

107<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# S. 2857

To amend titles XVIII and XIX of the Social Security Act to improve the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

AUGUST 1, 2002

Mr. ROCKEFELLER (for himself, Ms. COLLINS, and Mr. WYDEN) introduced the following bill; which was read twice and referred to the Committee on Finance

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## A BILL

To amend titles XVIII and XIX of the Social Security Act to improve the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, 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       “Advance Planning and Compassionate Care Act of  
6       2002”.

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

- Sec. 1. Short title; table of contents.
- Sec. 2. Development of standards to assess end-of-life care.
- Sec. 3. Study and report by the Secretary of Health and Human Services regarding the establishment and implementation of a national uniform policy on advance directives.
- Sec. 4. Improvement of policies related to the use of advance directives.
- Sec. 5. National information hotline for end-of-life decisionmaking and hospice care.
- Sec. 6. Demonstration project for innovative and new approaches to end-of-life care for medicare, medicaid, and SCHIP beneficiaries.
- Sec. 7. Establishment of End-of-Life Care Advisory Board.

3 **SEC. 2. DEVELOPMENT OF STANDARDS TO ASSESS END-OF-**  
 4 **LIFE CARE.**

5 (a) IN GENERAL.—The Secretary of Health and  
 6 Human Services, in consultation with the Administrator  
 7 of the Centers for Medicare & Medicaid Services, the Di-  
 8 rector of the National Institutes of Health, the Adminis-  
 9 trator of the Agency for Health Care Policy and Research,  
 10 and the End-of-Life Care Advisory Board (established  
 11 under section 7), shall develop outcome standards and  
 12 measures to—

13 (1) evaluate the performance of health care pro-  
 14 grams and projects that provide end-of-life care to  
 15 individuals, including the quality of the care pro-  
 16 vided by such programs and projects; and

17 (2) assess the access to, and utilization of, such  
 18 programs and projects, including differences in such  
 19 access and utilization in rural and urban areas and  
 20 for minority populations.

1 (b) REPORT TO CONGRESS.—Not later than 2 years  
2 after the date of enactment of this Act, the Secretary of  
3 Health and Human Services shall submit to Congress a  
4 report on the outcome standards and measures developed  
5 under subsection (a), together with recommendations for  
6 such legislation and administrative actions as the Sec-  
7 retary considers appropriate.

8 **SEC. 3. STUDY AND REPORT BY THE SECRETARY OF**  
9 **HEALTH AND HUMAN SERVICES REGARDING**  
10 **THE ESTABLISHMENT AND IMPLEMENTATION**  
11 **OF A NATIONAL UNIFORM POLICY ON AD-**  
12 **VANCE DIRECTIVES.**

13 (a) STUDY.—

14 (1) IN GENERAL.—The Secretary of Health and  
15 Human Services shall conduct a thorough study of  
16 all matters relating to the establishment and imple-  
17 mentation of a national uniform policy on advance  
18 directives for individuals receiving items and services  
19 under titles XVIII and XIX of the Social Security  
20 Act (42 U.S.C. 1395 et seq.; 1396 et seq.).

21 (2) MATTERS STUDIED.—The matters studied  
22 by the Secretary of Health and Human Services  
23 under paragraph (1) shall include issues  
24 concerning—

1 (A) family satisfaction that a patient's  
2 wishes, as stated in the patient's advance direc-  
3 tive, were carried out;

4 (B) the portability of advance directives,  
5 including cases involving the transfer of an in-  
6 dividual from 1 health care setting to another;

7 (C) immunity from civil liability and crimi-  
8 nal responsibility for health care providers that  
9 follow the instructions in an individual's ad-  
10 vance directive that was validly executed in, and  
11 consistent with the laws of, the State in which  
12 it was executed;

13 (D) conditions under which an advance di-  
14 rective is operative;

15 (E) revocation of an advance directive by  
16 an individual;

17 (F) the criteria used by States for deter-  
18 mining that an individual has a terminal condi-  
19 tion;

20 (G) surrogate decisionmaking regarding  
21 end-of-life care;

22 (H) the provision of adequate palliative  
23 care (as defined in paragraph (3)), including  
24 pain management; and

1           (I) adequate and timely referrals to hos-  
2           pice care programs.

3           (3) PALLIATIVE CARE.—For purposes of para-  
4           graph (2)(H), the term “palliative care” means  
5           interdisciplinary care for individuals with a life-  
6           threatening illness or injury relating to pain and  
7           symptom management and psychological, social, and  
8           spiritual needs and that seeks to improve the quality  
9           of life for the individual and the individual’s family.

10          (b) REPORT TO CONGRESS.—Not later than 18  
11          months after the date of enactment of this Act, the Sec-  
12          retary of Health and Human Services shall submit to Con-  
13          gress a report on the study conducted under subsection  
14          (a), together with recommendations for such legislation  
15          and administrative actions as the Secretary considers ap-  
16          propriate.

17          (c) CONSULTATION.—In conducting the study and  
18          developing the report under this section, the Secretary of  
19          Health and Human Services shall consult with the End-  
20          of-Life Care Advisory Board (established under section 7),  
21          the Uniform Law Commissioners, and other interested  
22          parties.

1 **SEC. 4. IMPROVEMENT OF POLICIES RELATED TO THE USE**  
2 **OF ADVANCE DIRECTIVES.**

3 (a) **MEDICARE.**—Section 1866(f) of the Social Secu-  
4 rity Act (42 U.S.C. 1395cc(f)) is amended—

5 (1) in paragraph (1)—

6 (A) in subparagraph (B), by inserting  
7 “and if presented by the individual, to include  
8 the content of such advance directive in a  
9 prominent part of such record” before the semi-  
10 colon at the end;

11 (B) in subparagraph (D), by striking  
12 “and” after the semicolon at the end;

13 (C) in subparagraph (E), by striking the  
14 period at the end and inserting “; and”; and

15 (D) by inserting after subparagraph (E)  
16 the following new subparagraph:

17 “(F) to provide each individual with the oppor-  
18 tunity to discuss issues relating to the information  
19 provided to that individual pursuant to subpara-  
20 graph (A) with an appropriately trained profes-  
21 sional.”;

22 (2) in paragraph (3), by striking “a written”  
23 and inserting “an”; and

24 (3) by adding at the end the following new  
25 paragraph:

1       “(5)(A) An advance directive validly executed outside  
2 of the State in which such advance directive is presented  
3 by an adult individual to a provider of services, a  
4 Medicare+Choice organization, or a prepaid or eligible or-  
5 ganization shall be given the same effect by that provider  
6 or organization as an advance directive validly executed  
7 under the law of the State in which it is presented would  
8 be given effect.

9       “(B)(i) The definition of an advanced directive shall  
10 also include actual knowledge of instructions made while  
11 an individual was able to express the wishes of such indi-  
12 vidual with regard to health care.

13       “(ii) For purposes of clause (i), the term ‘actual  
14 knowledge’ means the possession of information of an indi-  
15 vidual’s wishes communicated to the health care provider  
16 orally or in writing by the individual, the individual’s med-  
17 ical power of attorney representative, the individual’s  
18 health care surrogate, or other individuals resulting in the  
19 health care provider’s personal cognizance of these wishes.  
20 Other forms of imputed knowledge are not actual knowl-  
21 edge.

22       “(C) The provisions of this paragraph shall preempt  
23 any State law to the extent such law is inconsistent with  
24 such provisions. The provisions of this paragraph shall not  
25 preempt any State law that provides for greater port-

1 ability, more deference to a patient’s wishes, or more lati-  
2 tude in determining a patient’s wishes.”.

3 (b) MEDICAID.—Section 1902(w) of the Social Secu-  
4 rity Act (42 U.S.C. 1396a(w)) is amended—

5 (1) in paragraph (1)—

6 (A) in subparagraph (B)—

7 (i) by striking “in the individual’s  
8 medical record” and inserting “in a promi-  
9 nent part of the individual’s current med-  
10 ical record”; and

11 (ii) by inserting “and if presented by  
12 the individual, to include the content of  
13 such advance directive in a prominent part  
14 of such record” before the semicolon at the  
15 end;

16 (B) in subparagraph (D), by striking  
17 “and” after the semicolon at the end;

18 (C) in subparagraph (E), by striking the  
19 period at the end and inserting “; and”; and

20 (D) by inserting after subparagraph (E)  
21 the following new subparagraph:

22 “(F) to provide each individual with the oppor-  
23 tunity to discuss issues relating to the information  
24 provided to that individual pursuant to subpara-

1 graph (A) with an appropriately trained profes-  
2 sional.”;

3 (2) in paragraph (4), by striking “a written”  
4 and inserting “an”; and

5 (3) by adding at the end the following para-  
6 graph:

7 “(6)(A) An advance directive validly executed outside  
8 of the State in which such advance directive is presented  
9 by an adult individual to a provider or organization shall  
10 be given the same effect by that provider or organization  
11 as an advance directive validly executed under the law of  
12 the State in which it is presented would be given effect.

13 “(B)(i) The definition of an advanced directive shall  
14 also include actual knowledge of instructions made while  
15 an individual was able to express the wishes of such indi-  
16 vidual with regard to health care.

17 “(ii) For purposes of clause (i), the term ‘actual  
18 knowledge’ means the possession of information of an indi-  
19 vidual’s wishes communicated to the health care provider  
20 orally or in writing by the individual, the individual’s med-  
21 ical power of attorney representative, the individual’s  
22 health care surrogate, or other individuals resulting in the  
23 health care provider’s personal cognizance of these wishes.  
24 Other forms of imputed knowledge are not actual knowl-  
25 edge.

1       “(C) The provisions of this paragraph shall preempt  
2 any State law to the extent such law is inconsistent with  
3 such provisions. The provisions of this paragraph shall not  
4 preempt any State law that provides for greater port-  
5 ability, more deference to a patient’s wishes, or more lati-  
6 tude in determining a patient’s wishes.”.

7       (c) STUDY AND REPORT REGARDING IMPLEMENTA-  
8 TION.—

9           (1) STUDY.—The Secretary of Health and  
10 Human Services shall conduct a study regarding the  
11 implementation of the amendments made by sub-  
12 sections (a) and (b).

13           (2) REPORT.—Not later than 18 months after  
14 the date of enactment of this Act, the Secretary of  
15 Health and Human Services shall submit to Con-  
16 gress a report on the study conducted under para-  
17 graph (1), together with recommendations for such  
18 legislation and administrative actions as the Sec-  
19 retary considers appropriate.

20       (d) EFFECTIVE DATES.—

21           (1) IN GENERAL.—Subject to paragraph (2),  
22 the amendments made by subsections (a) and (b)  
23 shall apply to provider agreements and contracts en-  
24 tered into, renewed, or extended under title XVIII of  
25 the Social Security Act (42 U.S.C. 1395 et seq.),

1 and to State plans under title XIX of such Act (42  
2 U.S.C. 1396 et seq.), on or after such date as the  
3 Secretary of Health and Human Services specifies,  
4 but in no case may such date be later than 1 year  
5 after the date of enactment of this Act.

6 (2) EXTENSION OF EFFECTIVE DATE FOR  
7 STATE LAW AMENDMENT.—In the case of a State  
8 plan under title XIX of the Social Security Act (42  
9 U.S.C. 1396 et seq.) which the Secretary of Health  
10 and Human Services determines requires State legis-  
11 lation in order for the plan to meet the additional  
12 requirements imposed by the amendments made by  
13 subsection (b), the State plan shall not be regarded  
14 as failing to comply with the requirements of such  
15 title solely on the basis of its failure to meet these  
16 additional requirements before the first day of the  
17 first calendar quarter beginning after the close of  
18 the first regular session of the State legislature that  
19 begins after the date of enactment of this Act. For  
20 purposes of the previous sentence, in the case of a  
21 State that has a 2-year legislative session, each year  
22 of the session is considered to be a separate regular  
23 session of the State legislature.

1 **SEC. 5. NATIONAL INFORMATION HOTLINE FOR END-OF-**  
2 **LIFE DECISIONMAKING AND HOSPICE CARE.**

3 The Secretary of Health and Human Services, acting  
4 through the Administrator of the Centers for Medicare &  
5 Medicaid Services, shall operate directly, or by grant, con-  
6 tract, or interagency agreement, out of funds otherwise  
7 appropriated to the Secretary, a clearinghouse and a 24-  
8 hour toll-free telephone hotline in order to provide con-  
9 sumer information about advance directives (as defined in  
10 section 1866(f)(3) of the Social Security Act (42 U.S.C.  
11 1395cc(f)(3)), as amended by section 4(a)), end-of-life de-  
12 cisionmaking, and available end-of-life and hospice care  
13 services. In carrying out the preceding sentence, the Ad-  
14 ministrator may designate an existing clearinghouse and  
15 24-hour toll-free telephone hotline or, if no such entity is  
16 appropriate, may establish a new clearinghouse and a 24-  
17 hour toll-free telephone hotline.

18 **SEC. 6. DEMONSTRATION PROJECT FOR INNOVATIVE AND**  
19 **NEW APPROACHES TO END-OF-LIFE CARE**  
20 **FOR MEDICARE, MEDICAID, AND SCHIP BENE-**  
21 **FICIARIES.**

22 (a) ESTABLISHMENT.—

23 (1) IN GENERAL.—The Secretary, acting  
24 through the Administrator of the Centers for Medi-  
25 care & Medicaid Services, shall conduct a dem-  
26 onstration project under which the Secretary con-

1 tracts with entities operating programs in order to  
2 develop new and innovative approaches to providing  
3 end-of-life care to medicare beneficiaries, medicaid  
4 beneficiaries, and SCHIP beneficiaries.

5 (2) APPLICATION.—Any entity seeking to par-  
6 ticipate in the demonstration project shall submit to  
7 the Secretary an application in such form and man-  
8 ner as the Secretary may require.

9 (3) DURATION.—The authority of the Secretary  
10 to conduct the demonstration project shall terminate  
11 at the end of the 5-year period beginning on the  
12 date the Secretary implements the demonstration  
13 project.

14 (b) SELECTION CRITERIA.—

15 (1) IN GENERAL.—Subject to paragraphs (2)  
16 and (3), in selecting entities to participate in the  
17 demonstration project, the Secretary shall select en-  
18 tities that will allow for programs to be conducted  
19 in a variety of States, in an array of care settings,  
20 and that reflect—

21 (A) a balance between urban and rural set-  
22 tings;

23 (B) cultural diversity; and

24 (C) various modes of medical care and in-  
25 surance, such as fee-for-service, preferred pro-

1           vider organizations, health maintenance organi-  
2           zations, hospice care, home care services, long-  
3           term care, pediatric care, and integrated deliv-  
4           ery systems.

5           (2) PREFERENCES.—The Secretary shall give  
6           preference to entities operating programs that—

7                   (A) will serve medicare beneficiaries, med-  
8                   icaid beneficiaries, or SCHIP beneficiaries who  
9                   are dying of illnesses that are most prevalent  
10                  under the medicare program, the medicaid pro-  
11                  gram, or SCHIP, respectively; and

12                  (B) appear capable of sustained service  
13                  and broad replication at a reasonable cost with-  
14                  in commonly available organizational structures.

15           (3) SELECTION OF PROGRAM THAT PROVIDES  
16           PEDIATRIC END-OF-LIFE CARE.—The Secretary shall  
17           ensure that at least 1 of the entities selected to par-  
18           ticipate in the demonstration project operates a pro-  
19           gram that provides pediatric end-of-life care.

20           (c) EVALUATION OF PROGRAMS.—

21                   (1) IN GENERAL.—Each program operated by  
22                   an entity under the demonstration project shall be  
23                   evaluated at such regular intervals as the Secretary  
24                   determines are appropriate.

1           (2) USE OF PRIVATE ENTITIES TO CONDUCT  
2 EVALUATIONS.—The Secretary, in consultation with  
3 the End-of-Life Care Advisory Board (established  
4 under section 7), shall contract with 1 or more pri-  
5 vate entities to coordinate and conduct the evalua-  
6 tions under paragraph (1). Such a contract may not  
7 be awarded to an entity selected to participate in the  
8 demonstration project.

9           (3) REQUIREMENTS FOR EVALUATIONS.—

10           (A) USE OF OUTCOME MEASURES AND  
11 STANDARDS.—In coordinating and conducting  
12 an evaluation of a program conducted under the  
13 demonstration project, an entity shall use the  
14 outcome standards and measures required to be  
15 developed under section 2 as soon as those  
16 standards and measures are available.

17           (B) ELEMENTS OF EVALUATION.—In addi-  
18 tion to the use of the outcome standards and  
19 measures under subparagraph (A), an evalua-  
20 tion of a program conducted under the dem-  
21 onstration project shall include the following:

22           (i) A comparison of the quality of care  
23 provided by, and of the outcomes for medi-  
24 care beneficiaries, medicaid beneficiaries,  
25 and SCHIP beneficiaries, and the families

1 of such beneficiaries enrolled in, the pro-  
2 gram being evaluated to the quality of care  
3 and outcomes for such individuals that  
4 would have resulted if care had been pro-  
5 vided under existing delivery systems.

6 (ii) An analysis of how ongoing meas-  
7 ures of quality and accountability for im-  
8 provement and excellence could be incor-  
9 porated into the program being evaluated.

10 (iii) A comparison of the costs of the  
11 care provided to medicare beneficiaries,  
12 medicaid beneficiaries, and SCHIP bene-  
13 ficiaries under the program being evalu-  
14 ated to the costs of such care that would  
15 have been incurred under the medicare  
16 program, the medicaid program, and  
17 SCHIP if such program had not been con-  
18 ducted.

19 (iv) An analysis of whether the pro-  
20 gram being evaluated implements practices  
21 or procedures that result in improved pa-  
22 tient outcomes, resource utilization, or  
23 both.

24 (v) An analysis of—

1 (I) the population served by the  
2 program being evaluated; and

3 (II) how accurately that popu-  
4 lation reflects the total number of  
5 medicare beneficiaries, medicaid bene-  
6 ficiaries, and SCHIP beneficiaries re-  
7 siding in the area who are in need of  
8 services offered by such program.

9 (vi) An analysis of the eligibility re-  
10 quirements and enrollment procedures for  
11 the program being evaluated.

12 (vii) An analysis of the services pro-  
13 vided to beneficiaries enrolled in the pro-  
14 gram being evaluated and the utilization  
15 rates for such services.

16 (viii) An analysis of the structure for  
17 the provision of specific services under the  
18 program being evaluated.

19 (ix) An analysis of the costs of pro-  
20 viding specific services under the program  
21 being evaluated.

22 (x) An analysis of any procedures for  
23 offering medicare beneficiaries, medicaid  
24 beneficiaries, and SCHIP beneficiaries en-  
25 rolled in the program being evaluated a

1 choice of services and how the program re-  
2 sponds to the preferences of such bene-  
3 ficiaries.

4 (xi) An analysis of the quality of care  
5 provided to, and of the outcomes for, medi-  
6 care beneficiaries, medicaid beneficiaries,  
7 and SCHIP beneficiaries, and the families  
8 of such beneficiaries, that are enrolled in  
9 the program being evaluated.

10 (xii) An analysis of any ethical, cul-  
11 tural, or legal concerns—

12 (I) regarding the program being  
13 evaluated; and

14 (II) with the replication of such  
15 program in other settings.

16 (xiii) An analysis of any changes to  
17 regulations or of any additional funding  
18 that would result in more efficient proce-  
19 dures or improved outcomes under the pro-  
20 gram being evaluated.

21 (d) WAIVER AUTHORITY.—The Secretary may waive  
22 compliance with any of the requirements of titles XI,  
23 XVIII, XIX, and XXI of the Social Security Act (42  
24 U.S.C. 1301 et seq.; 1395 et seq.; 1396 et seq.; 1397aa  
25 et seq.) which, if applied, would prevent the demonstration

1 project carried out under this section from effectively  
2 achieving the purpose of such project.

3 (e) REPORTS TO CONGRESS.—

4 (1) ANNUAL REPORTS BY SECRETARY.—

5 (A) IN GENERAL.—Beginning 1 year after  
6 the date of enactment of this Act, and annually  
7 thereafter, the Secretary shall submit to Con-  
8 gress a report on the demonstration project and  
9 on the quality of end-of-life care under the  
10 medicare program, the medicaid program, and  
11 SCHIP, together with recommendations for  
12 such legislation and administrative actions as  
13 the Secretary considers appropriate.

14 (B) SUMMARY OF RECENT STUDIES.—A  
15 report submitted under subparagraph (A) shall  
16 include a summary of any recent studies and  
17 advice from experts in the health care field re-  
18 garding the ethical, cultural, and legal issues  
19 that may arise when attempting to improve the  
20 health care system to meet the needs of individ-  
21 uals with serious and eventually terminal condi-  
22 tions.

23 (C) CONTINUATION OR REPLICATION OF  
24 DEMONSTRATION PROJECTS.—The first report  
25 submitted under subparagraph (A) after the 3-

1 year anniversary of the date the Secretary im-  
2 plements the demonstration project shall in-  
3 clude recommendations regarding whether such  
4 demonstration project should be continued be-  
5 yond the period described in subsection (a)(3)  
6 and whether broad replication of any of the pro-  
7 grams conducted under the demonstration  
8 project should be initiated.

9 (2) REPORT BY END-OF-LIFE CARE ADVISORY  
10 BOARD ON DEMONSTRATION PROJECT.—

11 (A) IN GENERAL.—Not later than 2 years  
12 after the conclusion of the demonstration  
13 project, the End-of-Life Advisory Board shall  
14 submit a report to the Secretary and Congress  
15 on such project.

16 (B) CONTENTS.—The report submitted  
17 under subparagraph (A) shall contain—

18 (i) an evaluation of the effectiveness  
19 of the demonstration project; and

20 (ii) recommendations for such legisla-  
21 tion and administrative actions as the  
22 Board considers appropriate.

23 (f) FUNDING.—There are appropriated such sums as  
24 are necessary for conducting the demonstration project

1 and for preparing and submitting the reports required  
2 under subsection (e)(1).

3 (g) DEFINITIONS.—In this section:

4 (1) DEMONSTRATION PROJECT.—The term  
5 “demonstration project” means the demonstration  
6 project conducted under this section.

7 (2) MEDICAID BENEFICIARIES.—The term  
8 “medicaid beneficiaries” means individuals who are  
9 enrolled in the State medicaid program.

10 (3) MEDICAID PROGRAM.—The term “medicaid  
11 program” means the health care program under title  
12 XIX of the Social Security Act (42 U.S.C. 1395 et  
13 seq.).

14 (4) MEDICARE BENEFICIARIES.—The term  
15 “medicare beneficiaries” means individuals who are  
16 entitled to benefits under part A or enrolled for ben-  
17 efits under part B of the medicare program.

18 (5) MEDICARE PROGRAM.—The term “medicare  
19 program” means the health care program under title  
20 XVIII of the Social Security Act (42 U.S.C. 1395 et  
21 seq.).

22 (6) SCHIP BENEFICIARY.—The term “SCHIP  
23 beneficiary” means an individual who is enrolled in  
24 SCHIP.

1           (7) SCHIP.—The term “SCHIP” means the  
2 State children’s health insurance program under  
3 title XXI of the Social Security Act (42 U.S.C.  
4 1397aa et seq.).

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

7 **SEC. 7. ESTABLISHMENT OF END-OF-LIFE CARE ADVISORY**  
8 **BOARD.**

9           (a) ESTABLISHMENT.—There is established within  
10 the Department of Health and Human Services an End-  
11 of-Life Care Advisory Board (in this section referred to  
12 as the “Board”).

13           (b) STRUCTURE AND MEMBERSHIP.—

14           (1) IN GENERAL.—The Board shall be com-  
15 posed of 15 members who shall be appointed by the  
16 Secretary of Health and Human Services (in this  
17 section referred to as the “Secretary”).

18           (2) REQUIRED REPRESENTATION.—The Sec-  
19 retary shall ensure that the following groups, organi-  
20 zations, and associations are represented in the  
21 membership of the Board:

22           (A) An end-of-life consumer advocacy orga-  
23 nization.

24           (B) A senior citizen advocacy organization.

1 (C) A physician-based hospice or palliative  
2 care organization.

3 (D) A nurse-based hospice or palliative  
4 care organization.

5 (E) A hospice or palliative care provider  
6 organization.

7 (F) A hospice or palliative care representa-  
8 tive that serves the veterans population.

9 (G) A physician-based medical association.

10 (H) A physician-based pediatric medical  
11 association.

12 (I) A home health-based nurses associa-  
13 tion.

14 (J) A hospital-based or health system-  
15 based palliative care group.

16 (K) A children-based or family-based hos-  
17 pice resource group.

18 (L) A cancer pain management resource  
19 group.

20 (M) A cancer research and policy advocacy  
21 group.

22 (N) An end-of-life care policy advocacy  
23 group.

24 (O) An interdisciplinary end-of-life care  
25 academic institution.

1           (3) ETHNIC DIVERSITY REQUIREMENT.—The  
2 Secretary shall ensure that the members of the  
3 Board appointed under paragraph (1) represent the  
4 ethnic diversity of the United States.

5           (4) PROHIBITION.—No individual who is a Fed-  
6 eral officer or employee may serve as a member of  
7 the Board.

8           (5) TERMS OF APPOINTMENT.—Each member  
9 of the Board shall serve for a term determined ap-  
10 propriate by the Secretary.

11          (6) CHAIRPERSON.—The Secretary shall des-  
12 ignate a member of the Board as chairperson.

13          (c) MEETINGS.—The Board shall meet at the call of  
14 the chairperson but not less often than every 3 months.

15          (d) DUTIES.—

16           (1) IN GENERAL.—The Board shall advise the  
17 Secretary on all matters related to the furnishing of  
18 end-of-life care to individuals.

19           (2) SPECIFIC DUTIES.—The specific duties of  
20 the Board are as follows:

21           (A) CONSULTING.—The Board shall con-  
22 sult with the Secretary regarding—

23           (i) the development of the outcome  
24 standards and measures under section 2;

1 (ii) conducting the study and submit-  
2 ting the report under section 3; and

3 (iii) the selection of private entities to  
4 conduct evaluations pursuant to section  
5 6(c)(2).

6 (B) REPORT ON DEMONSTRATION  
7 PROJECT.—The Board shall submit the report  
8 required under section 6(e)(2).

9 (e) MEMBERS TO SERVE WITHOUT COMPENSA-  
10 TION.—

11 (1) IN GENERAL.—All members of the Board  
12 shall serve on the Board without compensation for  
13 such service.

14 (2) TRAVEL EXPENSES.—The members of the  
15 Board shall be allowed travel expenses, including per  
16 diem in lieu of subsistence, at rates authorized for  
17 employees of agencies under subchapter I of chapter  
18 57 of title 5, United States Code, while away from  
19 their homes or regular places of business in the per-  
20 formance of services for the Board.

21 (f) STAFF.—

22 (1) IN GENERAL.—The chairperson of the  
23 Board may, without regard to the civil service laws  
24 and regulations, appoint and terminate an executive  
25 director and such other additional personnel as may

1 be necessary to enable the Board to perform its du-  
2 ties. The employment of an executive director shall  
3 be subject to confirmation by the Board.

4 (2) COMPENSATION.—The chairperson of the  
5 Board may fix the compensation of the executive di-  
6 rector and other personnel without regard to chapter  
7 51 and subchapter III of chapter 53 of title 5,  
8 United States Code, relating to classification of posi-  
9 tions and General Schedule pay rates, except that  
10 the rate of pay for the executive director and other  
11 personnel may not exceed the rate payable for level  
12 V of the Executive Schedule under section 5316 of  
13 such title.

14 (3) PERSONNEL AS FEDERAL EMPLOYEES.—

15 (A) IN GENERAL.—The executive director  
16 and any personnel of the Board who are em-  
17 ployees shall be employees under section 2105  
18 of title 5, United States Code, for purposes of  
19 chapters 63, 81, 83, 84, 85, 87, 89, and 90 of  
20 that title.

21 (B) MEMBERS OF BOARD.—Subparagraph

22 (A) shall not be construed to apply to members  
23 of the Board.

24 (g) DETAIL OF GOVERNMENT EMPLOYEES.—Any  
25 Federal Government employee may be detailed to the

1 Board without additional reimbursement (other than the  
2 employee' regular compensation), and such detail shall be  
3 without interruption or loss of civil service status or privi-  
4 lege.

5 (h) PROCUREMENT OF TEMPORARY AND INTERMIT-  
6 TENT SERVICES.—The chairperson of the Board may pro-  
7 cure temporary and intermittent services under section  
8 3109(b) of title 5, United States Code, at rates for individ-  
9 uals which do not exceed the daily equivalent of the annual  
10 rate of basic pay prescribed for level V of the Executive  
11 Schedule under section 5316 of such title.

12 (i) FEDERAL ADVISORY COMMITTEE ACT.—Section  
13 14 of the Federal Advisory Committee Act (5 U.S.C.  
14 App.) shall not apply to the Board.

15 (j) TERMINATION.—The Board shall terminate 90  
16 days after the date on which the Board submits the report  
17 under section 6(e)(2).

18 (k) FUNDING.—Funding for the operation of the  
19 Board shall be from amounts otherwise appropriated to  
20 the Department of Health and Human Services.

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