

1 STATE OF OKLAHOMA

2 1st Session of the 59th Legislature (2023)

3 HOUSE BILL 2510

By: Pittman

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5  
6 AS INTRODUCED

7 An Act relating to pediatric palliative care;  
8 defining terms; creating program; defining program  
9 qualifications; authorizing standards; allowing State  
10 Department of Health to promulgate rules; requiring  
11 the Department to oversee administration of the  
12 program; requiring the Department to report to the  
13 Legislature; providing for codification; and  
14 providing an effective date.

15 BE IT ENACTED BY THE PEOPLE OF THE STATE OF OKLAHOMA:

16 SECTION 1. NEW LAW A new section of law to be codified  
17 in the Oklahoma Statutes as Section 1-245 of Title 63, unless there  
18 is created a duplication in numbering, reads as follows:

19 A. As used in this act:

20 1. "Department" means the State Department of Health;

21 2. "Palliative care" means care focused on expert assessment  
22 and management of pain and other symptoms, assessment and support of  
23 caregiver needs, and coordination of care. Palliative care attends  
24 to the physical, functional, psychological, practical, and spiritual  
consequences of a serious illness. It is a person-centered and  
family-centered approach to care, providing people living with a

1 serious illness relief from the symptoms and stress of the illness.  
2 Through early integration into the care plan for the seriously ill,  
3 palliative care improves quality of life for the patient and the  
4 family. Palliative care can be offered in all care settings and at  
5 any stage in a serious illness through collaboration of many types  
6 of care providers; and

7 3. "Serious illness" means a health condition that carries a  
8 high risk of mortality and negatively impacts a person's daily  
9 function or quality of life.

10 B. The Department shall develop a pediatric palliative care  
11 program, and the program shall cover community-based pediatric  
12 palliative care from a trained interdisciplinary team under which a  
13 qualifying child may also choose to continue curative or disease-  
14 directed treatments for a serious illness under the benefits  
15 available.

16 C. If applicable, the Department shall submit the necessary  
17 application to the federal Centers for Medicare and Medicaid  
18 Services for a waiver or state plan amendment to implement the  
19 program described in this act. After federal approval is secured,  
20 the Department shall implement the waiver or state plan amendment  
21 within twelve (12) months of the date of approval. The Department  
22 shall not draft any rules in contravention of this timetable for  
23 program development and implementation.

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1 D. For the purposes of this act, a qualifying child is a person  
2 under twenty-one (21) years of age who is enrolled in SoonerCare and  
3 is diagnosed by the child's primary physician or specialist as  
4 suffering from a serious illness.

5 E. The Department, in consultation with interested  
6 stakeholders, shall determine the serious illnesses that render a  
7 child eligible for the program under this act. Such serious  
8 illnesses shall include, but not be limited to, the following:

9 1. Cancer for which there is no known effective treatment, that  
10 does not respond to conventional protocol, that has progressed to an  
11 advanced stage, or where toxicities or other complications limit the  
12 administration of curative therapies;

13 2. End-stage lung disease, including, but not limited to,  
14 cystic fibrosis, that results in dependence on technology, such as  
15 mechanical ventilation;

16 3. Severe neurological conditions, including, but not limited  
17 to, hypoxic ischemic encephalopathy, acute brain injury, brain  
18 infections and inflammatory diseases, or irreversible severe  
19 alteration of mental status, with one of the following  
20 comorbidities:

- 21 a. intractable seizures, or
- 22 b. brain stem failure to control breathing or other  
23 automatic physiologic functions;

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- 1       4. Degenerative neuromuscular conditions, including, but not  
2 limited to, spinal muscular atrophy, or Duchenne muscular dystrophy,  
3 Type 1 or 2, requiring technological support;
- 4       5. Genetic syndromes, such as, Trisomy 13 or 18, where the  
5 child has substantial neurocognitive disability with no expectation  
6 of long-term survival;
- 7       6. Congenital or acquired end-stage heart disease without  
8 adequate medical or surgical treatments available;
- 9       7. End-stage liver disease, where a transplant is not a viable  
10 option or a transplant rejection or failure has occurred;
- 11       8. End-stage kidney failure, where a transplant is not a viable  
12 option or a transplant rejection or failure has occurred;
- 13       9. Metabolic or biochemical disorders, including, but not  
14 limited to, mitochondrial disease, leukodystrophies, Tay-Sachs  
15 disease, or Lesch-Nyhan syndrome, where no suitable therapies exist  
16 or available treatments, including stem cell transplant or bone  
17 marrow transplant, have failed;
- 18       10. Congenital or acquired diseases of the gastrointestinal  
19 system, such as short bowel syndrome, where a transplant is not a  
20 viable option or a transplant rejection or failure has occurred;
- 21       11. Congenital skin disorders, including, but not limited to,  
22 epidermolysis bullosa, where no suitable treatment exists; and  
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1 12. Any other serious illness that the Department, in  
2 consultation with interested stakeholders, determines to be  
3 appropriate.

4 The definition of a serious illness shall not include a  
5 definitive time period due to the difficulty and challenges of  
6 prognosticating life expectancy in children.

7 F. Providers authorized to deliver services under the program  
8 shall include licensed hospice agencies or home health agencies  
9 licensed to provide hospice care or entities with demonstrated  
10 expertise in pediatric palliative care and will be subject to  
11 further criteria developed by the Department, in consultation with  
12 interested stakeholders, for provider participation. At a minimum,  
13 the participating provider must house a pediatric interdisciplinary  
14 team that includes, but is not limited to:

15 1. A physician, acting as the program medical director, who is  
16 board certified or board eligible in pediatrics or hospice and  
17 palliative medicine;

18 2. A registered nurse; and

19 3. A licensed social worker with a background in pediatric  
20 care.

21 G. All members of the pediatric interdisciplinary team must  
22 meet criteria the Department may establish by rule, including  
23 demonstrated expertise in pediatric palliative care.

1 H. Subject to federal approval for matching funds, the  
2 reimbursable services offered under the program shall be provided by  
3 the interdisciplinary team, operating under the direction of a  
4 program medical director, and shall include, but not be limited to,  
5 the following:

6 1. Nursing for pain and symptom management;

7 2. Expressive therapies, such as music or art therapies, for  
8 age-appropriate counseling;

9 3. Client and family counseling provided by a licensed social  
10 worker, licensed professional counselor, child life specialist, or  
11 nondenominational chaplain or spiritual counselor;

12 4. Respite care;

13 5. Bereavement services;

14 6. Case management; or

15 7. Any other services that the Department determines to be  
16 appropriate.

17 I. The Department shall establish standards for and provide  
18 technical assistance to managed care organizations to ensure the  
19 delivery of pediatric palliative care services to qualifying  
20 children.

21 J. The Department shall oversee the administration of the  
22 program. The Department, in consultation with interested  
23 stakeholders, shall determine the appropriate process for review of  
24 referrals and enrollment of qualifying children. The Department

1 shall appoint an individual or entity to serve as program manager or  
2 an alternative position to assess level-of-care and target-  
3 population criteria for the program. The Department shall ensure  
4 that the individual or entity meets the criteria for demonstrated  
5 expertise in pediatric palliative care that the Department, in  
6 consultation with interested stakeholders, may establish by rule.  
7 The process for review of referrals and enrollment of qualifying  
8 children shall not include unnecessary delays and shall reflect the  
9 fact that treatment of pain and other distressing symptoms  
10 represents an urgent need for children with a serious illness. The  
11 process shall also acknowledge that children with a serious illness  
12 and their families require holistic and seamless care.

13 K. After the program has been in place for three (3) years, the  
14 Department shall prepare a report for the Legislature concerning the  
15 program's outcomes and effectiveness and shall also make  
16 recommendations for program improvement, including, but not limited  
17 to, the appropriateness of those serious illnesses that render a  
18 child who is enrolled in the medical assistance program eligible for  
19 the pediatric palliative care program and the necessary services  
20 needed to ensure high-quality care for qualifying children and their  
21 families.

22 L. Nothing in this act shall be construed so as to result in  
23 the elimination or reduction of any benefits or services covered  
24 under another program.

1 M. This act does not affect an individual's eligibility to  
2 receive, concurrently with the benefits provided for in this act,  
3 any services, including home health services, for which the  
4 individual would have been eligible in the absence of this act.

5 SECTION 2. This act shall become effective November 1, 2023.

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7 59-1-7036 TJ 12/29/22

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