AN ACT concerning government.

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

Section 5. The Pediatric Palliative Care Act is amended by changing Sections 5, 10, 15, 20, 25, 30, 35, 40, and 45 and by adding Section 37 as follows:

(305 ILCS 60/5)

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

(1) Each year, approximately 1,500 ~~1,185~~ Illinois children are diagnosed with a serious illness ~~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) Community-based pediatric palliative services have been shown to keep children out of the hospital by managing many symptoms in the home setting, thereby improving

childhood quality of life while maintaining budget neutrality. ~~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.~~

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/10)

Sec. 10. Definitions ~~Definition~~. In this Act: ~~,~~

"Department" means the Department of Healthcare and Family Services.

"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 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.

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

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/15)

Sec. 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 and may also choose to continue ~~while continuing~~ to pursue ~~aggressive~~ curative or disease-directed treatments for a serious ~~potentially life limiting~~ illness under the benefits available under Article V of the Illinois Public Aid Code.

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/20)

Sec. 20. ~~Federal waiver or~~ State Plan amendment. If applicable, the ~~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. The Department shall not draft any rules in contravention of this timetable for

program development and implementation. ~~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.~~

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/25)

Sec. 25. Qualifying child.

(a) For the purposes of this Act, a qualifying child is a person under 19 ~~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 serious illness ~~potentially life limiting medical condition~~, as defined in subsection (b). A child who is enrolled in the ~~pilot~~ program prior to the age 19 ~~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 serious illnesses ~~potentially life-limiting medical conditions~~ that render a pediatric medical assistance recipient eligible for the ~~pilot~~ program under this Act. Such serious illnesses ~~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 limit ~~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.

(12) Any other serious illness that the Department determines to be appropriate.

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

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/30)

Sec. 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, in consultation with interested stakeholders, for provider participation. At a minimum, the participating provider must house a pediatric interdisciplinary team that includes: (i) a physician, acting as the program medical director, who is board certified or board eligible in pediatrics or hospice and palliative medicine; (ii) a registered nurse; and (iii) a licensed social worker with a background in pediatric care ~~a pediatric medical director, a nurse, and a licensed social worker~~. All members of the pediatric interdisciplinary team must meet criteria the Department may establish by rule, including demonstrated expertise in pediatric palliative care. ~~submit to the Department proof of pediatric End-of-Life Nursing Education Curriculum (Pediatric ELNEC Training) or an equivalent.~~

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/35)

Sec. 35. Interdisciplinary team; services. The ~~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 or ~~and~~ art therapies) for age-appropriate counseling.

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

(4) Respite care.

(5) Bereavement services.

(6) Case management.

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

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/37 new)

Sec. 37. Medicaid managed care organizations; technical assistance. The Department, in consultation with interested stakeholders, shall establish standards for and provide technical assistance to managed care organizations, as defined

in Section 5-30.1 of the Illinois Public Aid Code, to ensure the delivery of pediatric palliative care services.

(305 ILCS 60/40)

Sec. 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 or entity meets the criteria for demonstrated expertise in pediatric palliative care that the Department, in consultation with interested stakeholders, may establish by rule ~~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 a serious illness ~~life-limiting medical conditions~~. The process shall also acknowledge that children with a serious illness ~~life limiting medical conditions~~ and their families require

holistic and seamless care.

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/45)

Sec. 45. Report. ~~Period of pilot program.~~ After the program has been in place for 3 years, 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 those serious illnesses that render a pediatric medical assistance recipient eligible for the program as defined in subsection (b) of Section 25 and the necessary services needed to ensure high-quality care for children and their families.

~~(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.~~

(Source: P.A. 96-1078, eff. 7-16-10.)

(305 ILCS 60/3 rep.)

Section 10. The Pediatric Palliative Care Act is amended by repealing Section 3.