

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 (4) Pediatric palliative programming can, and should,
5 be administered in a cost neutral fashion. Community-based
6 pediatric palliative care allows for children and families
7 to receive pain and symptom management and psychosocial
8 support in the comfort of the home setting, thereby
9 avoiding excess spending for emergency room visits and
10 certain hospitals. The National Hospice and Palliative
11 Care Organization's pediatric task force reported during
12 2001 that the average cost per child per year, cared for
13 primarily at home, receiving comprehensive palliative and
14 life prolonging services concurrently, is \$16,177,
15 significantly less than the \$19,000 to \$48,000 per child
16 per year when palliative programs are not utilized.

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

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

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

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

1 Section 25. Qualifying child.

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

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

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

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

24 (3) Severe neurological conditions, including, but not
25 limited to, hypoxic ischemic encephalopathy, acute brain

1 injury, brain infections and inflammatory diseases, or
2 irreversible severe alteration of mental status, with one
3 of the following co-morbidities: (i) intractable seizures
4 or (ii) brainstem failure to control breathing or other
5 automatic physiologic functions.

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

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

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

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

24 (8) End-stage kidney failure where (i) transplant is
25 not a viable option or (ii) transplant rejection or failure
26 has occurred.

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

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

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

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

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

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

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

9 (1) Pediatric nursing for pain and symptom management.

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

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

15 (4) Respite care.

16 (5) Bereavement services.

17 (6) Case management.

18 Section 40. Administration.

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

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

1 level-of-care and target-population criteria for the pilot
2 program. The Department shall ensure that the individual
3 receives pediatric End-of-Life Nursing Education Curriculum
4 (Pediatric ELNEC Training) or an equivalent to become
5 familiarized with the unique needs and difficulties facing this
6 population. The process for review of referrals and enrollment
7 of qualifying participants shall not include unnecessary
8 delays and shall reflect the fact that treatment of pain and
9 other distressing symptoms represents an urgent need for
10 children with life-limiting medical conditions. The process
11 shall also acknowledge that children with life-limiting
12 medical conditions and their families require holistic and
13 seamless care.

14 Section 45. Period of pilot program.

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

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

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

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

11 Section 50. Effect on medical assistance program.

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

16 (b) This Act does not affect an individual's eligibility to
17 receive, concurrently with the benefits provided for in this
18 Act, any services, including home health services, for which
19 the individual would have been eligible in the absence of this
20 Act.

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

23 (210 ILCS 60/15)

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

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

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

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

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

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

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

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

26 (7) One member selected from the recommendations of

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

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

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

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

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

1 on or after the effective date of this amendatory Act of the
2 95th General Assembly. Any such rule or amendment to a rule
3 proposed on or after the effective date of this amendatory Act
4 of the 95th General Assembly, except an emergency rule adopted
5 pursuant to Section 5-45 of the Illinois Administrative
6 Procedure Act, that is adopted without obtaining the advice of
7 the Board is null and void. If the Department fails to follow
8 the advice of the Board with respect to a proposed rule or
9 amendment to a rule, the Department shall, before adopting the
10 rule or amendment to a rule, transmit a written explanation of
11 the reason for its action to the Board. During its review of
12 rules, the Board shall analyze the economic and regulatory
13 impact of those rules. If the Board, having been asked for its
14 advice with respect to a proposed rule or amendment to a rule,
15 fails to advise the Department within 90 days, the proposed
16 rule or amendment shall be considered to have been acted upon
17 by the Board.

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

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

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