Task Force to Propose a State-wide Pediatric Palliative Care/Hospice Service Program in the State of Connecticut

Executive Summary: Working Group Task Force Recommendations

Established Pursuant to Proposed Bill 484
State of Connecticut

Connecticut General Assembly Committee on Public Health

March 2025

WORKING GROUP REPORT

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OVERVIEW

State Assembly Mandate for Working Group to Study Pediatric Hospice Services

Public Act 24-19 Section. 29*

Sec. 29. *(Effective from passage)*

(a) The chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to public health shall establish a working group to examine hospice services for pediatric patients across the state.

(b) The working group shall be responsible for the following:

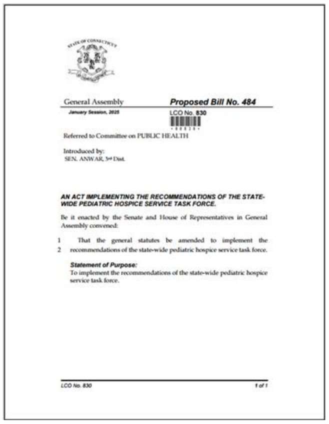
(1) **Reviewing existing hospice services for pediatric patients across the state.**
(2) **Making recommendations for appropriate levels of hospice services for pediatric patients across the state; and**
(3) **Evaluating payment and funding options for pediatric hospice care.**

(c) The co-chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to public health shall schedule the first meeting of the working group, which shall be held not later than sixty days after the effective date of this section.

(d) The members of the working group shall elect two chairpersons from among the members of the working group.

(e) The administrative staff of the joint standing committee of the General Assembly having cognizance of matters relating to public health shall serve as administrative staff of the working group.

(f) Not later than March 1, 2025, the chairpersons of the working group shall report, in accordance with the provisions of section 11-4a of the general statutes, to the joint standing committee of the General Assembly having cognizance of matters relating to public health concerning the findings of the working group.



General Assembly | **Proposed Bill No. 484**
January Session, 2025 | LCO No. 830

Referred to Committee on PUBLIC HEALTH

Introduced by:
SEN. ANWAR, 3rd Dist.

AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE STATE-WIDE PEDIATRIC HOSPICE SERVICE TASK FORCE.

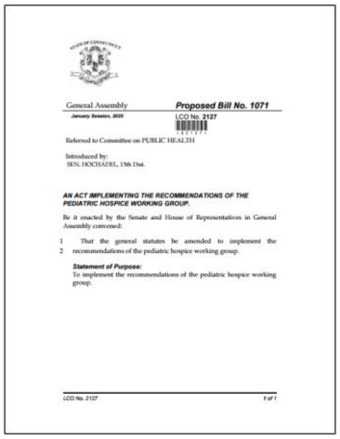
Be it enacted by the Senate and House of Representatives in General Assembly convened:

That the general statutes be amended to implement the recommendations of the state-wide pediatric hospice service task force.

Statement of Purpose:
To implement the recommendations of the state-wide pediatric hospice service task force.

LCO No. 830 | *1 of 1*

Proposed Bill no. 484 Introduced by Sen. Anwar, 3rd Dist.



General Assembly | **Proposed Bill No. 1071**
January Session, 2025 | LCO No. 2127

Referred to Committee on PUBLIC HEALTH

Introduced by:
SEN. HOCHADEL, 13th Dist.

AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE PEDIATRIC HOSPICE WORKING GROUP.

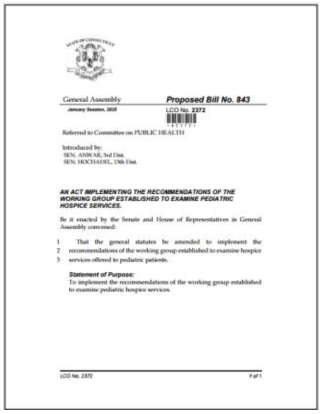
Be it enacted by the Senate and House of Representatives in General Assembly convened:

That the general statutes be amended to implement the recommendations of the pediatric hospice working group.

Statement of Purpose:
To implement the recommendations of the pediatric hospice working group.

LCO No. 2127 | *1 of 1*

Proposed Bill no. 1071 Introduced by Sen. Hochadel, 13th Dist.



General Assembly | **Proposed Bill No. 843**
January Session, 2025 | LCO No. 2372

Referred to Committee on PUBLIC HEALTH

Introduced by:
SEN. ANWAR, 3rd Dist.
SEN. HOCHADEL, 13th Dist.

AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE WORKING GROUP ESTABLISHED TO EXAMINE PEDIATRIC HOSPICE SERVICES.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

That the general statutes be amended to implement the recommendations of the working group established to examine hospice services offered to pediatric patients.

Statement of Purpose:
To implement the recommendations of the working group established to examine pediatric hospice services.

LCO No. 2372 | *1 of 1*

Proposed Bill no. 843 Introduced by Sen. Anwar, 3rd Dist. and Sen. Hochadel, 13th Dist.

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*Text taken from State of CT Public Act 24-19 Section 29: *PA 24-19 Section 29.pdf*

CT Working Group empowered to propose a state-wide program

Member Name	Role/Title
Albert, Ross MD	Medical Director, Hospice and Palliative Care, Hartford HealthCare at Home & medical director of the Hartford HealthCare at Home Hospice and HOPE palliative care teams
Alexander, Erica	Hospice Program Manager, Day Kimball Healthcare at Home
Anwar, Saud MD	Deputy President Pro Tempore; CT State Senator; serves 3rd Assembly Senate District; Senate Chair of the Public Health Committee, Vice Chair of the Insurance and Real Estate Committee and as a member of the Appropriations, Children's, and Environment Committees
Cass, Barbara	Healthcare Quality and Safety Branch Chief, CT DPH
Cournoyer, Brian	Director, Government Relations; Connecticut Hospital Association
Festa, Matthew	Legislative Analyst, CT Department of Social Services (DSS)
Garlie, Karen	Senior Manager of Yale New Haven Health at Home Hospice Services
Klarides-Ditria, Nicole	State Representative; serves 105th District (Beacon Falls, Seymour, part of Derby)
Marchione, ToniAnn *	CEO & President, Regional Hospice of Western CT; **Working Group Co-Chair**
Massaro, Stephanie MD	Medical Director of the Pediatric Hematology/Oncology Inpatient Unit and director of the Pediatric Palliative and Hospice Care Program at Yale-New Haven Children's Hospital
McCarthy-Vahey, Cristin	State Representative; serves 133rd Assembly District; House Chair of the Public Health Committee and a member of the Government Administration and Elections, Planning and Development, and Transportation Committees
Moss, Kerry MD *	Medical Director of Sunflower Kids Palliative Care Program, Connecticut Children's, Hartford; **Working Group Co-Chair**
Owusu, Regina	Program Manager, CT Department of Public Health
Schiessel, Carl	Senior Director, Regulatory Advocacy, Connecticut Hospital Association
Somers, Heather	State Senator; Chief Deputy Senate Republican Leader; serves 18th Assembly District; Ranking Senator on the Executive and Legislative Nominations Committee; member of the Appropriations Committee; Ranking Member of the Public Health Committee
Wodatch, Tracy	President and CEO, The Connecticut Association for Healthcare at Home

** Working group Co-Chairs*

The Public Health Committee is one of the joint standing committees of the Connecticut General Assembly. It has cognizance of all programs and matters relating to the Department of Public Health; the Department of Mental Health and Addiction Services and the Department of Developmental Services; the Office of Health Care Access; and all other matters relating to health, including emergency medical services, all licensing boards within the Department of Public Health, nursing homes, pure food and drugs, and controlled substances, including the treatment of substance abuse.

Working Group Activities

- Between September 2024 and March 2025, the Working Group to Study Pediatric Hospice Services met 9 times in core- and sub-working group forums to identify key challenges, and to share their data, expertise and intelligence about issues pertaining to pediatric palliative care and hospice needs.
- Dedicated state resources were surveyed to assess patient numbers and resources needs, other non-Connecticut agencies with pediatric programs were solicited for their best practices, and working group members identified key challenges in serving children's palliative & hospice care needs.
- This report provides some details for recommendations to the Connecticut General Assembly for their consideration.
- A proposal for a new model and a phased approach to develop and launch this program has been drafted to offer children with life-limiting conditions and their families a more comprehensive solution to support their challenging journey.

Working Group Calendar of Meetings

- Feb 22, 2024: State Assembly Discussion on Pediatric Palliative Care
- Mar 2024: State Assembly Approval to proceed through Working Group
- Sept 25, 2024: Full Working Group—Launch Meeting
- Oct 9, 2024: Full Working Group
- Oct 16, 2024: Working Group Subgroup
- Nov 13, 2024: Working Group Subgroup
- Dec 13, 2024: Working Group Subgroup
- Jan 8, 2025: Working Group Subgroup
- Jan 29, 2025: Working Group Subgroup
- Feb 11, 2025: Working Group Subgroup
- Feb 25, 2025: Full Working Group
- March 2025: Working Group report to Connecticut State Assembly

DEFINING THE NEED

Comparison Between Pediatric and Adult Hospice Services

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (ACA) into law enacting a new provision, Section 2302, termed the “Concurrent Care for Children” Requirement (CCCR). CCCR requires state Medicaid programs to pay for both curative, live prolonging treatment, and hospice services for children under the age of 21 who qualify.

Prior to the Affordable Care Act, both children and adults had to have (1) a 6-month prognosis and (2) forego any life-prolonging, curative treatments to enroll in hospice. With concurrent care, pediatric patients must still meet the 6-month prognosis, but **do not have to choose between life-prolonging, curative care and hospice.** (Life prolonging treatments are any therapies, medications, equipment, or modalities related to the serious illness which may postpone a child’s death.)

	Definitions of Palliative Care and Hospice Services
Pediatric Hospice	• Specialized medical treatments, curative therapies and concurrent ***care can be continued*** • Traditional hospice palliative care is ***offered in combination with*** other medical treatments and services
Adult Hospice	• Curative measures and specialized medical treatments are discontinued. • Traditional hospice/palliative care and end-of- life support is offered

Why this need exists: Metrics of Pediatric Hospice in the State of Connecticut

A 2024 NHPCO report identified a severe gap in pediatric palliative and hospice care services for children in the State of Connecticut who faced life-limiting conditions. Current practitioners in the field have identified gaps such as:

- Limited availability of agencies in CT who are skilled and certified to serve pediatric palliative and hospice care needs.
- The lack of skilled pediatric hospice resources, especially trained RNs, to support the current patient numbers
- Insufficient funding to support all children who face life-limiting conditions.
- Limited breadth of resources to offer a full range of services to children and their families (e.g., while medical services may be offered, bereavement counseling may not be available)
- Lack of public information to guide pediatric professionals and patients' families to help them gain access to pediatric palliative & hospice care.

This committee proposes to build a state-wide program that will serve the majority of children and families who are in desperate need of services and support to offer both palliative and hospice care as a combined service.

Some metrics to support this need:

***Total number of CT pediatric patients with complex medical conditions that limit their life expectancy**	**7,800**
^The number of reported children's deaths in our state *<1 yr=145; 1-14 yrs=57; 15-19 yrs=93*	**295**

Data from 2020 sources:
**National Survey of Children's Health (NSCH). (2019-2020). The National Survey of Children's Health. https://www.childhealthdata.org/learn-about-the-nsch/NSCH - and - PedEOL Care Research Group. (2023, March 10). Fact sheet: Connecticut: Sick kids [infographic]*

^2020 CDC Wonder data; CDC WONDER

Potential Barriers to Pediatric Palliative/Hospice Care*

The capacity, coordination, and funding for pediatric palliative/hospice care remains insufficient. A few themes articulate why this exists:

DIFFERENTIATING CHILDREN'S NEEDS

- There is a lack of understanding that children with life-limiting conditions can receive BOTH concurrent care and palliative/hospice care simultaneously.
- There is limited understanding of the unique perspectives and distinct needs of children requiring hospice and palliative care, which are fundamentally different from those of adults.
- Advances in medical technology have extended the survival of children with complex chronic conditions, but healthcare systems have not adapted to meet their unique palliative care needs.
- Children's developmental and family contexts demand specialized approaches (different from adult care)

COMPLICATIONS WITH PALLIATIVE & HOSPICE CARE

- Palliative care is often mistaken for hospice care, causing delays in referrals for pediatric patients which leads to lack of uniform criteria for identifying children who need palliative care.
- Many eligible children go unrecognized for palliative care, because of limiting funding, infrastructure and confusion, or lack of clarity regarding palliative care's breadth which can deter timely referrals.
- Comprehensive palliative and hospice care support is sometimes integrated much later in a child's illness; this combined support should start at diagnosis and extend throughout the illness—not just at the end of life.

LIMITED SKILLED PRACTITIONERS & PROVIDERS

- There are a limited number of certified agencies/organizations in CT who can offer pediatric palliative/hospice care services.
- With children's hospitals, there are variations in program structure, staffing, and financial support; for example, as recently as June 30, 2024, there were only 2 active ABMS Member Board certified physicians in pediatric hospice and palliative medicine in the state of Connecticut.
- Workforce shortages and limited pediatric hospice services exacerbate supporting pediatric needs.
- There is a critical service gap with neonatal patients - stigma, unclear definitions, and limited referral pathways - can deny the youngest and most vulnerable patients the necessary palliative support.

**More data to support these barriers are forthcoming from a variety of sources including a Yale Law School report to be published in early Spring 2025, focused on barriers. Future reports to the Assembly will include references to this study along with other sources.*

Best Practice Models Referenced During Working Group and Sub-Working Group Discussions

State of California

The California Medicaid program (Medi-Cal) pays for palliative care services provided to both children and adults and oversees managed care organizations' provision of the services. The California Children's Services (CCS) program pays for palliative care services provided to select *CYSHCN. *Covered Services:*

- Palliative care assessment and consultation
- Plan of care
- Mental health and medical social services
- Advance care planning
- Pain and symptom management
- Care coordination
- Palliative care team consultation

Commonwealth of Massachusetts (BEST PRACTICE MODEL)

The Massachusetts Title V *CYSHCN program centralizes and operates the pediatric palliative care program, the state pays for all palliative care services, they conduct outreach to families and referring providers and engages families in service delivery and program design. *Covered services:*

- Nursing
- Spiritual care
- Sibling support
- Respite care
- Pain and symptom management
- Complementary therapies such as music, art, massage, and others
- Assessment and case management
- Social services
- Volunteer support
- 24-hour nurse on call
- Bereavement care if needed

State of Vermont

Vermont Medicaid funds program administration and pays for palliative care services authorized by the state's Title V *CYSHCN program. Title V administers the program, fills gaps in program coverage, and coordinates with other initiatives to enhance access to palliative care services for Vermonters of all ages. *Covered services:*

- Family training
- Skilled respite
- Family grief/bereavement counseling
- Expressive therapy
- Care coordination

State of Washington

Washington State created a comprehensive website to reflect the depth and complexity of their residents and their palliative care needs. As such, the Washington Rural Palliative Care Initiative (WRPCI) was established to better serve patients with serious illness in rural communities. This public-private partnership is led by the Washington State Office of Rural Health at the state Department of Health involving over 24 organizations. This work aims to assist rural health systems and communities to integrate palliative care in multiple settings. *Covered services:*

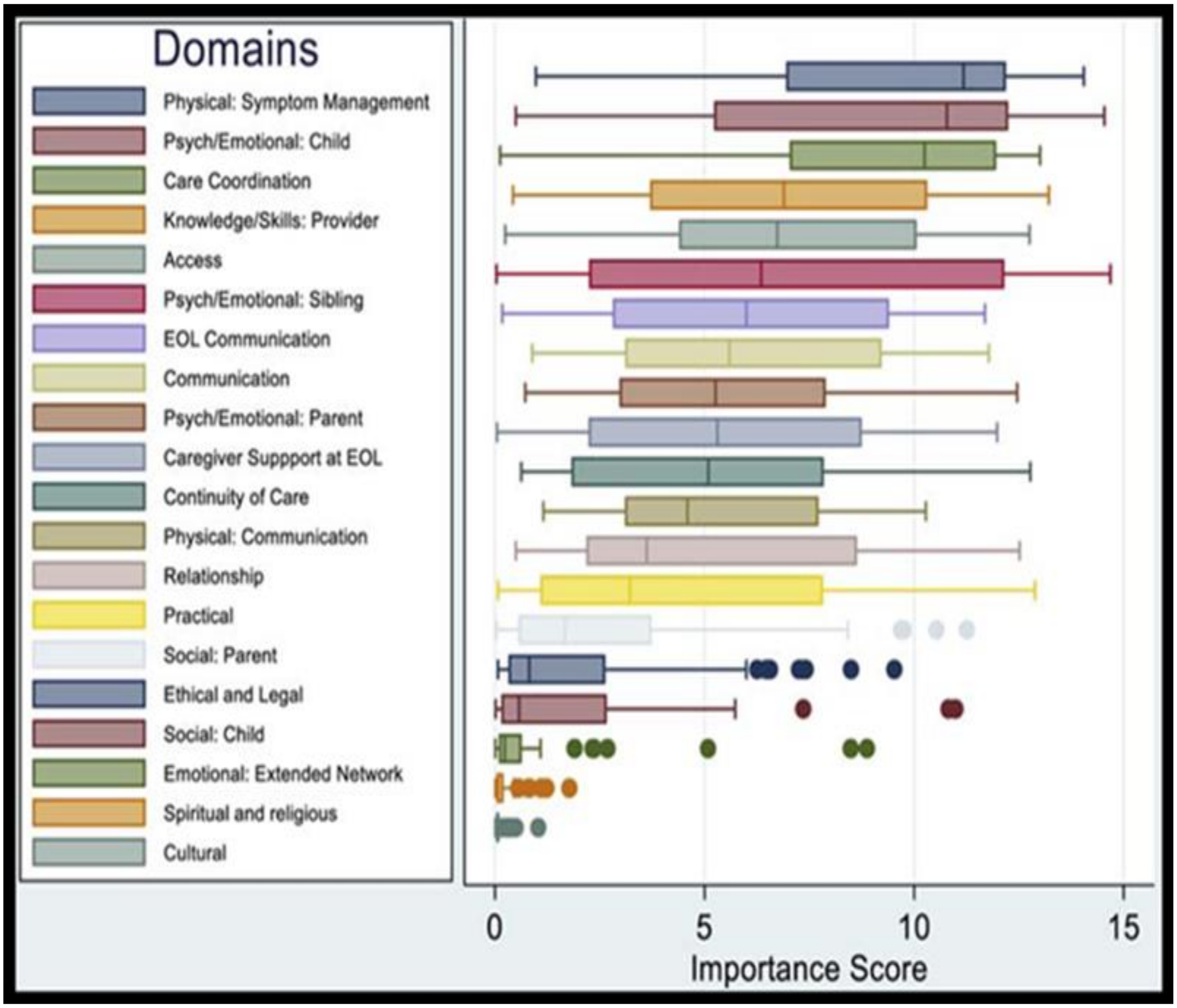
- emergency department
- skilled rehabilitation
- hospice Services
- long-term care
- Inpatient services
- home health care
- primary care

**CYSHCN – Children and Youth with Special Health Care Needs*

2020 Massachusetts Study on Parents' expectations/needs

To further emphasize elements that are most important to parents on behalf of their child and the family, a 2020 Massachusetts study asked parents what they valued regarding Pediatric Palliative and Hospice Care in the home setting.

Practitioner coordination, skills and access to services ranked high – just behind children's physical management and the psychological and emotional needs of the child and their siblings.



National Consensus Project's (NCP) Clinical Guidelines for Home-Based Quality Palliative Care

The framework for the domains used in this study came from the National Consensus Project's (NCP) Clinical Guidelines for Quality Palliative Care (fourth edition),[22] which were further adapted using pediatric palliative care (PPC)-specific guidelines and the literature[20,25–28] and informed by a panel of stakeholders (PPC providers and parent advocates). The adapted framework includes 20 PPHC@Home-specific domains and subdomains (Table 1).

Table 1.
Domains of High-Quality PPHC in the Home

Domains	**Description**
Communication between family and care team	Care team communicates with the child and family to make sure that the care provided meets the child's and family's values, preferences, goals, and needs
Relationship between family and care team	Relationship between care team and family is built on trust, respect, and advocacy for the child's and family's needs
Knowledge and skills of care team providers	Care team members have the necessary education and training to provide high-quality palliative care for children and families
Access to care	Care team provides access to palliative and hospice care to the child and family 24 hours a day, seven days a week
Physical care: Communication	Care team provides information about treatments for child's pain and other physical symptoms (e.g., nausea, fatigue, constipation)
Physical care: Symptom management	Care team assesses and manages pain and other physical symptoms, and side effects based on the best available medical evidence
Psychological and emotional aspects of care (child, parents, siblings, and extended social network)[a]	Care team assesses and manages psychological and emotional issues (such as anxiety, distress, coping, grief) of the child, family, and family's community based on the best available medical evidence
Practical aspects of care	Care team provides the family with assistance and resources for dealing with financial and insurance-related issues
Social aspects of care (child, parents)[a]	Care team helps with social issues to meet child-family needs, promote child-family goals, and maximize child-family strengths and well-being (examples include helping family maintain and strengthen their support network; help family develop strategies to balance caregiving, work, and family needs)
Spiritual and religious aspects of care	Care team assists with religious and spiritual rituals or practices as desired by the child and family
Cultural aspects of care	Care team respects the child's and family's cultural beliefs and language preferences
Communication at the end of life	Care team works with the child and family to develop and implement a care plan to address actual or potential symptoms at the end of life
Caregiver support at the end of life	Care team meets the emotional, spiritual, social, and cultural needs of families at the end of life (e.g., preparing parents for the end of life)
Ethical and legal aspects of care	Childs and family's goals, preferences, and choices are respected within the limits of state and federal law, current standards of medical care, and professional standards of practice These goals/preferences/choices are documented and shared with all professionals involved in the child's care
Coordination of care	Care team works to make sure that when there are transfers between health care settings and providers, that there is timely and thorough communication of the child's/family's goals, preferences, values, and clinical information to ensure continuity of care and seamless follow-up (e.g., getting needed services, arranging for medical equipment)
Continuity of care	Care team works to make sure that the delivery of palliative and hospice care is seamless across care settings and providers (e.g., the same providers work with family)

Data taken from National Library of Medicine: What Do Parents Value Regarding Pediatric Palliative and Hospice Care in the Home Setting?' https://pmc.ncbi.nlm.nih.gov/articles/PMC9747513/
PPHC = pediatric palliative and hospice care.
Note: These domains are based on the National Consensus Project's Clinical Guidelines for Quality Palliative Care (fourth edition),[22] which were further adapted using pediatric palliative care-specific guidelines and the literature[20,25–28] and informed by a panel of pediatric palliative care stakeholders (providers and parent advocates).
[a] Separate subdomain for each group.

WORKING GROUP RECOMMENDATIONS

Working Group Task Force Proposal for a Pediatric Palliative Care & Hospice Services Program

PROPOSAL: Create a new, best-in-class solution for children with life-limiting conditions and their families*

CT CHAMPION Care

Children's Health, Advocacy,
Management & Palliative Care

Opportunities & benefits that a dedicated, state-led program offers:

- Offers all children in Connecticut with life-limiting conditions and their families access to consistent quality of care and breadth of skilled services.
- Ensures delivery of concurrent care simultaneous to palliative/hospice care
- Is defined as a children's program based on number of visits that dictates palliative vs. hospice, all performed by one team
- Hospice based palliative care without parents having to choose – no prognosis criteria.
- Adherence to MOLST recommendations for pediatrics and those served in pediatric hospital systems.
- Creates a collaborative team—primary medical practitioners, skilled palliative/hospice nursing, CNA/Home Health Aide, financial & funding guidance, family/patient counseling & spiritual care—to support the broad and complex needs of the child and family. Also allows for proper grief and bereavement.
- Increases the number of skilled pediatric hospice practitioners and licensed agencies in CT through expanded training.
- Creates certification and licensure requirements for pediatric hospice agencies and organizations serving this population.
- Provides early introduction to and intervention by hospice/palliative care professionals to offer ongoing support to the child and family.
- Allows pediatric medical practitioners and dedicated agencies to secure access to the necessary resources to support pediatric palliative care and hospice needs while supporting concurrent care efforts
- Maintains quality assurance and consistency with oversight by State management and geographic delivery of services by licensed facilities.

** A best-in-class practice/solution is a method or technique that has been generally accepted as superior to alternatives because it typically produces superior results. Best practices are used to achieve quality as an alternative to mandatory standards.* [*https://en.wikipedia.org/wiki/Best_practice*](https://en.wikipedia.org/wiki/Best_practice)

Program Early Adopter: Create a Pediatric Palliative/Hospice Care Center of Excellence

The goals of a Center of Excellence (CoE):

- Serves as an enabler for transformation; acts as a change agent.
- Provides collaboration, knowledge sharing, & training; facilitates a community of awareness.
- Establishes gates and guardrails, creates policies and governance, develops tools, techniques & best practices.

Phase One Pilot: CT Champion Care CoE Proposal

Regional Hospice of Western CT will serve as the pilot agency for the proposed **CT Champion Care** program. As the CoE, Regional Hospice will:

- Support pediatric patients and their families as part of the full-service team for children with life-limiting conditions based on visit needs.
- Consult with and be guided by the full Working Group to develop more robust elements of this program and provide briefings to the State Assembly on progress, modifications, and needs.
- Collaborate with Fairfield University EGAN School of Nursing to deliver a dedicated curriculum to offer training, build a community of much-needed nursing pediatric practitioners and subsequent deployment of these practitioners.
- Collaborate with the CT Department of Public Health (DPH) with a focus on quality assurance, criteria development, and compliance with state and federal requirements.
- Collaborate with CT Children’s and Yale New Haven Children’s Hospital

Testimonials: How a dedicated program can offer healing

"I Didn't Know You" *(As relayed to ToniAnn Marchione, Regional Hospice of Western CT)*

A patient came to our Center and unfortunately, we only had 3 days to support him and his family before his death at age 16. At birth, this patient suffered complications and had lifelong health challenges. His family was committed to his well-being: they ensured he had the best medical care, that he enjoyed complementary therapies through music and art, and he attended school at his grade level. Unfortunately, he suffered a fall with an undiagnosed fracture, which resulted in a life-threatening infection that, after a year, ended his life. By the time he came to Regional Hospice's Center, the family had little opportunity to take advantage of the many services that Regional Hospice could offer them.

His mother was grateful for the few days with Regional Hospice but had sought services for her son for the year of his illness. *"We tried desperately to find pediatric care that could help us navigate his illness and end of life. Everywhere we turned we found no answers, and no one could tell me who could help us with our son's end-of-life care. My other children would have found tremendous solace in the counseling and support you offered us. But by the time we were introduced to you,* ***I didn't know you****. Had we been connected with you much earlier, I know my son - and our whole family - would have suffered less by taking advantage of the comfort and care you offered us.*

I can state with certainty that having a comprehensive program to support my son and my family would have changed our lives. I hope our state leaders know how important that having a dedicated program would mean to the children and families of Connecticut."

Rep. Farley Santos, D-Danbury: ***Praising the State Assembly's move to study the expansion of hospice services for children*** *(from CT Mirror, May 6, 2024)*

"*As the father of a son who passed away and required pediatric hospice care, what this…is going to do is outline the need throughout the state. It's…going to investigate how we can expand these services. As someone whose family had to rely on these services, I applaud the committee for putting this section in here*."

Karen Garlie: ***On behalf of establishing a Pediatric Palliative/Hospice Care Solution*** *(Testimony to the CT State Assembly)*

"*I am currently the Senior Manager of Yale New Haven Health at Home Hospice services and, although I am not speaking on behalf of YNHH, I would like to share some of the challenges accessing end-of life care for pediatric patients with a family story. Almost 2 years ago, I was contacted by Tracy Wodatch, the President, and CEO of the CT Association for Healthcare at Home to inquire if our agency could take on the care of an infant who was going home with her family for her final days. The providers caring for this infant were unable to find a hospice provider in their geographical area that had the capacity or expertise to provide end-of-life care for this infant. The ask was even if we could not provide all hospice services, could we be available to pronounce the infant when they died so they did not have to go back to the hospital. Luckily, our hospice was staffed with a team who had experience with pediatric care, including end-of-life care and were all willing to support this infant and her family. The team, including a nurse, social worker, spiritual care counselor, volunteer, and bereavement coordinator in partnership with the hospital providers, rallied around this family, which also included a very young sibling and sought to make every moment a special and meaningful one for them. They ensured the infant was comfortable and the family was supported throughout the process, and able to be where they chose to be…home*."

Support Needed to Advance Pediatric Palliative/Hospice Care

Ownership	*Need*	Actions/Benefits
State	*Program oversight*	- Approve the creation of a resolute, state-wide program that delivers palliative/hospice care resources, ensures quality of services, and provides thought leadership to support children and families in CT
State	*Funding / insurance coordination*	- Offer broad access to all children with life-limiting conditions, regardless of their payer sources
Working Group	*Codification of pediatric hospice provider certifications and licensing requirements*	- Oversee and maintain quality assurance by defining core competencies and licensing requirements for agencies and organizations and track metrics on their activities
Working Group	*Pediatric Program operating model*	- Create program framework to serve pediatric hospice needs; consult with CT DPH; collaborate with pediatric medical professionals; build curriculum to expand pediatric palliative/hospice care practitioners
State	*Regulatory oversight and coordination*	- Ensure compliance with State and Federal rules through a centralized program
State	*Fund workforce training to develop experienced pediatric resources*	- Integrate a curriculum for medical practitioners and implement specialized training through CT-based programs/universities (e.g., RNs), which will expand the resources able to serve the need
State & Working Group	*Database to track and deploy people and resources; manage and report metrics*	- STATE: Devote technology resources to build state-wide database which will identify child/family needs, maintain location of pediatric-trained professionals, monitor agency/facility licensing, manage metrics for CT funding and insurances, etc. - WORKING GROUP: Populate database as pilot matures to identify resources across the state
State & Working Group	*Communications and Public Relations*	- WORKING GROUP: Develop a comprehensive communications and media plan (for medical professionals, children's service providers, community organizations, and families) to help those who have a role with children to better understand the opportunity to focus on the child's complex needs. - STATE: Utilize dedicated communications resources to ensure conformity with State requirements and populate platforms to effectively connect with the public

Proposed Next Steps: Phases of Pilot Program Development

Pilot Phase	Timing	**Actions** *Regular reporting to and consultation with CT State Assembly will be ongoing and on as-requested basis*
Phase 1: Empowerment & Research	*Mar 2025-Aug 2025*	• State Assembly approves Working Group continuation to allow development of a pediatric palliative/hospice care solution. • State approves Regional Hospice of Western CT with Fairfield Univ EGAN School of Nursing as early pilot adopters. • Working group develops and recommends budget for State Assembly approval to fund pilot development & delivery. • Working Group develops pilot program framework. • Working group defines education requirements and frames curriculum to train RNs through Fairfield University EGAN School of Nursing and Regional Hospice • Working Group reports program framework to State Assembly • State identifies supporting resources to develop centralized monitoring and management of Pilot (and beyond) • Obtain further research from The Solomon Center for Health Law and Policy, Yale Law Scholl White Paper on Pediatric Care in CT
Phase 2: Building Program Elements	*Sept 2025-Mar 2026*	• Working Group (with CT DPH oversight) works to build certification and licensing requirements. • Working Group continues to build pilot program elements. • Training is delivered to RNs at Fairfield University EGAN School of Nursing for 2025 Fall semester to expand pediatric RN resources. • Working Group (with DPH oversight) finalizes certifications and licensing requirements and confirms regulatory monitoring to ensure compliance with State and Federal rules. • Working Group continues to collaborate with Regional Hospice (pilot agency) to explore needs, confirm functionality, ensure available resources, etc.
Phase 3: Pilot Launch, Assessments & Modifications	*Apr 2026-Dec 2026*	• Launch pediatric palliative care/hospice pilot utilizing approved, licensed agencies. • Pilot program tracks patient metrics to predict scope of future services needs. • Working Group solicits feedback from medical providers to assess quality of program protocols & services. • Working Group continues to expand and refine program elements to broaden scope across CT. • Report to CT Assembly on progress made, recommend changes, identify more agencies to expand services