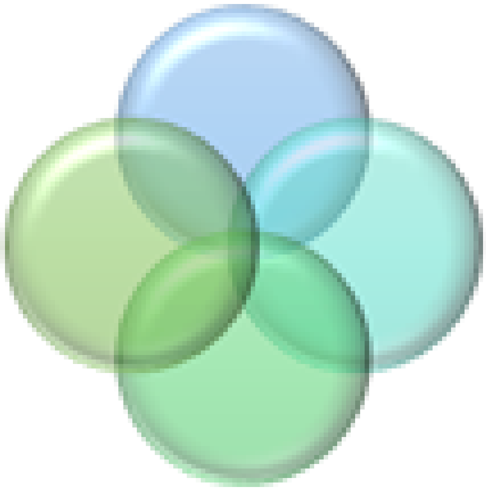
CHAMPION Care Action Team

Dec 3, 2025



Today's topics

- *Today's thought leader: Christine Mastropietro, Pediatric Nurse Consultant*
- *Other themes for the Action Team's consideration & feedback:*
    - *Our #1 challenge --> Access to data*
    - *Program barriers*
- *Next Steps --> timeline to finalize our report*
- *Reminder of our mandate*
- *Working Group Calendar*

Christine 'Chris' Mastropietro

- Pediatric Hospice Educator/Nurse Consultant with Regional Hospice of Western CT
- RN, CHPN, CHPPN, HPNA Certified in Pediatric Hospice

Kindness is at the core for Christine Mastropietro

"Three things in human life are important. The first is to be kind. The second is to be kind. And the third is to be kind."

Career Overview:

- Chris began her career as CNA then pursued her RN certification
- Upon graduating she worked in Labor and Delivery at Saint Mary's Hospital and later transitioned into hospice care, joining Regional Hospice's *Healing Hearts Center for Grief and Loss*
- Chris pursued advanced training, first becoming a CHPN (Certified Hospice and Palliative Nurse) and completed the highly specialized credential of CHPPN (Certified Hospice and Palliative Pediatric Nurse)
- Through her role with Regional Hospice, Chris supports and cares for babies who are diagnosed with life-limiting illness before birth (perinatal hospice)
- Chris participated in a pilot program, providing hospice care as part of an inpatient, hospice bed project for patients at Smilow Cancer Hospital at Yale New Haven
- She was selected as one of six national board members for the HPCC Pediatric Examination Development Committee

Our #1 challenge right now…getting data

Data is needed to prove and support the need for better and more comprehensive care for children in CT with life-limiting illnesses

What are all the sources of data about children in CT?

How can we get access to all viable data to prove our case? Who possesses this information?

How do we vet the full range of information sources to create accurate and provable information? (ie, to avoid duplicating sources)

Most importantly, what do these numbers tell us to help frame our proposal?

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Action Team Feedback: A Synopsis of Key Barriers

Our report will include identifying barriers and impediments that we face in creating a program that uses coalition of care approach. We need this team's experience and expertise to confirm we have the right list - and to refine them.

Theme	Overview
Nursing Resources	• Not enough trained pediatric palliative/hospice RNs to serve CT children with life-limiting conditions • Shift nurses receive low pay so disincentive to do shift work
Certification & Licensure	• No state-based minimum Certifications/Licensures – there are efforts in process with CT DPH Working Group to define baseline certifications
Geographic Access to Services	• Not enough certified facilities across CT that can accommodate children with life-limiting illnesses and/or who offer pediatric palliative and hospice care
Hospice Parameters	• Hospice care definitions impact and/or limit offering concurrent & palliative care o Physician diagnosis of 6 or less months to live is required which drives medical/care parameters and doesn't necessarily allow for pursuit of pediatric concurrent care options o Diagnosis drives insurances coverage which limits access to concurrent care – i.e., medical coding follows hospice designation
Continuity of Care/ Services delivery	• Inconsistent connections and handoffs within the medical community, hospice providers, case managers, etc, for example, there could be breaks in coordination between a facility and transition to home
Awareness of Available Resources	• Family testimonials tell us about their challenges trying to get the right information and complexity in navigating the healthcare system - they need the right services and support at the right time • Lack of awareness of available concurrent, palliative and hospice resources, both with the medical community, families, facilities, etc
Insurances	• A child may not have the right care and services because of confusing medical coding, getting insurance companies' approvals & reimbursements, help navigating the insurance landscape
Access to Medicaid	• Current federal funding, complexity of diagnoses/definitions, and program participation limits (eg, Katie Beckett Waiver) limit access to Medicaid funds
Fear of the 'H' word	• Families avoid engaging hospice resources because it may imply an end to their child's life, but it prevents them from having timely access to the right medical services, help with insurances navigation, comprehensive counseling, and important family support that could help with a child's transition if/when their condition worsens

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Next Steps – Finalizing our report – timing & action steps

Dec 10

- ***Action Team reviews elements of report***
- ***Action Team provides feedback following call***

Dec 11-Jan 2

- ***Individual team consultations held to refine and edit draft***
- ***By Jan 2 - New draft sent to Action Team to offer sufficient review time before in person meeting***

Dec 17

- **12/17 Advisory group call hosts speaker to share thought leadership**

Jan 7

- ***Action Team In person meeting to make 'deep dive' report edits***

Jan 8-18

- ***Feedback from Jan 7 meeting added to report***
- ***Individual team consultations held to make final edits***

Jan 21

- ***Report draft refined & shared with Action team***
- ***Continued individual consultations held to refine report***

Jan 28

- ***Thought leadership discussion with Advisory Group that reflect report themes/concepts***

Feb 6

- ***Report presentation to Assembly by Co-Chairs/Select Speakers***

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Working Group Mandate – A reminder of what we need to deliver

CT Senate Bill 1540: AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE PEDIATRIC HOSPICE WORKING GROUP.

To (1) require the working group concerning pediatric palliative and hospice care to develop recommendations for the establishment of a Children's Health, Advocacy, Management and Palliative Care program and Pediatric Palliative and Hospice Care Center of Excellence pilot program, and (2) require the Commissioner of Public Health to establish such programs.

Senate Bill No. 1540 aims to enhance the responsibilities of the existing working group focused on pediatric hospice services in Connecticut. The bill modifies the current duties of the working group, which were initially limited to reviewing existing services, making recommendations for appropriate service levels, and evaluating payment options. The new provisions require the working group to develop recommendations for establishing a Children's Health, Advocacy, Management, and Palliative Care program, which will include a Pediatric Palliative and Hospice Care Center of Excellence pilot program. This expanded scope will necessitate recommendations on appropriations, operational requirements, educational standards for nursing staff, and any necessary licensing or certification for the pilot program.

Key changes in the bill include the replacement of the existing responsibilities with a new timeline, specifying that the working group must complete its initial duties by March 1, 2025, and then focus on the new program until June 30, 2026. Additionally, the bill mandates that the chairpersons of the working group schedule a meeting within 30 days of the bill's passage to initiate work on these new responsibilities. The working group is also required to report its findings and recommendations to the Public Health Committee by March 1, 2026. Overall, the bill seeks to improve pediatric hospice care in the state by establishing a structured program and pilot initiative.

Comments / Expectations from Senator Anwar:

"We are hoping at the next legislative cycle to have some deliverables - so that there's a legislative opportunity to make things happen that you think would be critical. Of course, workforce is an issue, training is an issue. What that will entail is going to be an issue.

- *How do we actually prove that some of the things would work?*
- *How can we enhance existing hospice programs?*
- *What would be the cost associated with some of these implementations? (eg, workforce, training)*

Those are going to be critical. Money at times we say is tight, but I think this is one area which is so dear to literally every legislator that we will try and see what we can do to make sure we create something. So again, your collective wisdom and your focused asks of legislative results would be very helpful."

OUR 'ASK': Deliver a final draft proposal by Fri, Feb. 6, 2026 to the Assembly that will include:

- Prove the need for a pediatric program using metrics/data
- Analyze existing state programs to assess need for enhancements
- Propose pilot costs for Assembly budget

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Calendar

Upcoming Meetings (Calendar Invitations & Links Forthcoming)		Report Deadline
Action Team	Advisory Group	Feb 6, 2026
DEC • 12/10 o *Report elements reviewed & themes discussed* o *Action Team will receive a copy of draft report in early Jan in advance of Jan 7 meeting* **JAN** • 1/7 o *In person meeting to edit Assembly proposal* • 1/21 o *Review of updated Assembly proposal* **FEB** • 2/4 o *Final comments before Assembly submission*	**DEC** • 12/17 o *Offer thought leadership – consider including parent & caregiver testimonials to reinforce themes from our report* **JAN** • 1/28 o *Themes from proposal reviewed with Advisory Group*	• Final proposal is due to the CT Assembly by Friday, Feb 6, 2026