

General Assembly

January Session, 2025

Raised Bill No. 1540

LCO No. **6497**

Referred to Committee on PUBLIC HEALTH

Introduced by: (PH)

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:

Section 1. Section 29 of public act 24-19 is repealed and the following
 is substituted in lieu thereof (*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. The working group shall include, but need not
be limited to, the following members:

8 (1) At least one representative of each pediatric hospice association in9 the state;

(2) One representative of each organization licensed as a hospice by
the Department of Public Health pursuant to section 19a-122b of the
general statutes;

13 (3) At least one representative of an association of hospitals in the

14	state;		
15	(4) One representative each of two children's hospitals in the state;		
16	(5) One pediatric oncologist;		
17	(6) One pediatric intensivist;		
18 19 20	(7) The chairpersons and ranking members of the joint standing committee of the General Assembly having cognizance of matters relating to public health;		
21 22	(8) The Commissioner of Public Health, or the commissioner's designee; and		
23 24	(9) The Commissioner of Social Services, or the commissioner's designee.		
25 26	(b) [The] <u>(1) On and before March 1, 2025, the</u> working group shall be responsible for the following:		
27 28	[(1)] (<u>A</u>) Reviewing existing hospice services for pediatric patients across the state;		
29 30	[(2)] (<u>B</u>) Making recommendations for appropriate levels of hospice services for pediatric patients across the state; and		
31 32	[(3)] (<u>C</u>) Evaluating payment and funding options for pediatric hospice care.		
33	(2) On and after March 1, 2025, and before July 1, 2026, the working		
34	group shall be responsible for developing recommendations for the		
35	establishment of a Children's Health, Advocacy, Management and		
36	Palliative Care program and, within such program, a Pediatric Palliative		
37	and Hospice Care Center of Excellence pilot program, as described in		
38	the working group's report submitted pursuant to subdivision (1) of		
39	subsection (f) of this section, including, but not limited to,		
40	recommendations regarding (A) appropriations necessary to establish		

41 such program and pilot program, (B) requirements for the operation of 42 the pilot program, including, but not limited to, staff and facility requirements, (C) education and curriculum requirements for nurses 43 participating in the pilot program or providing pediatric palliative or 44 45 hospice care services, and (D) any licensing or certification requirements 46 necessary for the operation of the pilot program or expanding the 47 provision of pediatric palliative or hospice care services in the state. 48 (c) The cochairpersons of the joint standing committee of the General 49 Assembly having cognizance of matters relating to public health shall 50 schedule the first meeting of the working group, which shall be held not

51 later than [sixty days after the effective date of this section] July 20, 2024.

(d) The members of the working group shall elect two chairpersons
from among the members of the working group. Not later than thirty
<u>days after the effective date of this section, the chairpersons of the</u>
working group shall schedule a meeting of the working group to initiate
work on the responsibilities described in subdivision (2) of subsection
(b) of this section.

(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) (1) 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.

(2) Not later than March 1, 2026, 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 recommendations developed pursuant to subdivision (2)
of subsection (b) of this section.

72 Sec. 2. (NEW) (Effective from passage) Not later than July 1, 2026, the 73 Commissioner of Public Health shall, in collaboration with hospitals 74 and hospice agencies in the state, establish a Children's Health, 75 Advocacy, Management and Palliative Care program and, within such 76 program, a Pediatric Palliative and Hospice Care Center of Excellence 77 pilot program. Such pilot program shall (1) utilize best practices to 78 support the expansion of pediatric palliative and hospice care in the 79 state, and (2) include tracking of patient metrics to predict the scope of 80 future pediatric palliative and hospice care services needs in the state. 81 The commissioner may contract with a hospice agency in the state to 82 operate such pilot program. Not later than January 1, 2027, the 83 commissioner shall submit a report, in accordance with the provisions 84 of section 11-4a of the general statutes, to the joint standing committee 85 of the General Assembly having cognizance of matters relating to public 86 health regarding such pilot program. Such report shall include, but need 87 not be limited to, information regarding the number of pediatric 88 patients that received hospice care under the pilot program, a summary 89 of any relevant pilot program feedback received by the commissioner 90 from any patient, patient's family member, health care provider, 91 hospital or hospice agency and legislative recommendations for the 92 expansion of the Children's Health, Advocacy, Management and 93 Palliative Care program or the Pediatric Palliative and Hospice Care 94 Center of Excellence pilot program.

This act shall take effect as follows and shall amend the following			
sections:			
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Section 1	from passage	PA 24-19, Sec. 29	
Sec. 2	from passage	New section	

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Statement of Purpose:

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.

[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]