered nurses (13%), advance practice nurses (7%), child life specialists (6%), social workers (5%), alternative therapists (3%), chaplains (3%), and certified nursing assistants (<1%).

**Figure 13: Percentage of organizations with member of interdisciplinary team dedicated to pediatrics**



**Figure 14: Percentage of adult hospice staff with certification in pediatrics**



# Section 6: What Services are Provided?

## What types of services are provided?

For palliative and hospice care, many of the services provided are the same. The need for and intensity of those services and interventions will vary depending on the needs of the child. For both palliative and hospice care, quality of life as defined by the patient and family is the hallmark of quality care. Care is provided by collaborative efforts with the child, family, and interdisciplinary team. Ideally, interdisciplinary team members have training and expertise in pediatric palliative and hospice care or have access to specialists in pediatric palliative and hospice care.

Services include care management, pain and symptom management, psychosocial support, spiritual and practical support. Beginning with diagnosis to after death bereavement support, palliative and hospice care focuses on meeting the unique needs of each child and family, assisting with education for informed decision-making, identifying goals of care, and assisting with care coordination by facilitating communication between all care providers. At all times, palliative and hospice care must remain sensitive to the personal, cultural, religious, and spiritual values and beliefs of all involved – including the child.

## What alternate therapies are provided?

As with adult hospice, each hospice and palliative care provider may offer alternate or supportive therapies to assist their patients and families. The most common supportive pediatric therapies include pet, play, and music therapies. Other therapies include massage, reiki, acupressure, and other integrative therapies. For children, these supportive therapies may be covered under the state's Early and Periodic Screening, Diagnostic, and Treatment (EPDST) or waiver programs, if not covered by the Medicaid or private insurance palliative or hospice benefit.

Figure 15: Services provided through pediatric hospice and palliative care

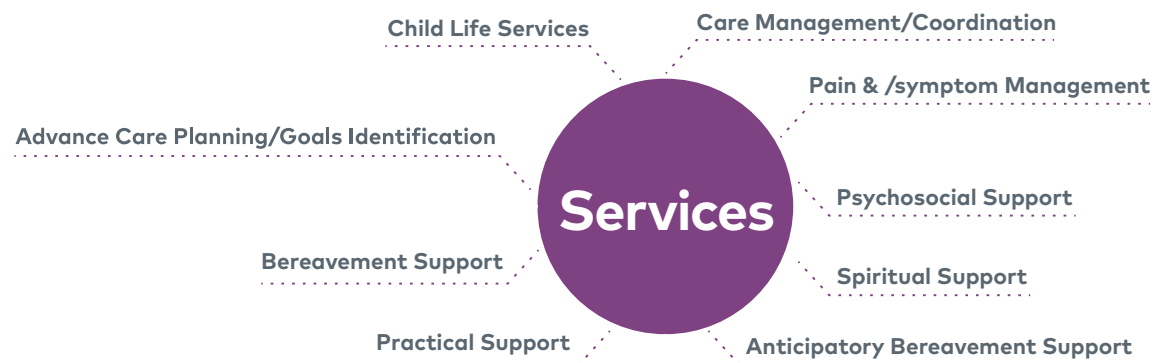
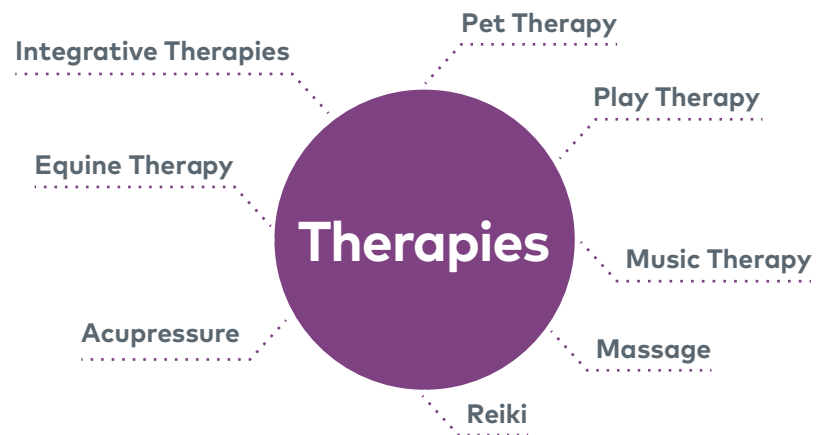


Figure 16: Therapies provided through pediatric hospice and palliative care



# Section 7: What are the Barriers and Facilitators to Care?

In the 2020 NHPCO Pediatric Needs Assessment, hospices cited multiple barriers and challenges to accepting pediatric patients. These included financial concerns related to reimbursement, lower patient referrals leading to prioritization of higher volume programs, inadequate training and education, and overall lack of confidence in caring for children.<sup>16</sup> Common threads for both adult and pediatric groups include financial, education/training needs, and attitudinal factors.

As we examine the state of service, the questions remain, what are the current barriers to providing pediatric care and what are the current facilitators? In this section, we will review what we know, comparing adult literature to the pediatric realm when possible and will conclude with suggestions for further increasing access.

## Barriers

- Poor communication
- Minority status
- Medicaid insurance
- Geography
- Pediatric trained staff
- Misunderstanding of pediatric hospice and palliative care
- Pediatric prognosis
- Financing care
- Lack of resources
- Larger organizations

## Facilitators

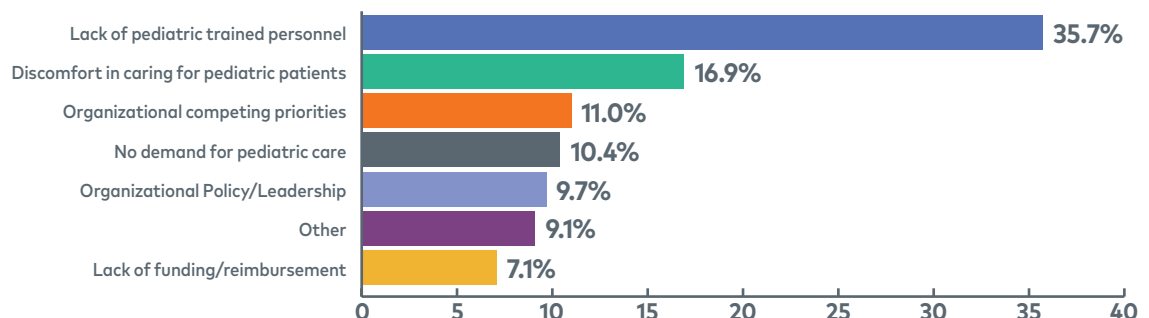
- Social workers, case managers, and child life specialists
- Palliative care
- Pediatric-focused community resources
- State and Federal pediatric policies
- Larger organizations
- Organizations with strong finances
- Organizations with large service area
- Pediatric champions

## Barriers

In the adult population, some barriers noted include poor communication with providers, minority status, rural geographic location, and fee for service insurance.<sup>38</sup> A qualitative study examined the perceptions of nurses and physicians in the emergency department (ED) regarding barriers and facilitators to home and community services for older adults.<sup>39</sup> The facilitators were noted to be personnel (social workers and case managers), and helpful services such as visiting nursing services and hospice. Barriers included insurance/payment, busy nature of the ED, services not available full time to receive referrals.<sup>39</sup> A study examining barriers and facilitators in rural Indiana revealed geographical barriers, along with common barriers such as misunderstandings of palliative care, lack of trained providers, financial barriers and attitudinal barriers.<sup>40</sup> In a scoping review of end-of-life care for elderly adults, barriers to end of life care included poor communication, difficulty in prognostication, poor acceptance of prognosis, and curative focus.<sup>41</sup>

The existing evidence for pediatric palliative care barriers and facilitators is sparse. In a regional survey of pediatric hospice and palliative care services conducted in the northwest U.S., the primary barriers identified included lack of trained staff, access to home infusions, and financial support.<sup>42</sup> A similar regional survey of hospice nurses in the south had similar findings.<sup>37</sup> A qualitative study examined barriers to pediatric palliative care identified individual attitudes towards palliative care, physician personalities and “emotional burden of providing” end of life care and fear of death. Organizational factors are both barriers and facilitators, such as management and lack of resources. Organizational facilitators included a palliative care center in the hospital, external resources, and resource management. Individual facilitators were identified as initiative, dedication and commitment and a sense of meaning. Of note, the provider facilitators had a buffering effect on the organizational barriers, thus highlighting the importance of provider champions.<sup>43</sup>

**Figure 17: Barriers and challenges identified by providers**



# What are the Barriers and Facilitators to Care? (continued)

## Facilitators

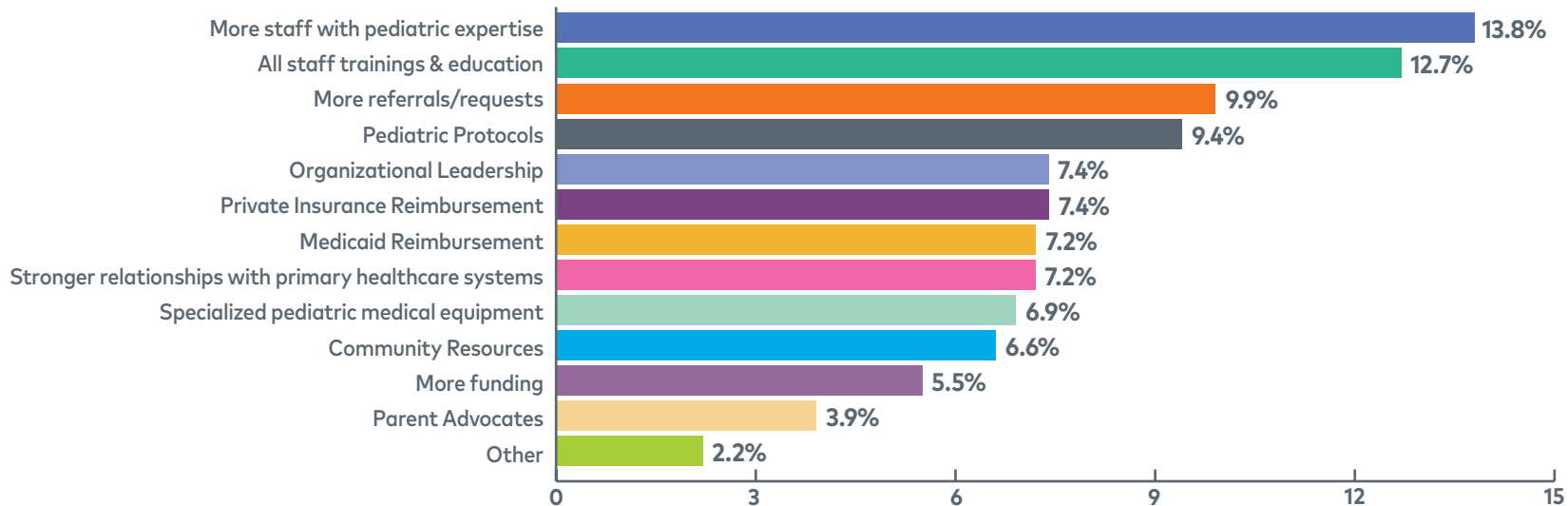
In the 2020 NHPCO Needs Assessment, multiple hospice facilitators enable the expansion of pediatric services. Larger, financially stable organizations with strong adult-based programs can more often absorb the higher costs of pediatric patients. These organizations also tend to serve a larger geographic area, allowing for higher pediatric service utilization. Additionally, the values, mission, and commitment of a hospice may motivate them to care for a child despite the higher costs and lack of confidence. Finally, the presence of a pediatric champion within the hospice team can bolster confidence and willingness to care for a child.

Another important facilitator for programs both currently enrolling children and those with plans to expand to enrolling children is to identify the current gap in palliative and hospice resources for children.<sup>15</sup>

## What can we do to address barriers and facilitators?

1. Regional coalitions can provide networking through a community of practice and provide tailored education to address regional informational needs.<sup>44</sup>
2. Cultivating provider champions can provide a buffer for organizational barriers.<sup>43,45</sup>
3. Partnership with external resources, hospital palliative care teams, regional pediatric hospice teams, pediatric primary care providers, and pediatric nurses can provide access to needed pediatric resources.
4. Addressing attitudes and lack of training through individual and group education and reducing misperceptions about pediatric care.
5. The use of primary palliative care when resources are inadequate for specialty palliative care and support the child's plan of care.<sup>45</sup>

Figure 18: Facilitators identified by providers





# References

1. U. S. Department of Health and Human Services, (2023). NIH style guide: Age. [https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20\(13%20years%20through%2017,adults%20\(65%20and%20older\)\\*](https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20(13%20years%20through%2017,adults%20(65%20and%20older)*)
2. National Quality Forum. National consensus project for quality palliative care, 4th edition (2018). <https://www.nationalcoalitionhpc.org/ncp/>
3. World Health Organization. Palliative care. WHO, 2023; <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
4. National Hospice and Palliative Care Organization. Standards for pediatric palliative care. NHPCO, 2022; [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)
5. Lindley, L.C. Health care reform and concurrent curative care for terminally ill children: A policy analysis. *J Hosp Palliat Nurs*, 2011; 13(2): 81–88.
6. Feudtner, C., et al., (2013). Pediatric palliative care and hospice care commitments, guidelines, and recommendations. American Academy of Pediatrics Policy Statement. *Pediatrics*, 32(5). <https://doi.org/10.1093/peds/2013-2731>
7. Friebert, S., & Williams, C. NHPCO's Facts and Figures Pediatric Palliative & Hospice Care in America, 2015 edition. National Hospice and Palliative Care Organization.
8. Thienprayoon R, San Julian Mark M, Grosseohme D. Provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio pediatric palliative care and end-of-life network. *J Palliat Med*. 2018;21(3):290–6.
9. Lindley, L.C., Cozad, M.J., Svynarenko, R., Keim-Malpass, J., & Mack, J.W. (2021). A national profile of children receiving pediatric concurrent hospice care, 2011 to 2013. *J Hosp Palliat Nurs*, 23(3), 214–220.
10. Oxford Languages. Oxford Dictionary. Oxford University Press, 2023. <https://www.dictionary.com/browse/transition>
11. Fornehed MLC, Svynarenko R, Lindley LC. Impact of concurrent hospice care on primary care visits among children in southern, rural Appalachia. *J Pediatr Health Care*. 2022;36(5):438–442.
12. Lindley LC, Cohrs AC, Keim-Malpass J, Leslie DL. Children enrolled in hospice care under commercial insurance: A comparison of different age groups. *Am J Hospice Palliat Med*. 2019;36(2):123–129.
13. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–538.
14. Keim-Malpass J, Cozad MJ, Svynarenko R, Mack JW, Lindley LC. Medical complexity and concurrent hospice care: A national study of Medicaid children from 2011 to 2013. *J Spec Pediatr Nurs*. 2021;26(4):e12333.
15. Lindley LC, Keim-Malpass, J. Quality of pediatric hospice care for children with and without multiple complex chronic conditions. *Intl J Palliat Nurs*. 2017;23(5):112–119.
16. Lotstein D, Klein M, Lindley L, Wolfe J. From Hospital to home: Referrals to pediatric hospice and home-based palliative care. *J Pain Symptom Manage*. 2023.
17. Lindley LC, Lyon ME. A profile of children with complex chronic conditions at end of life among Medicaid-beneficiaries: Implications for healthcare reform. *J Palliat Med*. 2013;16(11):1388–1393.

## References (continued)

18. Weaver MS, Chana T, Fisher D, Fost H, Hawley B, James K, Lindley LC, Samson K, Smith SM, Ware A, Torkildson C. The state of the service: Pediatric palliative and hospice coverage in the United States. *J Pall Med*. 2023; XX(XX): e-published June 13, 2023, 1-8. <https://www.liebertpub.com/doi/full/10.1089/jpm.2023.0204>.
19. Cozad MJ, Ssynarenko R, Hinds PS, Mack JW, Keim-Malpass J, Lindley LC. Pediatric concurrent hospice care: Cost implications of a hybrid payment model. *Am J Hospice Palliat Med*. 2022;39(12):1436-1442.
20. Chirico J, Donnelly JP, Gupton A, Cromwell P, Miller M, Dawson C, Korones DN. Costs of care and location of death in community-based pediatric palliative care. *J Palliat Med*. 2019;22(5):517-521.
21. Lindley LC, Richar CS, Hoit T, Steinhorn DM. The cost of pediatric concurrent hospice care: An economic analysis of relevant cost components, review of the literature, and case illustration. *J Palliat Med*. 2021;24(9):1291-1298.
22. Lindley LC. The effect of pediatric palliative care policy on hospice utilization among California Medicaid beneficiaries. *J Pain Symptom Manage*. 2016;52(5):688-694.
23. Lindley LC, Mark BA, Lee S-Y. Providing hospice care to children and young adults: A descriptive study of end-of-life organizations. *J Hospice Palliat Nurs*. 2009;11(6):315-323.
24. Keim-Malpass J, Cohrs AC, Lindley LC, Leslie DL. An economic examination of private insurance claims among adolescents and young adults who are enrolled in hospice during the last year of life. *J Adolesc Health Med Therap* 2018; 9:117-120.
25. Aetna. Compassionate Care Program. [http://www.aetna.com/producer/aetnalink/2009-4q/natlinkmm\\_hospice\\_4q09.html](http://www.aetna.com/producer/aetnalink/2009-4q/natlinkmm_hospice_4q09.html). Last updated 2009. Accessed February 1, 2023.
26. TRICARE Reimbursement Manual. 6010.61-M – concurrent care. <https://manuals.health.mil/pages/DisplayManualHtmlFile/2022-06-10/ChangeOnly/tr15/c11s5.html>. Last updated August 6, 2019. Accessed February 1, 2023
27. Wilson Smith MG, LaFond DA, Keim-Malpass J, Lindley LC, Matzo M. A new era in pediatric hospice care for military families. *Am J Nurs*. 2019;119(8):66-69.
28. Lindley LC. The effect of pediatric palliative care policy on hospice utilization among California Medicaid beneficiaries. *J Pain Symptom Manage*. 2016;52(5):688-694.
29. Lindley LC, Mark BA, Lee S-Y. Providing hospice care to children and young adults: A descriptive study of end-of-life organizations. *J Hospice Palliat Nurs*. 2009;11(6):315-323.
30. Lindley LC, Weaver MS. Unraveling EPSDT and pediatric hospice care: An exploratory policy analysis. *Am J Hospice Palliat Med*. 2022;39(12):1460-1466.
31. Aglio T, Autrey AK, Shostrom VK, Weaver MS, Kaye EC, Lindley LC. Continued challenges accessing pediatric hospice services. *J Pain Symptom Manage*. Dec 2022;64(6):e383-e385. doi:10.1016/j.jpainsymman.2022.08.009
32. Weaver MS, Shostrom VK, Kaye EC, Keegan A, Lindley LC. Palliative care programs in children's hospitals. *Pediatrics*. 2022; 150(4) doi:10.1542/peds.2022-057872
33. Lindley LSS. Who are the children using hospice care? *Journal for Specialists in Pediatric Nursing*. 2014;19(4):308-315.
34. Lindley LC, Edwards SL. Geographic access to hospice care for children with cancer in Tennessee, 2009 to 2011. *Am J Hospice Palliat Med*. 2015; 32(8):849-54. doi:10.1177/1049909114543641
35. Weaver MS, Shostrom VK, Kaye EC, Keegan A, Lindley LC. A Plateau in pediatric palliative program prevalence. *J Pain Symptom Manage*. 2022; 64(5): e310-e312. doi:10.1016/j.jpainsymman.2022.07.008

## References (continued)

36. Weaver MS, Rosenberg AR, Tager J, Wichman CS, Wiener L. A Summary of Pediatric Palliative Care Team Structure and Services as Reported by Centers Caring for Children with Cancer. *J Pall Med.* Apr 2018;21(4):452-462. doi:10.1089/jpm.2017.0405
37. Kaye EC, Gattas M, Kiefer A, et al. Provision of palliative and hospice care to children in the community: A population study of hospice nurses. *J Pain Symptom Manage.* Feb 2019;57(2):241-250. doi:10.1016/j.jpainsymman.2018.10.509
38. Parajuli J, Tark A, Jao YL, Hupcey J. Barriers to palliative and hospice care utilization in older adults with cancer: A systematic review. *J Geriatr Oncol.* 2020;11(1):8-16. doi:10.1016/j.jgo.2019.09.017
39. Hill JD, De Forcrand C, Cuthel AM, Adeyemi OJ, Shallcross AJ, Grudzen CR. Emergency provider perspectives on facilitators and barriers to home and community services for older adults with serious life limiting illness: A qualitative study. *PLoS One.* 2022;17(8):e0270961. Published 2022 Aug 5. doi:10.1371/journal.pone.0270961
40. Lalani N, Cai Y. Palliative care for rural growth and wellbeing: identifying perceived barriers and facilitators in access to palliative care in rural Indiana, USA. *BMC Palliat Care.* 2022;21(1):25. Published 2022 Feb 19. doi:10.1186/s12904-022-00913-8
41. Threapleton DE, Chung RY, Wong SYS, et al. Care toward the end of life in older populations and its implementation facilitators and barriers: A scoping review. *J Am Med Dir Assoc.* 2017;18(12):1000-1009.e4. doi:10.1016/j.jamda.2017.04.010
42. Bogetz JF, Johnston E, Ananth P, et al. Survey of pediatric palliative care quality improvement training, activities, and barriers. *J Pain Symptom Manage.* 2022;64(3):e123-e131. doi:10.1016/j.jpainsymman.2022.04.182
43. Laronne A, Granek L, Wiener L, Feder-Bubis P, Golan H. Organizational and individual barriers and facilitators to the integration of pediatric palliative care for children: A grounded theory study. *Palliat Med.* 2021;35(8):1612-1624. doi:10.1177/02692163211026171
44. Bogetz JF, Anderson A, Holland M, Macauley R. Pediatric hospice and palliative care services and needs across the northwest United States. *J Pain Symptom Manage.* 2022;64(1):e7-e14. doi:10.1016/j.jpainsymman.2022.02.015
45. Lafond D; Perko K; Fisher D; Mahmood LA; Hinds PS, Impact of pediatric primary palliative care education and mentoring in practice . *J Hospice Palliat Nurs.*; 2022; 24(1): 22-29; DOI: 10.1097/NJH.0000000000000802

# Appendix: Data Sources and Methodology

The data sources primarily used for this report are from the NHPCO 2020 Pediatric Needs Assessment and any uncited graphs are accounted to this survey. See cited sources throughout the report for each table and figure.

## Questions May Be Directed To:

National Hospice and Palliative Care Organization  
Attention: Communications  
Phone: 703.837.1500  
Web: [www.nhpc.org/pediatrics/](http://www.nhpc.org/pediatrics/)  
Email: [pediatrics@nhpc.org](mailto:pediatrics@nhpc.org)

©2023 National Hospice and Palliative Care Organization.

All rights reserved, including the right to reproduce this publication or portions thereof in any form. Public use of this report and reported data is authorized if the National Hospice and Palliative Care Organization is clearly referenced.

## Suggested Citation:

*2023 Edition: Pediatric Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization.*

# Acknowledgements

Facts and Figures are made available by the NHPCO Pediatric Advisory Council. The following individuals are recognized for their effort in the development of this resource:

**Deb Fisher**, PhD, RN, PPCNP-BC, CHPPN  
**Betsy Hawley**, MA  
**Kristin James**  
**Lisa C. Lindley**, PhD, RN, FPCN, FAAN

**Kaeli Samson**, MA, MPH  
**Steven M. Smith**, MD  
**Christy Torkildson**, PhD, RN, PHN  
**Meaghann S. Weaver**, MD, PhD, MPH, HEC-C



**NHPCO**

National Hospice and Palliative  
Care Organization

**NHPCO**

1731 King Street  
Alexandria, VA 22314

tel. 703.837.1500 | [nhpco.org](http://nhpco.org)

**JUNE 2023**