

## Public Health Committee JOINT FAVORABLE REPORT

**Bill No.:** SB-176  
AN ACT REQUIRING A PLAN TO ESTABLISH A HOSPICE PROGRAM FOR  
**Title:** CHILDREN.  
**Vote Date:** 3/4/2024  
**Vote Action:** Joint Favorable Substitute  
**PH Date:** 2/26/2024  
**File No.:** 16

***Disclaimer:** The following JOINT FAVORABLE Report is prepared for the benefit of the members of the General Assembly, solely for purposes of information, summarization and explanation and does not represent the intent of the General Assembly or either chamber thereof for any purpose.*

### **SPONSORS OF BILL:**

The Public Health Committee

### **REASONS FOR BILL:**

Connecticut recognizes the vital services and benefits provided through hospice care for both patients and their families experiencing an end-of-life event. Currently, hospice services are provided to adults. The intent of this legislation is to provide this same hospice and palliative care support for children and their families. This bill requires the Department of Public Health (DPH) to develop a plan to establish these programs, as well as expand existing programs, and report back to the Public Health Committee by January 1, 2025, on the plan and its anticipated timeframe.

### **RESPONSE FROM ADMINISTRATION/AGENCY:**

#### **Manisha Juthani, Commissioner, CT Department of Public Health (DPH):**

The Commissioner shared that the Department understands and appreciates the work done by hospice and palliative providers and recognizes the need to support existing programs as well as expand those currently in the state. However, it is beyond the scope of the DPH to develop plans to establish private entities in this state. To do so would require the DPH to hire an outside contractor to develop such a plan and require resources that were not included in the Governor's budget. The Department looks forward to continuing conversations on how best to address this very important service.

## **NATURE AND SOURCES OF SUPPORT:**

### **Tracy Wodatch, President and CEO, CT Association of Healthcare at Home:**

In her testimony, Ms. Wodatch explained the difference between hospice and palliative care. She also shared that she is a member of the legislatively mandated DPH-run council charged with analyzing the current state of palliative and hospice care in our state. The council submits an annual report with its findings and recommendations for improvement. Since 2018, this report has identified a gap in this type of care for children. Her agency has received many calls from CT Children's and Yale New Haven hospital seeking these services for children and she is saddened by having so few options to offer. There is a desperate need, not only to expand existing programs, but also create more such programs.

### **Toni Ann Marchione, President and CEO, Regional Hospice:**

Ms. Marchione shared that since 1983, Regional Hospice has been providing critical support to families caring for a child diagnosed with a critical or terminal condition, not only through hospice care, but also inpatient care for respite and pain management. The complexities associated with pediatric illnesses require specialized expertise and resources. There is a high demand and need for pediatric nurses which come with a premium cost. The need for such services is growing and without the support and funding needed will continue to be unmet. Our organization supports this critical bill as well as a similar bill introduced by Sen. Kushner in the Appropriations Committee for this vital funding.

### **Dr. Kerry Moss, Pediatric Physician, CT Children's:**

Unlike adults with terminal illnesses, children do not receive the same access to end-of-life support services. Adult agencies lack the expertise to appreciate and understand the unique developmental needs of children. It is unfair that children die in the hospital because we are unable to provide them with the appropriate home services to spend their last days surrounded by family in a familiar environment. In her testimony, Dr. Moss shared stories of her personal involvement in such cases.

### **Taryn Hamre, APRN, CT Children's:**

Ms. Harme shared that she is an APRN and a part of the Sunflower Kids Pediatric Palliative Care Team at CT Children's, as well as a member of the CT DPH Palliative Care Advisory Council. She emphasized the specialized care that is required to address the needs of children in these situations and supports any effort that ensures children receive age-appropriate care that is sensitive to their individual needs. The implementation of a hospice program specifically designed for children will also offer much needed support both physical and psychological to family members. Ms. Harme shared that one of the most challenging moments of her job is when she is unable to discharge a patient who wishes to finish out their final time in the comfort of their home and surrounded by family.

### **Karen Garlie, RN BSN, Yale New Haven Health:**

Ms. Garlie expressed her strong support for this legislation. As Senior Manager of Yale New Haven at Home Hospice Services, she has been contacted by providers seeking assistance with care for an infant or child hoping to go home to spend their final days. She has even been asked if the program would provide services as minimal as pronouncing an infant as

deceased so they would not have to return to the hospital for the pronouncement to be made. The need for these services is great and she urges support for this vital program.

- **Betty Burgess, Bereavement Volunteer, Bristol Health Home Care & Hospice**
- **Cocco Sellman, Co-Owner of All Pointe Home Care and Chair of Ct Association of Healthcare at Home**
- **Dr. Eileen O'Shea, President of the Palliative Care Coalition of CT, and Pediatric Nursing Professor at Fairfield University**

All the above submitted testimony in support of this legislation and shared personal experiences with actual cases.

**NATURE AND SOURCES OF OPPOSITION:**

None expressed.

**Reported by: Kathleen Panazza**

**Date: March 5, 2024**