

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 “(5) facilitate the development, assessment, and  
2 implementation of evidence-based (when available)  
3 and best practices (as available) clinical practice  
4 guidelines and institutional protocols and procedures  
5 for pediatric palliative, pain management, end-of-life,  
6 supportive, and bereavement care; and

7 “(6) assure that children with life-threatening  
8 conditions and the families of such children are an  
9 integral part of these family-centered processes.

10 “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
11 are authorized to be appropriated to carry out this section  
12 \$5,000,000 for each of fiscal years 2008 through 2012.”.

13 **SEC. 102. GRANTS TO EXPAND PEDIATRIC PALLIATIVE**  
14 **CARE.**

15 Part Q of title III of the Public Health Service Act  
16 (42 U.S.C. 280h et seq.) is amended by adding at the end  
17 the following:

18 **“SEC. 399Z–1. GRANTS TO EXPAND PEDIATRIC PALLIATIVE**  
19 **CARE.**

20 “(a) ESTABLISHMENT.—The Secretary, acting  
21 through the Administrator of the Health Resources and  
22 Services Administration, may award grants to eligible en-  
23 tities to implement or expand pediatric palliative care pro-  
24 grams for children with life-threatening conditions.

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



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

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

(vi) in the case of an agency or organization in any State in which State or applicable local law provides for the licensing of agencies or organizations of this nature, is licensed pursuant to such law;

(vii) seeks to ensure that eligible children and their families receive complete, timely, understandable information about diagnosis, prognosis, treatments, and palliative care options;

(viii) seeks to ensure access to routine pediatric care as appropriate for the eligible child;

(ix) ensures that children and their families participate in effective and timely prevention, assessment, and treatment of physical and psychological symptoms of 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-



onstration projects under section 201 and in accordance with the provisions of this subsection to demonstrate the provision of pediatric palliative care and pediatric palliative care consultation services to eligible children who are not entitled to (or enrolled for) coverage under the health plans described in subsection (a)(3)(C).

(2) PARTICIPATION.—

(A) ELIGIBLE ORGANIZATIONS.—The Secretary shall permit any eligible organization to participate in a demonstration project on a voluntary basis.

(B) ELIGIBLE CHILDREN.—Any eligible organization participating in a demonstration project shall permit any eligible child enrolled in an eligible health plan offered by the organization to participate in such project on a voluntary basis.

(c) SERVICES UNDER DEMONSTRATION PROJECTS.—

(1) PROVISION OF PEDIATRIC PALLIATIVE CARE AND CONSULTATION SERVICES.—Under a demonstration project, each eligible organization electing to participate in the demonstration project shall provide 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-

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

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

(E) AVAILABILITY OF SUPPORTIVE AND BEREAVEMENT COUNSELING.—Each eligible child and the family of such child shall receive supportive counseling and bereavement counseling, if appropriate.

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

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

(ii) that is effective and compassionate from diagnosis through death and 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

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

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

(d) CONDUCT OF DEMONSTRATION PROJECTS.—

(1) SITES.—The Secretary shall conduct demonstration projects in not less than 4, but not more than 8, sites.

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

(A) include both urban and rural eligible organizations;

(B) are geographically diverse and readily accessible to a significant number of eligible 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.

○