

110TH CONGRESS
2D SESSION

H. R. 5192

To improve the palliative and end-of-life care provided to children with life-threatening conditions, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 29, 2008

Ms. PRYCE of Ohio (for herself and Mr. MURTHA) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To improve the palliative and end-of-life care provided to children with life-threatening conditions, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Children’s Compassionate Care Act of 2007”.

6 (b) TABLE OF CONTENTS.—The table of contents of
7 this Act is as follows:

Sec. 1. Short title; table of contents.

TITLE I—GRANTS TO EXPAND PEDIATRIC PALLIATIVE CARE
SERVICES AND RESEARCH

- Sec. 101. Education and training.
 Sec. 102. Grants to expand pediatric palliative care.
 Sec. 103. Pediatric palliative care training and residency grants.
 Sec. 104. Model program grants.
 Sec. 105. Research.

TITLE II—PEDIATRIC PALLIATIVE CARE DEMONSTRATION
PROJECTS

- Sec. 201. Medicare pediatric palliative care demonstration projects.
 Sec. 202. Private sector pediatric palliative care demonstration projects.
 Sec. 203. Symposium on pediatric palliative care.
 Sec. 204. Evaluation and reports to Congress.
 Sec. 205. Authorization of appropriations.

1 **TITLE I—GRANTS TO EXPAND**
 2 **PEDIATRIC PALLIATIVE CARE**
 3 **SERVICES AND RESEARCH**

4 **SEC. 101. EDUCATION AND TRAINING.**

5 Subpart 2 of part E of title VII of the Public Health
 6 Service Act (42 U.S.C. 295 et seq.) is amended—

- 7 (1) in section 770(a) by inserting “except for
 8 section 771,” after “carrying out this subpart”; and
 9 (2) by adding at the end the following:

10 **“SEC. 771. PEDIATRIC PALLIATIVE CARE SERVICES EDU-**
 11 **CATION AND TRAINING.**

12 “(a) ESTABLISHMENT.—The Secretary, acting
 13 through the Administrator of the Health Resources and
 14 Services Administration, may award grants to eligible en-
 15 tities to provide training in pediatric palliative care and
 16 related services for children with life-threatening condi-
 17 tions.

18 “(b) ELIGIBLE ENTITY DEFINED.—

1 “(1) IN GENERAL.—In this section, the term
2 ‘eligible entity’ means a health care provider that is
3 affiliated with an academic institution, that is pro-
4 viding comprehensive interdisciplinary pediatric pal-
5 liative care services, alone or through an arrange-
6 ment with another entity, and that has dem-
7 onstrated experience in providing training and con-
8 sultative services in pediatric palliative care, includ-
9 ing—

10 “(A) children’s hospitals or other hospitals
11 or medical centers with demonstrated, or ac-
12 tively developing, capacity in providing pallia-
13 tive care for children with life-threatening con-
14 ditions;

15 “(B) pediatric hospices or hospices with
16 significant pediatric palliative care programs;

17 “(C) home health agencies with a dem-
18 onstrated or developing capacity to serve chil-
19 dren with life-threatening conditions and that
20 provide pediatric palliative care; and

21 “(D) any other entity that the Secretary
22 determines is appropriate.

23 “(2) LIFE-THREATENING CONDITION DE-
24 FINED.—In this subsection, the term ‘life-threat-
25 ening condition’ has the meaning given such term by

1 the Secretary (in consultation with hospice programs
2 (as defined in section 1861(dd)(2) of the Social Se-
3 curity Act (42 U.S.C. 1395x(dd)(2))) and academic
4 experts in end-of-life care), except that the Secretary
5 may not limit such term to individuals who are ter-
6 minally ill (as defined in section 1861(dd)(3) of the
7 Social Security Act (42 U.S.C. 1395x(dd)(3))).

8 “(c) AUTHORIZED ACTIVITIES.—Grant funds award-
9 ed under subsection (a) shall be used to—

10 “(1) provide short-term training and education
11 programs in pediatric palliative care for the range of
12 interdisciplinary health professionals and others pro-
13 viding such care;

14 “(2) provide consultative services and guidance
15 to health care providers that are developing and
16 building comprehensive interdisciplinary pediatric
17 palliative care programs;

18 “(3) develop regional information outreach and
19 other resources to assist clinicians and families in
20 local and outlying communities and rural areas;

21 “(4) develop or evaluate current curricula and
22 educational materials being used in providing such
23 education and guidance relating to pediatric pallia-
24 tive care;

1 “(b) ELIGIBLE ENTITY DEFINED.—In this section,
2 the term ‘eligible entity’ means—

3 “(1) children’s hospitals or other hospitals with
4 a capacity (or those developing a capacity) and abil-
5 ity to care for children with life-threatening condi-
6 tions;

7 “(2) hospices with a demonstrated or devel-
8 oping capacity and ability to provide palliative care
9 (including symptom management, assistance with
10 and support in decisionmaking) for children with
11 life-threatening conditions and their families in a
12 family-centered manner; and

13 “(3) home health agencies with—

14 “(A) a demonstrated capacity (or devel-
15 oping capacity) and ability to care for children
16 with life-threatening conditions; and

17 “(B) demonstrated expertise (or actively
18 developing capacity) in providing pediatric pal-
19 liative care.

20 “(c) AUTHORIZED ACTIVITIES.—Grant funds award-
21 ed under subsection (a) shall be used to—

22 “(1) create new or expand existing pediatric
23 palliative care programs;

24 “(2) start or expand needed additional care set-
25 tings, such as respite, hospice, outpatient, inpatient

1 day services, or other care settings to provide a con-
2 tinuum of care across inpatient, home, and commu-
3 nity-based settings for pediatric palliative care;

4 “(3) expand comprehensive pediatric palliative
5 care services, including care coordination services, to
6 greater numbers of children with life-threatening
7 conditions and broader service areas, including re-
8 gional and rural outreach; and

9 “(4) support communication linkages and care
10 coordination, applying telemedicine and teleconfer-
11 encing technologies, and measures to improve both
12 patient and family safety, and measures to improve
13 efficacy and quality.

14 “(d) APPLICATION.—Each eligible entity desiring a
15 grant under this section shall submit an application to the
16 Administrator at such time, in such manner, and con-
17 taining such information as the Administrator may re-
18 quire.

19 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
20 are authorized to be appropriated to carry out this section
21 \$10,000,000 for each of fiscal years 2008 through 2012.”.

1 **SEC. 103. PEDIATRIC PALLIATIVE CARE TRAINING AND**
2 **RESIDENCY GRANTS.**

3 Part A of title IV of the Public Health Service Act
4 (42 U.S.C. 281 et seq.) is amended by adding at the end
5 the following:

6 **“SEC. 404I. PEDIATRIC PALLIATIVE CARE TRAINING AND**
7 **RESIDENCY GRANTS.**

8 “(a) **ESTABLISHMENT.**—The Director of the Na-
9 tional Institutes of Health is authorized to award training
10 grants to eligible entities to expand the number of physi-
11 cians, nurses, mental health professionals, and appropriate
12 allied health professionals and specialists (as determined
13 by the Secretary) with interdisciplinary pediatric palliative
14 clinical training and research experience.

15 “(b) **ELIGIBLE ENTITY DEFINED.**—In this section,
16 the term ‘eligible entity’ means—

17 “(1) a pediatric department of a medical school
18 and other related departments including—

19 “(A) oncology;

20 “(B) virology;

21 “(C) neurology;

22 “(D) psychiatry; or

23 “(E) pain medicine;

24 “(2) a school of nursing (when partnering with
25 physicians or a provider eligible to receive payments

1 under title XVIII of the Social Security Act (42
2 U.S.C. 1395 et seq.), as available);

3 “(3) a school of psychology (when partnering
4 with physicians or a provider eligible to receive pay-
5 ments under title XVIII of the Social Security Act
6 (42 U.S.C. 1395 et seq.), as available);

7 “(4) a school of social work (when partnering
8 with physicians or a provider eligible to receive pay-
9 ments under title XVIII of the Social Security Act
10 (42 U.S.C. 1395 et seq.), as available);

11 “(5) a children’s hospital or other hospital with
12 demonstrated expertise or developing capacity to
13 serve pediatric patients with life-threatening condi-
14 tions; and

15 “(6) an entity that has access to a continuum
16 of care such as acute care, inpatient, hospice, out-
17 patient, or home-based hospice to fully expose the
18 trainee to palliative care.

19 “(c) APPLICATION.—Each eligible entity desiring a
20 grant under this section shall submit an application to the
21 Director at such time, in such manner, and containing
22 such information as the Director may require. Such appli-
23 cation shall include a plan for evaluating outcomes.

1 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
2 are authorized to be appropriated to carry out this section
3 \$5,000,000 for each of fiscal years 2008 through 2012.”.

4 **SEC. 104. MODEL PROGRAM GRANTS.**

5 Part Q of title III of the Public Health Service Act
6 (42 U.S.C. 280h et seq.), as amended by section 102, is
7 further amended by adding at the end the following:

8 **“SEC. 399Z-2. MODEL PROGRAM GRANTS.**

9 “(a) ESTABLISHMENT.—The Secretary may award
10 grants to eligible entities to enhance pediatric palliative
11 care and care for children with life-threatening conditions
12 in general pediatric or family practice residency training
13 programs and general or pediatric nursing education pro-
14 grams through the development of model interdisciplinary
15 programs that partner with other health professional
16 schools such as psychology, pharmacology, nursing, or so-
17 cial work, when practicable.

18 “(b) ELIGIBLE ENTITY DEFINED.—In this section,
19 the term ‘eligible entity’ means a provider eligible to re-
20 ceive payments under title XVIII of the Social Security
21 Act (42 U.S.C. 1395 et seq.), in either a pediatric depart-
22 ment of—

23 “(1) a medical school;

24 “(2) a nursing school;

25 “(3) a children’s hospital; or

1 “(4) any other hospital with a general pediatric
2 or family practice residency program serving pedi-
3 atric patients with life-threatening conditions.

4 “(c) APPLICATION.—Each eligible entity desiring a
5 grant under this section shall submit an application to the
6 Administrator at such time, in such manner, and con-
7 taining such information as the Administrator may require
8 (including a plan for evaluating outcomes).

9 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
10 are authorized to be appropriated to carry out this section
11 \$5,000,000 for each of fiscal years 2008 through 2012.”.

12 **SEC. 105. RESEARCH.**

13 (a) PAIN AND SYMPTOM MANAGEMENT.—The Direc-
14 tor of the National Institutes of Health (in this section
15 referred to as the “Director”) shall provide research
16 grants to fund interdisciplinary research in pediatric pain
17 and symptom management that will utilize existing facili-
18 ties of the National Institutes of Health including—

- 19 (1) pediatric pharmacological research units;
20 (2) clinical translational science awardees; and
21 (3) other centers providing infrastructure for
22 patient-oriented research.

23 (b) ELIGIBLE ENTITIES.—In carrying out subsection
24 (a), the Director may award grants for the conduct of pe-
25 diatric pain and symptom management research to—

1 (1) children's hospitals or other hospitals serv-
2 ing a significant number of children with life-threat-
3 ening conditions;

4 (2) pediatric departments of medical schools;

5 (3) pediatric departments of nursing schools;

6 (4) institutions currently participating in Na-
7 tional Institutes of Health network of pediatric
8 pharmacological research units;

9 (5) hospices with pediatric palliative care pro-
10 grams and academic affiliations;

11 (6) pediatric departments of social work
12 schools;

13 (7) pediatric departments of psychology schools;

14 (8) pediatric departments of pharmacology
15 schools; and

16 (9) pediatric pain medicine programs.

17 (c) AUTHORIZATION OF APPROPRIATIONS.—There
18 are authorized to be appropriated to carry out this section
19 \$10,000,000, to remain available until expended.

20 **TITLE II—PEDIATRIC PALLIA-**
21 **TIVE CARE DEMONSTRATION**
22 **PROJECTS**

23 **SEC. 201. MEDICARE PEDIATRIC PALLIATIVE CARE DEM-**
24 **ONSTRATION PROJECTS.**

25 (a) DEFINITIONS.—In this section:

1 (1) CARE COORDINATION SERVICES.—The term
2 “care coordination services” means services that pro-
3 vide for the coordination of, and assistance with, re-
4 ferral for clinical and other services, including inter-
5 disciplinary care conferences, coordination with other
6 providers involved in caring for the eligible child
7 with a life-threatening condition, patient and family-
8 centered caregiver education and counseling, and
9 such other services as the Secretary determines to be
10 appropriate in order to facilitate the coordination
11 and continuity of care furnished to an eligible child
12 and the family of such child.

13 (2) DEMONSTRATION PROJECT.—The term
14 “demonstration project” means a demonstration
15 project established by the Secretary under sub-
16 section (b)(1).

17 (3) ELIGIBLE CHILD.—The term “eligible
18 child” means an individual with a life-threatening
19 condition who is entitled to benefits under part A of
20 the Medicare program and who is under 21 years of
21 age.

22 (4) ELIGIBLE PROVIDER.—The term “eligible
23 provider” means—

1 (A) a pediatric palliative care program that
2 is a public agency or private organization (or a
3 subdivision thereof) which—

4 (i)(I) is primarily engaged in pro-
5 viding the care and services described in
6 section 1861(dd)(1) of the Social Security
7 Act (42 U.S.C. 1395(dd)(1)) and makes
8 such services available (as needed) on a
9 24-hour basis and which also provides fam-
10 ily-centered counseling (including sup-
11 portive and bereavement counseling) for
12 the eligible child and the immediate family
13 of such child;

14 (II) provides for such care and serv-
15 ices in eligible children’s homes, on an out-
16 patient basis, and on a short-term inpa-
17 tient basis, directly or under arrangements
18 made by the agency or organization, except
19 that—

20 (aa) the agency or organization
21 must routinely provide directly sub-
22 stantially all of each of the services
23 described in subparagraphs (A), (C),
24 and (H) of such section 1861(dd)(1);

1 (bb) in the case of other services
2 described in such section 1861(dd)(1)
3 which are not provided directly by the
4 agency or organization, the agency or
5 organization must maintain profes-
6 sional management responsibility for
7 all such services furnished to an eligi-
8 ble child and the family of such child,
9 regardless of the location or facility in
10 which such services are furnished; and
11 (III)(aa) identifies medical, commu-
12 nity, and social service needs;
13 (bb) simplifies access to service;
14 (cc) uses the full range of community
15 resources, including the friends and family
16 of the eligible child; and
17 (dd) provides educational opportuni-
18 ties relating to health care; and
19 (ii) has an interdisciplinary group of
20 personnel which—
21 (I) includes at least—
22 (aa) 1 physician (as defined
23 in section 1861(r)(1) of the So-
24 cial Security Act (42 U.S.C.
25 1395x(r)(1)));

1 (bb) 1 registered profes-
2 sional nurse;

3 (cc) 1 licensed mental health
4 professional; and

5 (dd) 1 licensed social work-
6 er;

7 employed by or, in the case of a physi-
8 cian described in item (aa), under
9 contract with the agency or organiza-
10 tion;

11 (II) provides (or supervises the provi-
12 sion of) the care and services described in
13 such section 1861(dd)(1); and

14 (III) establishes the policies governing
15 the provision of such care and services;

16 (iii) maintains central clinical records
17 on all patients;

18 (iv) does not discontinue the palliative
19 care it provides with respect to an eligible
20 child and the family of such child because
21 of the inability of the eligible child to pay
22 for such care;

23 (v)(I) uses volunteers in its provision
24 of care and services in accordance with
25 standards set by the Secretary, which

1 standards shall ensure a continuing level of
2 effort to use such volunteers; and

3 (II) maintains records on the use of
4 these volunteers and the cost savings and
5 expansion of care and services achieved
6 through the use of these volunteers;

7 (vi) in the case of an agency or orga-
8 nization in any State in which State or ap-
9 plicable local law provides for the licensing
10 of agencies or organizations of this nature,
11 is licensed pursuant to such law;

12 (vii) seeks to ensure that eligible chil-
13 dren and their families receive complete,
14 timely, understandable information about
15 diagnosis, prognosis, treatments, and pal-
16 liative care options;

17 (viii) seeks to ensure access to routine
18 pediatric care as appropriate for the eligi-
19 ble child;

20 (ix) ensures that children and their
21 families participate in effective and timely
22 prevention, assessment, and treatment of
23 physical and psychological symptoms of
24 distress; and

1 (x) meets such other requirements as
2 the Secretary may find necessary in the in-
3 terest of the health and safety of the eligi-
4 ble children who are provided with pallia-
5 tive care by such agency or organization;
6 and

7 (B) any other individual or entity with an
8 agreement under section 1866 of the Social Se-
9 curity Act (42 U.S.C. 1395cc) that—

10 (i) has demonstrated expertise in pro-
11 viding palliative care to pediatric popu-
12 lations; and

13 (ii) the Secretary determines is appro-
14 priate.

15 (5) LIFE-THREATENING CONDITION.—The term
16 “life-threatening condition” has the meaning given
17 such term by the Secretary (in consultation with
18 hospice programs (as defined in section 1861(dd)(2)
19 of the Social Security Act (42 U.S.C. 1395x(dd)(2)))
20 and academic experts in end-of-life care), except that
21 the Secretary may not limit such term to individuals
22 who are terminally ill (as defined in section
23 1861(dd)(3) of the Social Security Act (42 U.S.C.
24 1395x(dd)(3))).

1 (6) MEDICARE PROGRAM.—The term “Medicare
2 program” means the health benefits program under
3 title XVIII of the Social Security Act (42 U.S.C.
4 1395 et seq.).

5 (7) SECRETARY.—The term “Secretary” means
6 the Secretary of Health and Human Services.

7 (b) PEDIATRIC PALLIATIVE CARE DEMONSTRATION
8 PROJECTS.—

9 (1) ESTABLISHMENT.—The Secretary shall es-
10 tablish demonstration projects in accordance with
11 the provisions of this subsection to provide pediatric
12 palliative care to eligible children.

13 (2) PARTICIPATION.—

14 (A) ELIGIBLE PROVIDERS.—Any eligible
15 provider may furnish items or services covered
16 under the pediatric palliative care benefit.

17 (B) ELIGIBLE CHILDREN.—The Secretary
18 shall permit any eligible child residing in the
19 service area of an eligible provider participating
20 in a demonstration project to participate in
21 such project on a voluntary basis.

22 (c) SERVICES UNDER DEMONSTRATION
23 PROJECTS.—

24 (1) IN GENERAL.—Except as otherwise pro-
25 vided in this subsection, the provisions of section

1 1814(i) of the Social Security Act (42 U.S.C.
2 1395f(i)) shall apply to the payment for pediatric
3 palliative care provided under the demonstration
4 projects in the same manner in which such section
5 applies to the payment for hospice care (as defined
6 in section 1861(dd)(1) of the Social Security Act (42
7 U.S.C. 1395x(dd)(1))) provided under the Medicare
8 program.

9 (2) COVERAGE OF PEDIATRIC PALLIATIVE
10 CARE.—

11 (A) IN GENERAL.—Notwithstanding sec-
12 tion 1862(a)(1)(C) of the Social Security Act
13 (42 U.S.C. 1395y(a)(1)(C)), the Secretary shall
14 provide for reimbursement for items and serv-
15 ices provided under the pediatric palliative care
16 benefit made available under the demonstration
17 projects in a manner that is consistent with the
18 requirements of subparagraph (B).

19 (B) BENEFIT.—Under the pediatric pallia-
20 tive care benefit, the following requirements
21 shall apply:

22 (i) WAIVER OF REQUIREMENT TO
23 ELECT HOSPICE CARE.—Each eligible child
24 may receive benefits without an election
25 under section 1812(d)(1) of the Social Se-

1 curity Act (42 U.S.C. 1395d(d)(1)) to re-
2 ceive hospice care (as defined in section
3 1861(dd)(1) of such Act (42 U.S.C.
4 1395x(dd)(1))) having been made with re-
5 spect to the eligible child.

6 (ii) AUTHORIZATION FOR CURATIVE
7 TREATMENT.—Each eligible child may con-
8 tinue to receive benefits for disease and
9 symptom modifying treatment under the
10 Medicare program.

11 (iii) PROVISION OF CARE COORDINA-
12 TION SERVICES.—Each eligible child shall
13 receive care coordination services (as de-
14 fined in subsection (a)(1)) and hospice
15 care (as so defined) through an eligible
16 provider participating in a demonstration
17 project, regardless of whether such indi-
18 vidual has been determined to be termi-
19 nally ill (as defined in section 1861(dd)(3)
20 of the Social Security Act (42 U.S.C.
21 1395x(dd)(3))).

22 (iv) AVAILABILITY OF INFORMATION
23 ON PEDIATRIC PALLIATIVE CARE.—Each
24 eligible child and the family of such child
25 shall receive information and education in

1 order to better understand the utility of
2 pediatric palliative care.

3 (v) AVAILABILITY OF SUPPORTIVE
4 AND BEREAVEMENT COUNSELING.—Each
5 eligible child and the family of such child
6 shall receive supportive counseling and be-
7 reavement counseling, if appropriate.

8 (vi) PROVISION OF INDIVIDUAL
9 CARE.—Each eligible child and the family
10 of such child shall receive appropriate care
11 that is—

12 (I) designed to fit the child’s
13 physical, cognitive, emotional, and
14 spiritual level of development that
15 shall involve and respect both the
16 child and the family of such child; and

17 (II) effective and compassionate
18 from diagnosis through death and be-
19 reavement.

20 (vii) PROFESSIONAL EDUCATION.—
21 Each professional caring for an eligible
22 child shall have special responsibilities for
23 educating themselves and others about the
24 identification, management, and discussion

1 of the last phase of a child’s fatal medical
2 problem.

3 (viii) ADDITIONAL BENEFITS.—Under
4 the demonstration projects, the Secretary
5 may include any other item or service—

6 (I) for which payment may other-
7 wise be made under the Medicare pro-
8 gram; and

9 (II) that is consistent with the
10 recommendations contained in the re-
11 port published in 2003 by the Insti-
12 tute of Medicine of the National
13 Academy of Sciences entitled “When
14 Children Die: Improving Palliative
15 and End-of-Life Care for Children
16 and Their Families”.

17 (C) PAYMENT.—

18 (i) ESTABLISHMENT OF PAYMENT
19 METHODOLOGY.—The Secretary shall es-
20 tablish a methodology for determining the
21 amount of payment for pediatric palliative
22 care furnished under the demonstration
23 projects that is similar to the methodology
24 for determining the amount of payment for
25 hospice care (as defined in section

1 1861(dd)(1) of the Social Security Act (42
2 U.S.C. 1395x(dd)(1))) under section
3 1814(i) of such Act (42 U.S.C. 1395f(i)),
4 except as provided in the following sub-
5 clauses:

6 (I) AMOUNT OF PAYMENT.—Sub-
7 ject to subclauses (II) and (III), the
8 amount of payment for pediatric pal-
9 liative care shall be equal to the
10 amount that would be paid for hospice
11 care (as so defined), increased by an
12 appropriate percentage to account for
13 the additional costs of providing sup-
14 portive and bereavement counseling
15 and care coordination services (as de-
16 fined in subsection (a)(1)).

17 (II) WAIVER OF HOSPICE CAP.—
18 The limitation under section
19 1814(i)(2) of the Social Security Act
20 (42 U.S.C. 1395f(i)(2)) shall not
21 apply with respect to pediatric pallia-
22 tive care and amounts paid for pedi-
23 atric palliative care under this sub-
24 paragraph shall not be counted

1 against the cap amount described in
2 such section.

3 (III) SEPARATE PAYMENT FOR
4 COUNSELING SERVICES.—Notwith-
5 standing section 1814(i)(1)(A) of the
6 Social Security Act (42 U.S.C.
7 1395f(i)(1)(A)), the Secretary may
8 pay for bereavement counseling as a
9 separate service.

10 (ii) SPECIAL RULES FOR PAYMENT OF
11 MEDICARE+CHOICE ORGANIZATIONS.—The
12 Secretary shall establish procedures under
13 which the Secretary provides for an appro-
14 priate adjustment in the monthly payments
15 made under section 1853 of the Social Se-
16 curity Act (42 U.S.C. 1395w–23) to any
17 Medicare+Choice organization that pro-
18 vides health care items or services to an el-
19 igible child who is participating in a dem-
20 onstration project.

21 (3) COVERAGE OF PEDIATRIC PALLIATIVE CARE
22 CONSULTATION SERVICES.—Under the demonstra-
23 tion projects, the Secretary shall provide for a one-
24 time payment on behalf of each eligible child who
25 has not yet elected to participate in the demonstra-

1 tion project for services that are furnished by a phy-
2 sician or advanced practice registered nurse who is
3 either the medical or nursing director or an em-
4 ployee of a provider eligible to receive payments
5 under title XVIII of the Social Security Act (42
6 U.S.C. 1395 et seq.) participating in such a project
7 and that consist of—

8 (A) an evaluation of the individual’s need
9 for pain and symptom management, including
10 the need for pediatric palliative care;

11 (B) counseling the individual and the fam-
12 ily of such individual with respect to the bene-
13 fits of pediatric palliative care and care options;

14 (C) if appropriate, advising the individual
15 and the family of such individual regarding ad-
16 vanced care planning; and

17 (D) care coordination.

18 (d) CONDUCT OF DEMONSTRATION PROJECTS.—

19 (1) SITES.—The Secretary shall conduct dem-
20 onstration projects in not less than 4, but not more
21 than 8, sites.

22 (2) SELECTION OF SITES.—The Secretary shall
23 select demonstration sites on the basis of proposals
24 submitted under paragraph (3) that are located in
25 geographic areas that—

1 (A) include both urban and rural eligible
2 organizations;

3 (B) are geographically diverse and readily
4 accessible to eligible children; and

5 (C) take into account adequate representa-
6 tion of children of ethnic and racial minorities.

7 (3) PROPOSALS.—The Secretary shall accept
8 proposals to furnish pediatric palliative care under
9 the demonstration projects from any eligible provider
10 at such time, in such manner, and in such form as
11 the Secretary may reasonably require.

12 (4) FACILITATION OF EVALUATION.—The Sec-
13 retary shall design the demonstration projects to fa-
14 cilitate the evaluation conducted under subsection
15 (e)(1).

16 (5) DURATION.—The Secretary shall complete
17 the demonstration projects within a period of 5
18 years that includes a period of 1 year during which
19 the Secretary shall complete the evaluation under
20 section 204.

21 (e) WAIVER OF MEDICARE REQUIREMENTS.—The
22 Secretary shall waive compliance with such requirements
23 of the Medicare program to the extent and for the period
24 the Secretary finds necessary to conduct the demonstra-
25 tion projects.

1 **SEC. 202. PRIVATE SECTOR PEDIATRIC PALLIATIVE CARE**
2 **DEMONSTRATION PROJECTS.**

3 (a) DEFINITIONS.—In this section:

4 (1) CARE COORDINATION SERVICES.—The term
5 “care coordination services” has the meaning given
6 the term in section 201.

7 (2) DEMONSTRATION PROJECT.—The term
8 “demonstration project” means a demonstration
9 project established by the Secretary under sub-
10 section (b)(1).

11 (3) ELIGIBLE CHILD.—The term “eligible
12 child” means an individual with a life-threatening
13 condition who is—

14 (A) under 21 years of age;

15 (B) enrolled for health benefits coverage
16 under an eligible health plan; and

17 (C) not enrolled under (or entitled to) ben-
18 efits under a health plan described in para-
19 graph (5)(C).

20 (4) ELIGIBLE PROVIDER.—The term “eligible
21 provider” has the meaning given the term in section
22 201.

23 (5) ELIGIBLE HEALTH PLAN.—

24 (A) IN GENERAL.—Subject to subpara-
25 graphs (B) and (C), the term “eligible health
26 plan” means an individual or group plan that

1 provides, or pays the cost of, medical care (as
2 such term is defined in section 2791 of the
3 Public Health Service Act (42 U.S.C. 300gg–
4 91)).

5 (B) TYPES OF PLANS INCLUDED.—For
6 purposes of subparagraph (A), the term “eligi-
7 ble health plan” includes the following health
8 plans, and any combination thereof:

9 (i) A group health plan (as defined in
10 section 2791(a) of the Public Health Serv-
11 ice Act (42 U.S.C. 300gg–91(a))), but only
12 if the plan—

13 (I) has 50 or more participants
14 (as defined in section 3(7) of the Em-
15 ployee Retirement Income Security
16 Act of 1974 (29 U.S.C. 1002(7))); or

17 (II) is administered by an entity
18 other than the employer who estab-
19 lished and maintains the plan.

20 (ii) A health insurance issuer (as de-
21 fined in section 2791(b) of the Public
22 Health Service Act (42 U.S.C. 300gg–
23 91(b))).

24 (iii) A health maintenance organiza-
25 tion (as defined in section 2791(b) of the

1 Public Health Service Act (42 U.S.C.
2 300gg-91(b)).

3 (iv) A long-term care policy, including
4 a nursing home fixed indemnity policy (un-
5 less the Secretary determines that such a
6 policy does not provide sufficiently com-
7 prehensive coverage of a benefit so that the
8 policy should be treated as a health plan).

9 (v) An employee welfare benefit plan
10 or any other arrangement which is estab-
11 lished or maintained for the purpose of of-
12 fering or providing health benefits to the
13 employees of 2 or more employers.

14 (vi) Health benefits coverage provided
15 under a contract under the Federal em-
16 ployees health benefits program under
17 chapter 89 of title 5, United States Code.

18 (C) TYPES OF PLANS EXCLUDED.—For
19 purposes of subparagraph (A), the term “eligi-
20 ble health plan” does not include any of the fol-
21 lowing health plans:

22 (i) The Medicare program under title
23 XVIII of the Social Security Act (42
24 U.S.C. 1395 et seq.).

1 (ii) The Medicaid program under title
2 XIX of the Social Security Act (42 U.S.C.
3 1396 et seq.).

4 (iii) A Medicare supplemental policy
5 (as defined in section 1882(g)(1) of the
6 Social Security Act (42 U.S.C. 1395ss et
7 seq.).

8 (iv) The health care program for ac-
9 tive military personnel under title 10,
10 United States Code.

11 (v) The veterans health care program
12 under chapter 17 of title 38, United States
13 Code.

14 (vi) The Civilian Health and Medical
15 Program of the Uniformed Services
16 (CHAMPUS), as defined in section
17 1072(4) of title 10, United States Code.

18 (vii) The Indian health service pro-
19 gram under the Indian Health Care Im-
20 provement Act (25 U.S.C. 1601 et seq.).

21 (6) ELIGIBLE ORGANIZATION.—The term “eligi-
22 ble organization” means an organization that pro-
23 vides health benefits coverage under an eligible
24 health plan.

1 (7) LIFE-THREATENING CONDITION.—The term
2 “life-threatening condition” has the meaning given
3 the term in section 201.

4 (8) MEDICARE PROGRAM.—The term “Medicare
5 program” means the health benefits program under
6 title XVIII of the Social Security Act (42 U.S.C.
7 1395 et seq.).

8 (9) PEDIATRIC PALLIATIVE CARE.—The term
9 “pediatric palliative care” means services of the type
10 to be furnished under the demonstration projects
11 under section 201, including care coordination serv-
12 ices.

13 (10) PEDIATRIC PALLIATIVE CARE CONSULTA-
14 TION SERVICES.—The term “pediatric palliative care
15 consultation services” means services of the type de-
16 scribed in section 201(c)(3).

17 (11) SECRETARY.—The term “Secretary”
18 means the Secretary of Health and Human Services,
19 acting through the Director of the Agency for
20 Healthcare Research and Quality.

21 (b) NONMEDICARE PEDIATRIC PALLIATIVE CARE
22 DEMONSTRATION PROJECTS.—

23 (1) ESTABLISHMENT.—The Secretary shall es-
24 tablish demonstration projects under this section at
25 the same time as the Secretary establishes the dem-

1 onstration projects under section 201 and in accord-
2 ance with the provisions of this subsection to dem-
3 onstrate the provision of pediatric palliative care and
4 pediatric palliative care consultation services to eligi-
5 ble children who are not entitled to (or enrolled for)
6 coverage under the health plans described in sub-
7 section (a)(3)(C).

8 (2) PARTICIPATION.—

9 (A) ELIGIBLE ORGANIZATIONS.—The Sec-
10 retary shall permit any eligible organization to
11 participate in a demonstration project on a vol-
12 untary basis.

13 (B) ELIGIBLE CHILDREN.—Any eligible or-
14 ganization participating in a demonstration
15 project shall permit any eligible child enrolled in
16 an eligible health plan offered by the organiza-
17 tion to participate in such project on a vol-
18 untary basis.

19 (c) SERVICES UNDER DEMONSTRATION
20 PROJECTS.—

21 (1) PROVISION OF PEDIATRIC PALLIATIVE CARE
22 AND CONSULTATION SERVICES.—Under a dem-
23 onstration project, each eligible organization electing
24 to participate in the demonstration project shall pro-
25 vide pediatric palliative care and pediatric palliative

1 care consultation services to each eligible child who
2 is enrolled with the organization and who elects to
3 participate in the demonstration project. Under the
4 pediatric palliative care benefit, the following re-
5 quirements shall apply:

6 (A) WAIVER OF REQUIREMENT TO ELECT
7 HOSPICE CARE.—Each eligible child may receive
8 benefits without an election under section
9 1812(d)(1) of the Social Security Act (42
10 U.S.C. 1395d(d)(1)) to receive hospice care (as
11 defined in section 1861(dd)(1) of such Act (42
12 U.S.C. 1395x(dd)(1))) having been made with
13 respect to the eligible child.

14 (B) AUTHORIZATION FOR CURATIVE
15 TREATMENT.—Each eligible child may continue
16 to receive benefits for disease and symptom
17 modifying treatment under the Medicare pro-
18 gram.

19 (C) PROVISION OF CARE COORDINATION
20 SERVICES.—Each eligible child shall receive
21 care coordination services (as defined in sub-
22 section (a)(1)) and hospice care (as so defined)
23 through an eligible provider participating in a
24 demonstration project, regardless of whether
25 such individual has been determined to be ter-

1 minally ill (as defined in section 1861(dd)(3) of
2 the Social Security Act (42 U.S.C.
3 1395x(dd)(3))).

4 (D) AVAILABILITY OF INFORMATION ON
5 PEDIATRIC PALLIATIVE CARE.—Each eligible
6 child and the family of such child shall receive
7 information and education in order to better
8 understand the utility of pediatric palliative
9 care.

10 (E) AVAILABILITY OF SUPPORTIVE AND
11 BEREAVEMENT COUNSELING.—Each eligible
12 child and the family of such child shall receive
13 supportive counseling and bereavement coun-
14 seling, if appropriate.

15 (F) PROVISION OF INDIVIDUAL CARE.—
16 Each eligible child and the family of such child
17 shall receive appropriate care—

18 (i) that is designed to fit the child’s
19 physical, cognitive, emotional, and spiritual
20 level of development that shall involve and
21 respect both the child and the family of
22 such child;

23 (ii) that is effective and compas-
24 sionate from diagnosis through death and
25 bereavement;

1 (iii) that involves and respects both
2 the eligible child and the family of the eli-
3 gible child; and

4 (iv) in which the family of the eligible
5 child is a part of the care team.

6 (G) PROFESSIONAL EDUCATION.—Each
7 professional caring for an eligible child shall
8 have special responsibilities for educating
9 themselves and others about the identification,
10 management, and discussion of the last phase
11 of a child’s fatal medical problem.

12 (H) ADDITIONAL BENEFITS.—Under the
13 demonstration projects, the Secretary may in-
14 clude any other item or service that is con-
15 sistent with the recommendations contained in
16 the report published in 2003 by the Institute of
17 Medicine of the National Academy of Sciences
18 entitled “When Children Die: Improving Pallia-
19 tive and End-of-Life Care for Children and
20 Their Families”.

21 (2) AVAILABILITY OF ADMINISTRATIVE
22 GRANTS.—

23 (A) IN GENERAL.—Subject to subpara-
24 graph (B), the Secretary shall award grants to
25 eligible organizations electing to participate in a

1 demonstration project for the administrative
2 costs incurred by the eligible organization in
3 participating in the demonstration project (in-
4 cluding care coordination), including the costs
5 of collecting and submitting the data required
6 to be submitted under subsection (d)(4)(B).

7 (B) NO PAYMENT FOR SERVICES.—The
8 Secretary may not pay eligible organizations for
9 pediatric palliative care or pediatric palliative
10 care consultation services furnished under the
11 demonstration projects.

12 (d) CONDUCT OF DEMONSTRATION PROJECTS.—

13 (1) SITES.—The Secretary shall conduct dem-
14 onstration projects in not less than 4, but not more
15 than 8, sites.

16 (2) SELECTION OF SITES.—The Secretary shall
17 select demonstration sites on the basis of proposals
18 submitted under paragraph (3) that are located in
19 geographic areas that—

20 (A) include both urban and rural eligible
21 organizations;

22 (B) are geographically diverse and readily
23 accessible to a significant number of eligible
24 children; and

1 (C) take into account adequate representa-
2 tion of children of ethnic and racial minorities.

3 (3) PROPOSALS.—

4 (A) IN GENERAL.—The Secretary shall ac-
5 cept proposals to furnish pediatric palliative
6 care and pediatric palliative care consultation
7 services under the demonstration projects from
8 any eligible organization at such time, in such
9 manner, and in such form as the Secretary may
10 require.

11 (B) APPLICATION FOR ADMINISTRATIVE
12 GRANTS.—If the eligible organization desires to
13 receive an administrative grant under sub-
14 section (c)(2), the proposal submitted under
15 subparagraph (A) shall include a request for
16 the grant, specify the amount requested, and
17 identify the purposes for which the organization
18 will use any funds made available under the
19 grant.

20 (4) COLLECTION AND SUBMISSION OF DATA.—

21 (A) COLLECTION.—Each eligible organiza-
22 tion participating in a demonstration project
23 shall collect such data as the Secretary may re-
24 quire to facilitate the evaluation to be com-
25 pleted under section 204.

1 (B) SUBMISSION.—Each eligible organiza-
2 tion shall submit the data collected under sub-
3 paragraph (A) to the Secretary at such time, in
4 such manner, and in such form as the Secretary
5 may require.

6 (5) DURATION.—The Secretary shall complete
7 the demonstration projects within a period of 5
8 years that includes a period of 1 year during which
9 the Secretary shall complete the evaluation under
10 section 204.

11 **SEC. 203. SYMPOSIUM ON PEDIATRIC PALLIATIVE CARE.**

12 (a) CONVENING A SYMPOSIUM.—The Secretary of
13 Health and Human Services shall convene a symposium
14 on Pediatric Palliative Care (in this section referred to as
15 the “symposium”). The symposium shall occur not later
16 than June 30, 2008.

17 (b) PURPOSES.—The purposes of the symposium
18 shall be to—

19 (1) assess the initial response to the Institute
20 of Medicine’s 2003 report on “When Children Die:
21 Improving Palliative and End-of-Life Care for Chil-
22 dren and Their Families”; and

23 (2) increase awareness of a child’s life-threat-
24 ening condition or death on the child, the family of
25 the child, and society as a whole, and the importance

1 of providing quality pediatric palliative care to chil-
2 dren with life-threatening conditions and the families
3 of such children in the United States.

4 (c) ATTENDEES.—The Secretary of Health and
5 Human Services, or the designee of the Secretary, shall
6 attend the symposium along with other nongovernmental
7 organizations, interested parties, and clinicians.

8 (d) REPORT.—The symposium shall report to the
9 Secretary of Health and Human Services and the appro-
10 priate committees of Congress on recommendations de-
11 rived from the symposium and on the status of depart-
12 mental research activities concerning palliative care for
13 children with life-threatening conditions.

14 (e) AUTHORIZATION OF APPROPRIATIONS.—There
15 are authorized to be appropriated to carry out this section
16 \$300,000 for fiscal year 2008.

17 **SEC. 204. EVALUATION AND REPORTS TO CONGRESS.**

18 (a) EVALUATIONS.—During the 1-year period fol-
19 lowing the first 4 years of the demonstration projects, the
20 Secretary shall complete an evaluation of the demonstra-
21 tion projects using outcomes in order—

22 (1) to determine the short-term and long-term
23 costs and benefits of changing hospice care (as de-
24 fined in section 1861(dd)(1) of the Social Security

1 Act (42 U.S.C. 1395x(dd)(1))) provided under the
2 Medicare program to children, to include—

3 (A) the pediatric palliative care furnished
4 under the demonstration projects; and

5 (B) the Medicare program to permit eligi-
6 ble children to receive curative and palliative
7 care simultaneously;

8 (2) to review the implementation of the dem-
9 onstration projects compared to recommendations
10 contained in the report published in 2003 by the In-
11 stitute of Medicine of the National Academy of
12 Sciences entitled “When Children Die: Improving
13 Palliative and End-of-Life Care for Children and
14 Their Families”;

15 (3) to determine the quality and duration of
16 palliative care for individuals who receive such care
17 under the demonstration projects who would not be
18 eligible to receive such care under the Medicare pro-
19 gram;

20 (4) to determine whether any increase in pay-
21 ments for pediatric palliative care is offset by sav-
22 ings in other parts of the Medicare program; and

23 (5) to determine the projected cost of imple-
24 menting the demonstration projects on a national
25 basis.

1 (b) REPORTS.—

2 (1) INTERIM REPORT.—Not later than the date
3 that is 2 years after the date on which the dem-
4 onstration projects are implemented, the Secretary
5 shall submit an interim report to Congress on the
6 demonstration projects.

7 (2) FINAL REPORT.—Not later than the date
8 that is 1 year after the date on which the dem-
9 onstration projects end, the Secretary shall submit a
10 final report to Congress on the demonstration
11 projects that includes the results of the evaluation
12 conducted under paragraph (1) together with such
13 recommendations for legislation or administrative
14 action as the Secretary determines is appropriate.

15 **SEC. 205. AUTHORIZATION OF APPROPRIATIONS.**

16 (a) IN GENERAL.—There are authorized to be appro-
17 priated—

18 (1) \$2,500,000, to carry out the demonstration
19 projects under section 201;

20 (2) \$2,500,000, to carry out the demonstration
21 projects under section 202, including for awarding
22 grants under subsection (c)(2) of such section; and

23 (3) \$300,000, to carry out section 203.

1 (b) AVAILABILITY.—Sums appropriated under sub-
2 section (a) shall remain available without fiscal year limi-
3 tation until expended.

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