SB2931

LRB09617757KTG35199b

96TH GENERAL ASSEMBLY

State of Illinois

2009 and 2010

SB2931

Introduced 1/28/2010, by Sen. Dale A. Righter

SYNOPSIS AS INTRODUCED:

New Act
210 ILCS 60/15

Creates the Pediatric Palliative Care Act. Provides that the Department of Healthcare and Family Services shall develop a pediatric palliative care pilot program under which a qualifying child may receive community-based pediatric palliative care from a trained interdisciplinary team while continuing to pursue aggressive curative treatments for a potentially life-limiting medical condition under the benefits available under the Medicaid program. Provides that the Department shall apply for a federal waiver or State Plan amendment to conduct the program. Provides that if the Department applies for a State Plan amendment, the amendment shall be filed prior to December 31, 2010. Provides that a "qualifying child" for the pilot program is a child under the age of 18 years who is enrolled in the Medicaid program and suffers from a potentially life-limiting medical condition. Requires a report to the General Assembly at the end of the 3-year pilot period. Effective immediately.

LRB096 17757 KTG 35199 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

AN ACT concerning public aid.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 1. Short title. This Act may be cited as the Pediatric Palliative Care Act.

Section 5. Legislative findings. The General Assembly finds as follows:

(1) Each year, approximately 1,185 Illinois children are diagnosed with a potentially life-limiting illness.

(2) There are many barriers to the provision of pediatric palliative services, the most significant of which include the following: (i) challenges in predicting life expectancy; (ii) the reluctance of families and professionals to acknowledge a child's incurable condition; and (iii) the lack of an appropriate, pediatric-focused reimbursement structure leading to insufficient community-based resources.

(3) It is tremendously difficult for physicians to prognosticate pediatric life expectancy due to the resiliency of children. In addition, parents are rarely prepared to cease curative efforts in order to receive hospice or palliative care. Community-based pediatric palliative services, however, keep children out of the

hospital by managing many symptoms in the home setting, thereby improving childhood quality of life while maintaining budget neutrality.

(4) Pediatric palliative programming can, and should, be administered in a cost neutral fashion. Community-based pediatric palliative care allows for children and families to receive pain and symptom management and psychosocial support in the comfort of the home setting, thereby avoiding excess spending for emergency room visits and certain hospitals. The National Hospice and Palliative Care Organization's pediatric task force reported during 2001 that the average cost per child per year, cared for primarily at home, receiving comprehensive palliative and life prolonging services concurrently, is $16,177, significantly less than the $19,000 to $48,000 per child per year when palliative programs are not utilized.

Section 10. Definition. In this Act, "Department" means the Department of Healthcare and Family Services.

Section 15. Pediatric palliative care pilot program. The Department shall develop a pediatric palliative care pilot program under which a qualifying child as defined in Section 25 may receive community-based pediatric palliative care from a trained interdisciplinary team while continuing to pursue aggressive curative treatments for a potentially life-limiting

illness under the benefits available under Article V of the Illinois Public Aid Code.

Section 20. Federal waiver or State Plan amendment. 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 pilot program described in this Act. If the application is in the form of a State Plan amendment, the State Plan amendment shall be filed prior to December 31, 2010. If the Department does not submit a State Plan amendment prior to December 31, 2010, the pilot program shall be created utilizing a waiver authority. The waiver request shall be included in any appropriate waiver application renewal submitted prior to December 31, 2011, or shall be submitted as an independent 1915(c) Home and Community Based Medicaid Waiver within that same time period. After federal approval is secured, the Department shall implement the waiver or State Plan amendment within 12 months of the date of approval. By federal requirement, the application for a 1915 (c) Medicaid waiver program must demonstrate cost neutrality per the formula laid out by the Centers for Medicare and Medicaid Services. The Department shall not draft any rules in contravention of this timetable for pilot program development and implementation. This pilot program shall be implemented only to the extent that federal financial participation is available.

Section 25. Qualifying child.

(a) For the purposes of this Act, a qualifying child is a person under 18 years of age who is enrolled in the medical assistance program under Article V of the Illinois Public Aid Code and suffers from a potentially life-limiting medical condition, as defined in subsection (b). A child who is enrolled in the pilot program prior to the age 18 may continue to receive services under the pilot program until the day before his or her twenty-first birthday.

(b) The Department, in consultation with interested stakeholders, shall determine the potentially life-limiting medical conditions that render a pediatric medical assistance recipient eligible for the pilot program under this Act. Such medical conditions shall include, but need not be limited to, the following:

(1) Cancer (i) for which there is no known effective treatment, (ii) that does not respond to conventional protocol, (iii) that has progressed to an advanced stage, or (iv) where toxicities or other complications prohibit 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 co-morbidities: (i) intractable seizures or (ii) brainstem failure to control breathing or other automatic physiologic functions.

(4) Degenerative neuromuscular conditions, including, but not limited to, spinal muscular atrophy, Type I or II, or Duchenne Muscular Dystrophy, requiring technological support.

(5) Genetic syndromes, such as Trisomy 13 or 18, where (i) it is more likely than not that the child will not live past 2 years of age or (ii) the child is severely compromised with no expectation of long-term survival.

(6) Congenital or acquired end-stage heart disease, including but not limited to the following: (i) single ventricle disorders, including hypoplastic left heart syndrome; (ii) total anomalous pulmonary venous return, not suitable for curative surgical treatment; and (iii) heart muscle disorders (cardiomyopathies) without adequate medical or surgical treatments.

(7) End-stage liver disease where (i) transplant is not a viable option or (ii) transplant rejection or failure has occurred.

(8) End-stage kidney failure where (i) transplant is not a viable option or (ii) 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 (i) no suitable therapies exist or (ii) available treatments, including stem cell ("bone marrow") transplant, have failed.

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

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

The definition of a life-limiting medical condition shall not include a definitive time period due to the difficulty and challenges of prognosticating life expectancy in children.

Section 30. Authorized providers. Providers authorized to deliver services under the pilot waiver program shall include licensed hospice agencies or home health agencies licensed to provide hospice care and will be subject to further criteria developed by the Department for provider participation. At a minimum, the participating provider must house a pediatric interdisciplinary team that includes a pediatric medical director, a nurse, and a licensed social worker. All members of the pediatric interdisciplinary team must submit to the

Department proof of pediatric End-of-Life Nursing Education Curriculum (Pediatric ELNEC Training) or an equivalent.

Section 35. Interdisciplinary team; services. Subject to federal approval for matching funds, the reimbursable services offered under the pilot program shall be provided by an interdisciplinary team, operating under the direction of a pediatric medical director, and shall include, but not be limited to, the following:

(1) Pediatric nursing for pain and symptom management.

(2) Expressive therapies (music and art therapies) for age-appropriate counseling.

(3) Client and family counseling (provided by a licensed social worker or non-denominational chaplain or spiritual counselor).

(4) Respite care.

(5) Bereavement services.

(6) Case management.

Section 40. Administration.

(a) The Department shall oversee the administration of the pilot program. The Department, in consultation with interested stakeholders, shall determine the appropriate process for review of referrals and enrollment of qualifying participants.

(b) The Department shall appoint an individual or entity to serve as case manager or an alternative position to assess

level-of-care and target-population criteria for the pilot program. The Department shall ensure that the individual receives pediatric End-of-Life Nursing Education Curriculum (Pediatric ELNEC Training) or an equivalent to become familiarized with the unique needs and difficulties facing this population. The process for review of referrals and enrollment of qualifying participants 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 life-limiting medical conditions. The process shall also acknowledge that children with life-limiting medical conditions and their families require holistic and seamless care.

Section 45. Period of pilot program.

(a) The program implemented under this Act shall be considered a pilot program for 3 years following the date of program implementation or, if the pilot program is created utilizing a waiver authority, until the waiver that includes the services provided under the program undergoes the federally mandated renewal process.

(b) During the period of time that the waiver program is considered a pilot program, pediatric palliative care shall be included in the issues reviewed by the Hospice and Palliative Care Advisory Board. The Board shall make recommendations regarding changes or improvements to the program, including but

not limited to advisement on potential expansion of the potentially life-limiting medical conditions as defined in subsection (b) of Section 25.

(c) At the end of the 3-year pilot program, the Department shall prepare a report for the General Assembly concerning the program's outcomes effectiveness and shall also make recommendations for program improvement, including, but not limited to, the appropriateness of the potentially life-limiting medical conditions as defined in subsection (b) of Section 25.

Section 50. Effect on medical assistance program.

(a) Nothing in this Act shall be construed so as to result in the elimination or reduction of any benefits or services covered under the medical assistance program under Article V of the Illinois Public Aid Code.

(b) 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 90. The Hospice Program Licensing Act is amended by changing Section 15 as follows:

(210 ILCS 60/15)

Sec. 15. Hospice and Palliative Care Advisory Board.

(a) The Director shall appoint a Hospice and Palliative Care Advisory Board ("the Board") to consult with the Department as provided in this Section. The membership of the Board shall be as follows:

(1) The Director, ex officio, who shall be a nonvoting member and shall serve as chairman of the Board.

(2) One representative of each of the following State agencies, each of whom shall be a nonvoting member: the Department of Healthcare and Family Services, the Department of Human Services, and the Department on Aging.

(3) One member who is a physician licensed to practice medicine in all its branches, selected from the recommendations of a statewide professional society representing physicians licensed to practice medicine in all its branches in all specialties.

(4) One member who is a registered nurse, selected from the recommendations of professional nursing associations.

(5) Four members selected from the recommendations of organizations whose primary membership consists of hospice programs.

(6) Two members who represent the general public and who have no responsibility for management or formation of policy of a hospice program and no financial interest in a hospice program.

(7) One member selected from the recommendations of

consumer organizations that engage in advocacy or legal representation on behalf of hospice patients and their immediate families.

(b) Of the initial appointees, 4 shall serve for terms of 2 years, 4 shall serve for terms of 3 years, and 5 shall serve for terms of 4 years, as determined by lot at the first meeting of the Board. Each successor member shall be appointed for a term of 4 years. A member appointed to fill a vacancy before the expiration of the term for which his or her predecessor was appointed shall be appointed to serve for the remainder of that term.

(c) The Board shall meet as frequently as the chairman deems necessary, but not less than 4 times each year. Upon the request of 4 or more Board members, the chairman shall call a meeting of the Board. A Board member may designate a replacement to serve at a Board meeting in place of the member by submitting a letter stating that designation to the chairman before or at the Board meeting. The replacement member must represent the same general interests as the member being replaced, as described in paragraphs (1) through (7) of subsection (a).

(d) Board members are entitled to reimbursement for their actual expenses incurred in performing their duties.

(e) The Board shall advise the Department on all aspects of the Department's responsibilities under this Act, including the format and content of any rules adopted by the Department

on or after the effective date of this amendatory Act of the 95th General Assembly. Any such rule or amendment to a rule proposed on or after the effective date of this amendatory Act of the 95th General Assembly, except an emergency rule adopted pursuant to Section 5-45 of the Illinois Administrative Procedure Act, that is adopted without obtaining the advice of the Board is null and void. If the Department fails to follow the advice of the Board with respect to a proposed rule or amendment to a rule, the Department shall, before adopting the rule or amendment to a rule, transmit a written explanation of the reason for its action to the Board. During its review of rules, the Board shall analyze the economic and regulatory impact of those rules. If the Board, having been asked for its advice with respect to a proposed rule or amendment to a rule, fails to advise the Department within 90 days, the proposed rule or amendment shall be considered to have been acted upon by the Board.

(f) The Board shall also review pediatric palliative care issues as provided in the Pediatric Palliative Care Act.

(Source: P.A. 95-133, eff. 1-1-08.)

Section 99. Effective date. This Act takes effect upon becoming law.