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.

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. The Department shall submit the necessary application to the federal Centers for Medicare and Medicaid Services for a waiver to implement the pilot program described in this Act. The waiver request shall be included in any appropriate waiver application renewal submitted within 12 months after the effective date of this Act, 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 pilot program under the waiver within 12 months after the date of

approval. The 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 program shall include licensed hospice programs or home health agencies licensed to provide hospice care and are subject to further criteria developed by the Department for provider participation. At a minimum, a participating provider must employ a pediatric-trained 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. Included counties. Services under the pilot program shall be made available in Illinois counties with licensed hospice programs that report and demonstrate, as described in Section 30, the ability to deliver the pediatric palliative services described in this Act. Without limiting the ability of licensed hospice programs in other counties to apply for participation in the pilot program, the following counties shall be included in the pilot program: Boone, Cass, Christian, Clark, Coles, Cook, Crawford, Cumberland, DeWitt, Douglas, DuPage, Edgar, Effingham, Fayette, Grundy, Jasper, Kane, Kankakee, Kendall, Logan, Macon, Mason, McHenry, Menard, Morgan, Moultrie, Ogle, Piatt, Sangamon, Shelby, Will, and Winnebago.

Section 40. Interdisciplinary team; services. 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 45. 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 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 50. 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 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 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 advice 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 submit a report to 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 55. 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.