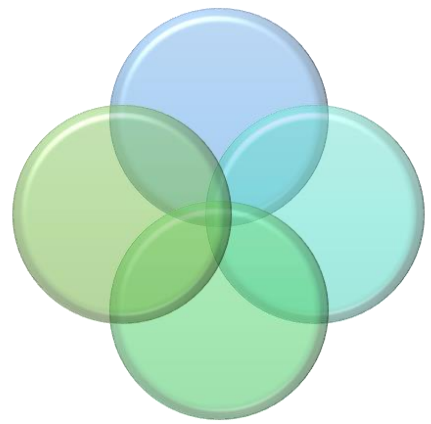


Pediatric Hospice Care
Working Group Proposal to the
Connecticut General Assembly
Public Health Committee

February 2026



*CT Public Act 24-19, Sec. 29: An Act Implementing the
Recommendations of the Pediatric Hospice Working Group*

Next Steps in Developing a Statewide
Pediatric Hospice Care Program



In 2025, Connecticut S.B. No. 1540 was introduced to the General Assembly by the Public Health Committee and, subsequent to this introduction, the General Assembly created [Public Act 24-19, Sec 29](#) which reflects the goals of this effort, namely **the General Assembly empowered a dedicated Working Group to continue development of a solution to address critical needs of medically fragile children with life-limiting illnesses**. Reflected in the original CT General Assembly bill and the subsequent Public Act are elements of the US Govt, Dept of HHS, 'Affordable Care Act', Section 2302, which allows for both concurrent (curative) pediatric services as well as hospice.

Our Working Group has researched and identified the current gaps in provider care, limits on skilled resources, and the negative impact these challenges have on families to care for their children. Our efforts going forward will address barriers including: insufficient number of nursing resources; limited geographic access to services; disconnects with continuity of care/services delivery; limited awareness of available resources; restrictions due to hospice definition parameters; limits with insurances/payer sources; limited access to Medicaid; limits to the scope of care received and lack of continuity for services provided.

To emphasize why we are proposing a new approach, it is important to know the **scope and breadth of children in CT who are in need of customized services and care**. From a 2025 whitepaper by the Yale Solomon Center '[Building a Strong Foundation](#)', we know that In Connecticut, about 300,000 children in total are enrolled in Medicaid (50,000 of whom are enrolled in Medicaid either alone or as a supplement to private insurance). There are **approximately 170,000 CT children with special health care needs** and according to information reported by the NSCH's 2019–2020 National Survey of Children's Health*, **approximately 7,800 children in Connecticut are estimated to have more complex medical conditions**, ranging from incurable neurodegenerative diseases to various forms of cancer. However, many of these children may not qualify for hospice care due to specific criteria that generally require a terminal diagnosis with an expected life of six months or less to survive. We also know that because of limited pediatric hospice nursing resources, a child at the end of their life (or who might have already passed away), must be brought to an emergency room to be 'pronounced'. So rather than a peaceful transition at home supported by skilled hospice care, the circumstances surrounding the child's death are instead filled with anguish.

As the first phase of our effort, **we propose two major objectives: 1) to establish a Pediatric Hospice Nurse Capacity Grant Program to expand pediatric hospice nursing access** through pediatric-skilled, licensed hospice agencies, who will respond to the needs of medically fragile children with life-limiting illnesses, and **2) to create a structured framework for a more inclusive and focused program that enables a centralized coalition of care for a child-centered approach**. These elements will ensure that the comprehensive needs of both the child and their family are addressed, promoting the medical and psychosocial well-being and long-term health of the child. This effort will also involve investigating legislative measures aimed at ensuring that every aspect of a child's care is supported. This investigation will include evaluating current federal and state laws, existing programs, payment options, and potential expansions of care.

Because we believe that hospice will be imperative to offering the right support at a critical time in a child's disease progression, we want to emphasize why we are focusing on this concern. Hospice has traditionally been avoided by parents but in reality, hospice services focus on the patient rather than the disease. With hospice support, children who may receive hospice support for a lengthy period of time can live in an environment where their care team minimizes their pain, maximizes their comfort, can 'pronounce' in their home, and provides bereavement services for loved ones. Simply said, including hospice as part of the care team allows the family to concentrate on their child without the burden of other distractions. **Having a dedicated program will allow our children the ability to participate in leading edge medical interventions, it will give them access to certified and trained pediatric hospice professionals, and it will allow them to continue supportive therapies and medications, thereby taking advantage of skilled resources to improve their quality of life.**

In order to begin our efforts, we are proposing a phased approach. **During our first phase, we are requesting that the Assembly approve funding to: 1) Expand pediatric hospice nursing services immediately through the aforementioned grant, and, 2) Build a comprehensive framework - CHAMPIONCare (Children's Health, Advocacy, Management and Palliative Hospice Care) - that will offer a longer-term solution to offer more complete care for these children.** Both of these Phase One elements are outlined in this document and would be developed simultaneously. We believe that both areas of focus are necessary to ensure immediate support and long-term continuity for medically fragile children with life-limiting illnesses and respectfully request support for these proposed efforts.

We believe that creating a comprehensive, child-centered approach will ultimately remove unnecessary impediments to the right care and services and offer children and their families a significantly improved quality of life as they continue on their journey.

*NSCH captures data for community-based children, including those not hospitalized. While not all these children are dying, this estimate is a risk and needs-based estimate.



Objectives/Purpose of Request

This grant program would offer medically fragile children with life-limiting illnesses who are in need of skilled hospice resources immediate access to pediatric hospice nurses. As part of this effort, this would support the recruitment, training, and retention of 15 pediatric-trained hospice nurses statewide, ensuring sufficient coverage while building a sustainable pediatric hospice workforce. Offering skilled pediatric hospice nursing resources will address urgent hospice needs for all children in Connecticut. We also propose to **build out a more comprehensive solution to enable CHAMPIONCare to operate a centralized pediatric hospice advocacy program to serve medically complex and life-limited children statewide**, while directing hospice care delivery through 10-12 licensed hospice agencies. While CHAMPIONCare is being developed, each independent agency can provide services through their own intake/referral process.

Expectations/Structure

In order to provide these services, 10–12 licensed, pediatric-skilled hospice agencies would be required to designate or hire at least one nurse to be trained in pediatric hospice care, commit to accepting pediatric hospice referrals, participate in standardized training, data reporting, and quality oversight to be shared with the continuing Pediatric Hospice Advisory Council in the building of CHAMPIONCare. These agencies would be selected based on geographic distribution, referral volume, and demonstrated readiness to provide pediatric hospice care. While **there are many hospice organizations across the state** who offer adult-specific services, **only a smaller number are currently able to offer pediatric hospice services**. As such, **this grant would assist with building a workforce to respond to children in their geographic areas**.

Allocation of Funds

Focusing on how these grant fund would be used, we anticipate that allowable expenditures would be allocated as follows:

- **Personnel Costs:** Salary and benefits support for pediatric-trained hospice nurses, and backfill coverage for existing staff during training, as applicable
- **Training and Education:** Standardized pediatric hospice training developed and delivered by [Regional Hospice](#) in partnership with [Connecticut Children's](#), ongoing clinical mentorship, consultation, and competency development
- **Workforce Incentives & Loan Forgiveness:** To address workforce shortages and improve recruitment and retention, state funds would support direct nurse incentives, including training stipends for nurses completing pediatric hospice training; loan forgiveness or loan-repayment assistance for nurses committing to pediatric hospice service for a defined period (e.g., 2–3 years); and incentives structured to encourage long-term workforce stability and statewide distribution of pediatric expertise
- **Program Development:** Development of pediatric-specific policies, protocols, and care pathways; participation in statewide coordination, evaluation, and reporting efforts

Accountability & Reporting

To ensure quality of services and compliance with goals, participating hospice agencies would report data to the Pediatric Hospice Advisory Council on pediatric hospice census and referral trends, geographic access and service coverage, workforce training and retention outcomes, utilization of concurrent care under Medicaid, and identified barriers to care and system gaps. **These data would directly support CHAMPIONCare planning, pediatric hospice policy evaluation, and future legislative decisions.**

Conclusion

A targeted appropriation supporting 10–12 hospice agencies and 15 pediatric-trained nurses, combined with workforce incentives and loan-forgiveness support, offers a pragmatic and fiscally responsible strategy to expand pediatric hospice access in Connecticut. Appropriations would be structured as a time-limited pilot (e.g., 2–3 fiscal years), with defined performance metrics to guide expansion, modification, or transition into CHAMPIONCare. This pilot will provide immediate benefit to children and families while building a sustainable workforce and infrastructure to support the long-term success of CHAMPIONCare. **We propose that this effort be pursued immediately to address hospice care for children with urgent support needs.**



Background and Need

Children with life-limiting and medically complex conditions in Connecticut often face limited access to specialized pediatric hospice care. We propose that having a central coordinating entity – CHAMPIONCare – would offer a comprehensive approach to the child’s and family’s needs. CHAMPIONCare would be responsible for intake; referral management; family advocacy; health system and community liaison functions; program administration; data oversight and system navigation for pediatric patients. As previously noted, direct hospice service would be delivered by 10-12 participating licensed hospice agencies, selected to ensure geographic coverage and pediatric readiness.

Estimated Fiscal Impact Framework

While specific Medicaid cost savings will vary by case complexity, potential cost avoidance includes:

- Reduction in pediatric ICU days
- Decrease in repeat ED visits
- Fewer late-stage hospital readmissions
- Improved alignment of concurrent care billing

Program Development, Administration, Accountability & Reporting

Having dedicated leadership is essential for developing and executing key initiatives and achieving milestones, and it will be crucial for addressing patient needs and ensuring program quality. As previously approved by the State Assembly, CHAMPIONCare, with support from the Pediatric Hospice Advisory Council, will develop Phase 1 efforts. **We propose having 3 key roles that will oversee quality and compliance, drive key actions and ensure progress is reached** to develop the CHAMPIONCare program.

- **CHAMPIONCare Leader:** The program Leader will set strategic goals and drive results, they will serve as the liaison with participating organizations and the Pediatric Hospice Advisory Council, they will oversee budgets and ensure accountability, and they will drive education and services for families and practitioners.
- **CHAMPIONCare Navigator:** The Care Navigator will act as a central link, guiding families, medical practitioners, hospice facilities, insurance providers, and external organizations to sources to assist them in making informed decisions. And while technology will be an important element of this solution, having a human contact offers a level of emotional support that technology cannot provide.
- **CHAMPIONCare Program Coordinator:** This role would support both the CoE Leader and Care Navigator to develop and deliver all program initiatives and activities.

Allocation of Funds

Funding for the development of CHAMPIONCare would focus on the following elements:

- **Personnel Costs:** Per the descriptions noted above, there would be dedicated salary costs for a program Leader, Care Navigator and Program Coordinator.
- **Program Development:** Managed by the CHAMPIONCare team, external vendors would be required to create communications strategies, training and technologies to offer families and practitioners seamless navigation and critical information to find the right answers at the right time. Collaboration with existing resources, both at the state and federal levels, would be pursued to offer thought leadership and guide activities.

Accountability & Reporting

To ensure quality of services and compliance with stated goals, **the Pediatric Hospice Advisory Council and the CHAMPIONCare team would monitor progress against goals, liaise with participating organizations, pursue thought leadership to enhance deliverables, and consult with families** to ensure this reflects their needs. The CHAMPIONCare team, along with members of the Pediatric Hospice Advisory Council, would provide updates to the CT Assembly Public Health Committee so that stated objectives reflect the expectations of the Assembly leaders.

Conclusion

Over the next 12-18 months, this program would be developed with the goal of implementing a Pilot in Phase 2. **We believe that creating a more comprehensive, child-centric coalition of care through a dedicated program will ensure that all the needs of medically fragile children and their families are met to support their medical, psychosocial and spiritual health needs.**



Consultation on Legislative Considerations

As part of its research process, the Working Group consulted with experts at the Solomon Center for Health Law and Policy at Yale Law School about **a broader set of reforms Connecticut could undertake to improve the lives of children with serious illness.**

Recommendations

The Working Group considered the following and received feedback from the Solomon Center for Health Law and Policy at Yale Law School*:

- To support care for the greatest number of children living with serious illness in CT, CT should consider [following the growing number of states that have formally incorporated palliative care into their state Medicaid plans by developing a HUSKY palliative care benefit through a Medicaid State Plan Amendment \(SPA\).](#)
- Because childhood illnesses can have uncertain trajectories, and Medicaid enrollees can receive curative treatment and hospice care concurrently, CT should consider [extending hospice eligibility to pediatric patients with a prognosis of one year or less \(as opposed to the current requirement of six months or less\).](#)
- To protect concurrent care in the event of a change to the Affordable Care Act or related federal regulations, CT should consider **codifying concurrent care in its Medicaid state plan.**
- CT should **fully implement the recommendations of the Katie Beckett Working Group** and prioritize eliminating the waiting list for the Katie Beckett Waiver program.
- To fill gaps for children not covered by Medicaid, CT should **evaluate the feasibility of a state-funded payor of last resort program for children living with serious illness**, as exists in Massachusetts.

**For more information about these recommendations, see Wendy Jiang, Elle Rothermich & Eugene Rusyn, "Building a Strong Foundation for Pediatric Palliative Care in Connecticut" (Solomon Center for Health Law & Policy White Paper, June 2025) and Elle Rothermich & Eugene Rusyn, "Improving Data Collection" (Solomon Center for Health Law & Policy White Paper, October 2025). Both white papers can be accessed at <https://law.yale.edu/solomon-center/projects-publications>.*



In Summary

This Working Group's primary goal is that all services, resources, and support are focused on the needs of the child. As such, these efforts will focus on the requirements of both the child and the family, fostering collaboration through a coalition of care. This coalition would include concurrent (curative) and hospice/palliative care services from pediatricians, specialty MDs (eg, oncology, neurology), pediatric hospice RNs, CNAs, medications, occupational/other therapies, assistive equipment, volunteer/respite services, case management, counseling and bereavement services, and insurances/payer coordination.

As noted in the executive summary, our findings led to the identification of **two key objectives aimed at driving change:**

- 1) **Create a Pediatric Hospice Nurse Capacity Grant Program to expand pediatric hospice nursing access** through pediatric-skilled, licensed hospice agencies, and,
- 2) **Build a framework for a more comprehensive and dedicated program – CHAMPIONCare** - through which a centralized coalition of resources will offer a child-centric view of care to ensure that all the needs of the child and their family are met to support the medical and psychosocial health and longevity of the child.



Requested: Enabling Success Through State Support

In order to offer the best resources and care for our children and their families, we ask for the Connecticut General Assembly's support for the following:

- We ask that the **General Assembly Public Health Committee continue to champion these efforts** in order to change the landscape and enhance the outcomes of our most fragile pediatric population.
- We ask that the **General Assembly empower this legacy Working Group to proceed forward as the 'Pediatric Hospice Advisory Council'** to continue to research and guide pediatric hospice and all pediatric care solutions.
- We ask that the **General Assembly support the creation of, and approve funding for Phase 1 building blocks,** namely:
 - Creation and delivery of a **Pediatric Hospice Nurse Capacity Grant Program**
 - Framework development to **create a CHAMPIONCare Pilot** that will be launched in Phase 2
 - Exploring **potential legislation** to guide enhancements to ensure that we offer the broadest possible access to the right pediatric services and care
- We request that the **General Assembly endorse the establishment and empowerment of a dedicated CHAMPIONCare team,** who will collaborate with the Pediatric Hospice Advisory Council. Their combined expertise, guidance, and navigation support will assist children and their families while developing and delivering critical solutions to support these individuals.

These elements will ensure that we reach important milestones and effectively implement key early benchmarks with the goal of expanding pediatric hospice services.

We believe that with support from the State of Connecticut, these efforts will ultimately offer more comprehensive access to skilled and trained pediatric hospice resources and allow a broader scope of hospice care at the right time for medically-fragile children with life-limiting illnesses and their families.



PROPOSED PHASES FOR DEVELOPMENT & DELIVERY

<p>Phase 1:</p> <ul style="list-style-type: none"> • Pediatric Hospice Nurse Capacity Grant Program deployment • CHAMPIONCare Framework development <p>Phase 2:</p> <ul style="list-style-type: none"> • Pediatric Hospice Nurse Capacity Grant continuation • CHAMPIONCare Pilot Launch 	<p>Phase 1: Spring 2026- Fall 2027 (Planned)</p>	<p>Phase 2: Fall 2027- Winter 2028 (Projected)</p>
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NURSING REQUIREMENTS

RN Staffing

<ul style="list-style-type: none"> • Pediatric Hospice Nurse Capacity Grant: Annual salary & benefits for (15) RNs, ~\$150K per RN per year (100% for Phases 1 & 2) <ul style="list-style-type: none"> ◦ <i>NOTE: On average, a pediatric hospice nurse can support 12-15 patients, so adding 15 RNs per year offers hospice care for an additional 200 children per year</i> 	\$ 2,250,000	\$ 2,250,000
<ul style="list-style-type: none"> • RN Workforce incentives/training stipends (Phase 2 costs will depend upon reaching full staffing capacity in Phase 1) 	\$ 500,000	\$ 300,000
<ul style="list-style-type: none"> • RN Shift Nurse Salary Augmentation (100% Phases 1 & 2): Hourly salary supplement for pediatric hospice shift nurses to bring them in line with full time RN pay 	\$ 100,000	\$ 100,000

RN Training

<ul style="list-style-type: none"> • Hospice Practicums (100% Phases 1 & 2): In service training for RNs through pediatric hospice facilities & pediatric hospital exposure 	\$ 200,000	\$ 200,000
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CHAMPIONCare ADMINISTRATION

<ul style="list-style-type: none"> • CHAMPIONCare Leader to build & launch program (100% Phases 1 & 2) 	\$ 200,000	\$ 200,000
<ul style="list-style-type: none"> • CHAMPIONCare Care Navigator – (2) professionals to develop knowledge sources, begin services coordination (\$120K per yr per professional - 100% Phases 1 & 2) 	\$ 240,000	\$240,000
<ul style="list-style-type: none"> • CHAMPIONCare Program Coordinator to drive program development & delivery (50% Phase 1 / 100% Phase 2) 	\$ 40,000	\$ 80,000
<ul style="list-style-type: none"> • Vendor to develop customized program education materials and link existing knowledge sources (100% Phases 1 & 2) • Vendor to develop brand/marketing materials, content, collaterals (100% Phases 1 & 2) • Vendor to develop technology-based solutions: dedicated website, virtual navigation resources, consultation/chat support (100% Phase 1 & 75% Phase 2) 	\$ 200,000	\$ 150,000

ANNUAL FUNDING REQUESTED	\$ 3,730,000	\$ 3,520,000
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Pediatric Hospice Nurse Capacity Grant:

- Assembly approves Grant and existing nursing resources are deployed
- Pediatric hospice nursing certification is pursued and maintained through the Hospice and Palliative Credentialing Center (HPCC)
- Pediatric hospice nursing practicums are implemented through hospice organizations & pediatric hospitals

CHAMPIONCare:

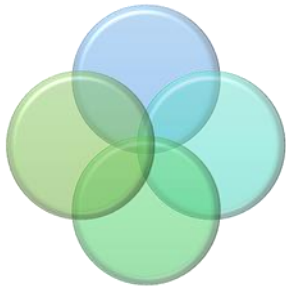
- Dedicated team formalizes roles and builds Pilot framework, supported by Pediatric Hospice Advisory Council & other stakeholders
- Care Navigators are engaged and begin to offer navigation and support
- Team supports Pediatric Hospice Nurse Capacity Grant needs
- Public education and resources are under development
- Legislative options being researched for future proposed changes

Pediatric Hospice Nurse Capacity Grant:

- Continued expansion of pediatric hospice nursing resources through training, practicums
- Broad geographic deployment of trained pediatric hospice nurses to cover all CT geographies
- Efforts continue to identify and cultivate future pediatric hospice RNs

CHAMPIONCare:

- With support of Pediatric Hospice Advisory Council, Team finalizes broad education content for in-person, virtual and print collaterals and begins to socialize with key advisors/stakeholders
- Education & curated resources are launched and socialized with pediatric practitioners, hospice agencies, CT DSS/DPH, hospitals, universities
- Legislative options under consideration
- Care Navigators continue to offer personalized support to families and practitioners



CHAMPIONCare

Children's Health, Advocacy,
Management & Palliative Hospice Care