STATE OF OKLAHOMA

2nd Session of the 58th Legislature (2022)

HOUSE BILL 4396 By: Pittman

AS INTRODUCED

An Act relating to pediatric palliative care; defining terms; creating program; defining program qualifications; authorizing standards; allowing State Department of Health to promulgate rules; providing for codification; and providing an effective date.

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

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

A. As used in this act:

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

2. "Palliative care" means care focused on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends 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 serious illness relief from the symptoms and stress of an illness.

Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family. Palliative care can be offered in all care settings and at any stage in a serious illness through collaboration of many types of care providers; and

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

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

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

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

E. The Department, in consultation with interested stakeholders, shall determine the serious illnesses that render a child who is enrolled in the medical assistance program eligible for the program under this act. Such serious illnesses shall include, but not be limited to, the following:

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

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

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

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

4. Degenerative neuromuscular conditions, including, but not limited to, spinal muscular atrophy, Duchenne Muscular Dystrophy, or Type 1 or 2, requiring technological support;

5. Genetic syndromes, such as, but not limited to, Trisomy 13 or 18, where the child has substantial neurocognitive disability with no expectation of long-term survival;

6. Congenital or acquired end-stage heart disease without adequate medical or surgical treatments available;

7. End-stage liver disease, where a transplant is not a viable option or a transplant rejection or failure has occurred;

8. End-stage kidney failure, where a transplant is not a viable option or a transplant rejection or failure has occurred;

9. Metabolic or biochemical disorders, including, but not limited to, mitochondrial disease, leukodystrophies, Tay-Sachs disease, or Lesch-Nyhan syndrome, where no suitable therapies exist or available treatments, including stem cell transplant, or bone marrow transplant, have failed;

10. Congenital or acquired diseases of the gastrointestinal system, such as short bowel syndrome, where a transplant is not a viable option or a transplant rejection or failure has occurred;

11. Congenital skin disorders, including but not limited to, epidermolysis bullosa, where no suitable treatment exists; and

12. Any other serious illness that the Department, in consultation with interested stakeholders, determines to be appropriate.

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

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

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

2. A registered nurse; and

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

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

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

1. Nursing for pain and symptom management;

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

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

4. Respite care;

5. Bereavement services;

6. Case management; or

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

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

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

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

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

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

SECTION 2. This act shall become effective November 1, 2022.

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