



96TH GENERAL ASSEMBLY

State of Illinois

2009 and 2010

HB2634

Introduced 2/20/2009, by Rep. Julie Hamos

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 to conduct the program. 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. Sets forth certain counties to be included in the pilot program. Requires a report to the General Assembly at the end of the 3-year pilot period. Effective immediately.

LRB096 10826 DRJ 21049 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning public aid.

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

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

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

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

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

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

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

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

6 Section 15. Pediatric palliative care pilot program. The
7 Department shall develop a pediatric palliative care pilot
8 program under which a qualifying child as defined in Section 25
9 may receive community-based pediatric palliative care from a
10 trained interdisciplinary team while continuing to pursue
11 aggressive curative treatments for a potentially life-limiting
12 illness under the benefits available under Article V of the
13 Illinois Public Aid Code.

14 Section 20. Federal waiver. The Department shall submit the
15 necessary application to the federal Centers for Medicare and
16 Medicaid Services for a waiver to implement the pilot program
17 described in this Act. The waiver request shall be included in
18 any appropriate waiver application renewal submitted within 12
19 months after the effective date of this Act, or shall be
20 submitted as an independent 1915(c) Home and Community Based
21 Medicaid Waiver within that same time period. After federal
22 approval is secured, the Department shall implement the pilot
23 program under the waiver within 12 months after the date of

1 approval. The pilot program shall be implemented only to the
2 extent that federal financial participation is available.

3 Section 25. Qualifying child.

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

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

18 (1) Cancer (i) for which there is no known effective
19 treatment, (ii) that does not respond to conventional
20 protocol, (iii) that has progressed to an advanced stage,
21 or (iv) where toxicities or other complications prohibit
22 the administration of curative therapies.

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

1 (3) Severe neurological conditions, including, but not
2 limited to, hypoxic ischemic encephalopathy, acute brain
3 injury, brain infections and inflammatory diseases, or
4 irreversible severe alteration of mental status, with one
5 of the following co-morbidities: (i) intractable seizures
6 or (ii) brainstem failure to control breathing or other
7 automatic physiologic functions.

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

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

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

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

26 (8) End-stage kidney failure where (i) transplant is

1 not a viable option or (ii) transplant rejection or failure
2 has occurred.

3 (9) Metabolic or biochemical disorders, including, but
4 not limited to, mitochondrial disease, leukodystrophies,
5 Tay-Sachs disease, or Lesch-Nyhan syndrome where (i) no
6 suitable therapies exist or (ii) available treatments,
7 including stem cell ("bone marrow") transplant, have
8 failed.

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

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

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

19 Section 30. Authorized providers. Providers authorized to
20 deliver services under the pilot program shall include licensed
21 hospice programs or home health agencies licensed to provide
22 hospice care and are subject to further criteria developed by
23 the Department for provider participation. At a minimum, a
24 participating provider must employ a pediatric-trained
25 interdisciplinary team that includes a pediatric medical

1 director, a nurse, and a licensed social worker. All members of
2 the pediatric interdisciplinary team must submit to the
3 Department proof of pediatric End-of-Life Nursing Education
4 Curriculum (Pediatric ELNEC) Training or an equivalent.

5 Section 35. Included counties. Services under the pilot
6 program shall be made available in Illinois counties with
7 licensed hospice programs that report and demonstrate, as
8 described in Section 30, the ability to deliver the pediatric
9 palliative services described in this Act. Without limiting the
10 ability of licensed hospice programs in other counties to apply
11 for participation in the pilot program, the following counties
12 shall be included in the pilot program: Boone, Cass, Christian,
13 Clark, Coles, Cook, Crawford, Cumberland, DeWitt, Douglas,
14 DuPage, Edgar, Effingham, Fayette, Grundy, Jasper, Kane,
15 Kankakee, Kendall, Logan, Macon, Mason, McHenry, Menard,
16 Morgan, Moultrie, Ogle, Piatt, Sangamon, Shelby, Will, and
17 Winnebago.

18 Section 40. Interdisciplinary team; services. The
19 reimbursable services offered under the pilot program shall be
20 provided by an interdisciplinary team, operating under the
21 direction of a pediatric medical director, and shall include,
22 but not be limited to, the following:

- 23 (1) Pediatric nursing for pain and symptom management.
24 (2) Expressive therapies (music and art therapies) for

1 age-appropriate counseling.

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

5 (4) Respite care.

6 (5) Bereavement services.

7 (6) Case management.

8 Section 45. Administration.

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

13 (b) The Department shall appoint an individual to serve as
14 case manager or an alternative position to assess level-of-care
15 and target-population criteria for the pilot program. The
16 Department shall ensure that the individual receives pediatric
17 End-of-Life Nursing Education Curriculum (Pediatric ELNEC)
18 Training or an equivalent to become familiarized with the
19 unique needs and difficulties facing this population. The
20 process for review of referrals and enrollment of qualifying
21 participants shall not include unnecessary delays and shall
22 reflect the fact that treatment of pain and other distressing
23 symptoms represents an urgent need for children with
24 life-limiting medical conditions. The process shall also
25 acknowledge that children with life-limiting medical

1 conditions and their families require holistic and seamless
2 care.

3 Section 50. Period of pilot program.

4 (a) The program implemented under this Act shall be
5 considered a pilot program for 3 years following the date of
6 program implementation or until the waiver that includes the
7 services provided under the program undergoes the federally
8 mandated renewal process.

9 (b) During the period of time that the program is
10 considered a pilot program, pediatric palliative care shall be
11 included in the issues reviewed by the Hospice and Palliative
12 Care Advisory Board. The Board shall make recommendations
13 regarding changes or improvements to the program, including but
14 not limited to advice on potential expansion of the potentially
15 life-limiting medical conditions as defined in subsection (b)
16 of Section 25.

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

24 Section 55. Effect on medical assistance program.

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

5 (b) This Act does not affect an individual's eligibility to
6 receive, concurrently with the benefits provided for in this
7 Act, any services, including home health services, for which
8 the individual would have been eligible in the absence of this
9 Act.

10 Section 90. The Hospice Program Licensing Act is amended by
11 changing Section 15 as follows:

12 (210 ILCS 60/15)

13 Sec. 15. Hospice and Palliative Care Advisory Board.

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

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

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

24 (3) One member who is a physician licensed to practice

1 medicine in all its branches, selected from the
2 recommendations of a statewide professional society
3 representing physicians licensed to practice medicine in
4 all its branches in all specialties.

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

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

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

14 (7) One member selected from the recommendations of
15 consumer organizations that engage in advocacy or legal
16 representation on behalf of hospice patients and their
17 immediate families.

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

26 (c) The Board shall meet as frequently as the chairman

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

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

12 (e) The Board shall advise the Department on all aspects of
13 the Department's responsibilities under this Act, including
14 the format and content of any rules adopted by the Department
15 on or after the effective date of this amendatory Act of the
16 95th General Assembly. Any such rule or amendment to a rule
17 proposed on or after the effective date of this amendatory Act
18 of the 95th General Assembly, except an emergency rule adopted
19 pursuant to Section 5-45 of the Illinois Administrative
20 Procedure Act, that is adopted without obtaining the advice of
21 the Board is null and void. If the Department fails to follow
22 the advice of the Board with respect to a proposed rule or
23 amendment to a rule, the Department shall, before adopting the
24 rule or amendment to a rule, transmit a written explanation of
25 the reason for its action to the Board. During its review of
26 rules, the Board shall analyze the economic and regulatory

1 impact of those rules. If the Board, having been asked for its
2 advice with respect to a proposed rule or amendment to a rule,
3 fails to advise the Department within 90 days, the proposed
4 rule or amendment shall be considered to have been acted upon
5 by the Board.

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

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

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