Public Health Committee
JOINT FAVORABLE REPORT

Bill No.: SB-1540
Title: AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE PEDIATRIC HOSPICE WORKING GROUP.
Vote Date: 3/27/2025
Vote Action: Joint Favorable Change of Reference to Appropriations
PH Date: 3/24/2025
File No.:

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SPONSORS OF BILL:

The Public Health Committee.

REASONS FOR BILL:

A Working Group to study the issue of pediatric hospice services was established last year with the passage of PA 24-19. This Working Group has requested additional time to continue their research into this issue. This bill addresses the extension request and expands the responsibilities of the group to include the following:

- Develop recommendations to establish a Children's Health, Advocacy Management and Palliative Care Program.
- Devise a Palliative and Hospice Care Center of Excellence pilot program and report the recommendations of the program to the Public Health Committee by March 1, 2026.
- Requires the commissioner of the Department of Public Health (DPH), in collaboration with Connecticut hospitals and hospice agencies, to establish both the new program and pilot program by July1, 2026.

The pilot program must do the following:

- Use best practices to support expanding pediatric hospice care in the state.
- Include tracking patient metrics to predict the scope of the state's future need for these services.

In addition, the bill allows the commissioner to contract with a Connecticut hospice agency to operate the pilot program. It requires the commissioner to report on its status to the Public Health Committee by January 1, 2027.

RESPONSE FROM ADMINISTRATION/AGENCY:

None expressed.

NATURE AND SOURCES OF SUPPORT:

Connecticut Hospital Association, CHA:
SB 1540 would continue the efforts of the Working Group to develop programs that would enhance the quality of life, when at the end of life, for children and their families before, during and after their death. For almost 20 years, Massachusetts has provided palliative and hospice services to children and their families though the Pediatric Palliative Care Network. This program has provided children and their families with programs and supports that are absent in our state. With the passage of this bill, we could develop and support these same programs in Connecticut.

Kim Sandor, Executive Director, Connecticut Nurses Association:
Ms. Sandor pointed out that pediatric hospice and palliative care provide a holistic approach to addressing the unique needs of children with complex medical conditions. Research supports pediatric palliative care and hospice, not only because it is the compassionate care a child and family deserve, but also improves the quality of life for children and critical support for families at a very difficult time. In addition, research has shown that these type of services reduce hospitalizations and healthcare costs and address disparities in pediatric care.

Toni-Ann Marchione, President, and CEO of Regional Hospice:
As Co-Chair of the Task Force to Study Pediatric Hospice in our state, Ms. Marchione explained the main goal of their work is to ensure that children facing life-limiting illnesses and their families have access to the care, support, and the dignity they deserve during this challenging time. Each of their recommendations is made with this goal in mind. Nurses are the heart of hospice and educating them in pediatric and hospice care is essential, as well as the need for physicians to understand concurrent care. We also learned that many families are not fully aware of the scope of pediatric hospice services due to a lack of consistent communication. With the need for additional work, the Task Force has requested more time to develop a pilot program and conduct further research into successful models from other states that have effectively implemented pediatric hospice programs.

Tracy Wodatch, President and CEO, The Connecticut Association for Healthcare at Home:
Ms. Wodatch pointed out that back in 2010 as part of the Affordable Care Act (ACA), a law was established that state Medicaid programs are now required to pay for both curative, life prolonging treatment, and hospice services for children under age 21 who qualify. Prior to the ACA, both children and adults had to have a 6-month prognosis and forego any life - prolonging, curative treatments to enroll in hospice. The reality that families experience when their child is facing a terminal illness is one of fight to the end and never give up. We need a program in our state that supports families facing such life-altering challenges.

Kerry Moss, MD Medical Director, Connecticut Children's Palliative Care Program:
Unlike adults with terminal illness, children do not receive the same access to hospice and related end-of-life support services. In fact, the data shows that there is not a single agency that provides services exclusively for children and most adult agencies lack the expertise or training to provide such services The reality that children die in the hospital because we are unable to provide them with the appropriate home services is unconscionable. We can and must do better.

The following submitted similar testimony in support of this bill:

- Karen Garlie, Senior Manager and Hospice Program Director, Yale New Haven Health at Home
- Regional Hospice, Danbury, CT.
- Eileen O'Shea, President, Pediatric Palliative Care Coalition of Connecticut.

NATURE AND SOURCES OF OPPOSITION:

None expressed.

Reported by: Kathleen Panazza **Date: March 28, 2025.**