107TH CONGRESS
2D 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.

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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the ''Advance Planning and Compassionate Care Act of 2002''.

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

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

(a) IN GENERAL.—The Secretary of Health and Human Services, in consultation with the Administrator of the Centers for Medicare & Medicaid Services, the Director of the National Institutes of Health, the Administrator of the Agency for Health Care Policy and Research, and the End-of-Life Care Advisory Board (established under section 7), shall develop outcome standards and measures to—

(1) evaluate the performance of health care programs and projects that provide end-of-life care to individuals, including the quality of the care provided by such programs and projects; and

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

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

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.

(a) STUDY.—

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

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

(A) family satisfaction that a patient's wishes, as stated in the patient's advance directive, were carried out;

(B) the portability of advance directives, including cases involving the transfer of an individual from 1 health care setting to another;

(C) immunity from civil liability and criminal responsibility for health care providers that follow the instructions in an individual's advance directive that was validly executed in, and consistent with the laws of, the State in which it was executed;

(D) conditions under which an advance directive is operative;

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

(F) the criteria used by States for determining that an individual has a terminal condition;

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

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

(I) adequate and timely referrals to hospice care programs.

(3) PALLIATIVE CARE.—For purposes of paragraph (2)(H), the term ''palliative care'' means interdisciplinary care for individuals with a life-threatening illness or injury relating to pain and symptom management and psychological, social, and spiritual needs and that seeks to improve the quality of life for the individual and the individual's family.

(b) REPORT TO CONGRESS.—Not later than 18 months after the date of enactment of this Act, the Secretary of Health and Human Services shall submit to Congress a report on the study conducted under subsection (a), together with recommendations for such legislation and administrative actions as the Secretary considers appropriate.

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

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

(a) MEDICARE.—Section 1866(f) of the Social Security Act (42 U.S.C. 1395cc(f)) is amended—

(1) in paragraph (1)—

(A) in subparagraph (B), by inserting ''and if presented by the individual, to include the content of such advance directive in a prominent part of such record'' before the semicolon at the end;

(B) in subparagraph (D), by striking ''and'' after the semicolon at the end;

(C) in subparagraph (E), by striking the period at the end and inserting ''; and''; and

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

''(F) to provide each individual with the opportunity to discuss issues relating to the information provided to that individual pursuant to subparagraph (A) with an appropriately trained professional.'';

(2) in paragraph (3), by striking ''a written'' and inserting ''an''; and

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

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

''(B)(i) The definition of an advanced directive shall also include actual knowledge of instructions made while an individual was able to express the wishes of such individual with regard to health care.

''(ii) For purposes of clause (i), the term 'actual knowledge' means the possession of information of an individual's wishes communicated to the health care provider orally or in writing by the individual, the individual's medical power of attorney representative, the individual's health care surrogate, or other individuals resulting in the health care provider's personal cognizance of these wishes. Other forms of imputed knowledge are not actual knowledge.

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

ability, more deference to a patient's wishes, or more latitude in determining a patient's wishes.''.

(b) MEDICAID.—Section 1902(w) of the Social Security Act (42 U.S.C. 1396a(w)) is amended—

(1) in paragraph (1)—

(A) in subparagraph (B)—

(i) by striking ''in the individual's medical record'' and inserting ''in a prominent part of the individual's current medical record''; and

(ii) by inserting ''and if presented by the individual, to include the content of such advance directive in a prominent part of such record'' before the semicolon at the end;

(B) in subparagraph (D), by striking ''and'' after the semicolon at the end;

(C) in subparagraph (E), by striking the period at the end and inserting ''; and''; and

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

''(F) to provide each individual with the opportunity to discuss issues relating to the information provided to that individual pursuant to subpara-

graph (A) with an appropriately trained professional.'';

(2) in paragraph (4), by striking ''a written'' and inserting ''an''; and

(3) by adding at the end the following paragraph:

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

''(B)(i) The definition of an advanced directive shall also include actual knowledge of instructions made while an individual was able to express the wishes of such individual with regard to health care.

''(ii) For purposes of clause (i), the term 'actual knowledge' means the possession of information of an individual's wishes communicated to the health care provider orally or in writing by the individual, the individual's medical power of attorney representative, the individual's health care surrogate, or other individuals resulting in the health care provider's personal cognizance of these wishes. Other forms of imputed knowledge are not actual knowledge.

''(C) The provisions of this paragraph shall preempt any State law to the extent such law is inconsistent with such provisions. The provisions of this paragraph shall not preempt any State law that provides for greater portability, more deference to a patient's wishes, or more latitude in determining a patient's wishes.''.

(c) STUDY AND REPORT REGARDING IMPLEMENTATION.—

(1) STUDY.—The Secretary of Health and Human Services shall conduct a study regarding the implementation of the amendments made by subsections (a) and (b).

(2) REPORT.—Not later than 18 months after the date of enactment of this Act, the Secretary of Health and Human Services shall submit to Congress a report on the study conducted under paragraph (1), together with recommendations for such legislation and administrative actions as the Secretary considers appropriate.

(d) EFFECTIVE DATES.—

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

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

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

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

The Secretary of Health and Human Services, acting through the Administrator of the Centers for Medicare & Medicaid Services, shall operate directly, or by grant, contract, or interagency agreement, out of funds otherwise appropriated to the Secretary, a clearinghouse and a 24-hour toll-free telephone hotline in order to provide consumer information about advance directives (as defined in section 1866(f)(3) of the Social Security Act (42 U.S.C. 1395cc(f)(3)), as amended by section 4(a)), end-of-life decisionmaking, and available end-of-life and hospice care services. In carrying out the preceding sentence, the Administrator may designate an existing clearinghouse and 24-hour toll-free telephone hotline or, if no such entity is appropriate, may establish a new clearinghouse and a 24-hour toll-free telephone hotline.

SEC. 6. DEMONSTRATION PROJECT FOR INNOVATIVE AND NEW APPROACHES TO END-OF-LIFE CARE FOR MEDICARE, MEDICAID, AND SCHIP BENEFICIARIES.

(a) ESTABLISHMENT.—

(1) IN GENERAL.—The Secretary, acting through the Administrator of the Centers for Medicare & Medicaid Services, shall conduct a demonstration project under which the Secretary con-

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

(2) APPLICATION.—Any entity seeking to participate in the demonstration project shall submit to the Secretary an application in such form and manner as the Secretary may require.

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

(b) SELECTION CRITERIA.—

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

(A) a balance between urban and rural settings;

(B) cultural diversity; and

(C) various modes of medical care and insurance, such as fee-for-service, preferred pro-

vider organizations, health maintenance organizations, hospice care, home care services, long-term care, pediatric care, and integrated delivery systems.

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

(A) will serve medicare beneficiaries, medicaid beneficiaries, or SCHIP beneficiaries who are dying of illnesses that are most prevalent under the medicare program, the medicaid program, or SCHIP, respectively; and

(B) appear capable of sustained service and broad replication at a reasonable cost within commonly available organizational structures.

(3) SELECTION OF PROGRAM THAT PROVIDES PEDIATRIC END-OF-LIFE CARE.—The Secretary shall ensure that at least 1 of the entities selected to participate in the demonstration project operates a program that provides pediatric end-of-life care.

(c) EVALUATION OF PROGRAMS.—

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

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

(3) REQUIREMENTS FOR EVALUATIONS.—

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

(B) ELEMENTS OF EVALUATION.—In addition to the use of the outcome standards and measures under subparagraph (A), an evaluation of a program conducted under the demonstration project shall include the following:

(i) A comparison of the quality of care provided by, and of the outcomes for medicare beneficiaries, medicaid beneficiaries, and SCHIP beneficiaries, and the families

of such beneficiaries enrolled in, the program being evaluated to the quality of care and outcomes for such individuals that would have resulted if care had been provided under existing delivery systems.

(ii) An analysis of how ongoing measures of quality and accountability for improvement and excellence could be incorporated into the program being evaluated.

(iii) A comparison of the costs of the care provided to medicare beneficiaries, medicaid beneficiaries, and SCHIP beneficiaries under the program being evaluated to the costs of such care that would have been incurred under the medicare program, the medicaid program, and SCHIP if such program had not been conducted.

(iv) An analysis of whether the program being evaluated implements practices or procedures that result in improved patient outcomes, resource utilization, or both.

(v) An analysis of—

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

(II) how accurately that population reflects the total number of medicare beneficiaries, medicaid beneficiaries, and SCHIP beneficiaries residing in the area who are in need of services offered by such program.

(vi) An analysis of the eligibility requirements and enrollment procedures for the program being evaluated.

(vii) An analysis of the services provided to beneficiaries enrolled in the program being evaluated and the utilization rates for such services.

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

(ix) An analysis of the costs of providing specific services under the program being evaluated.

(x) An analysis of any procedures for offering medicare beneficiaries, medicaid beneficiaries, and SCHIP beneficiaries enrolled in the program being evaluated a

choice of services and how the program responds to the preferences of such beneficiaries.

(xi) An analysis of the quality of care provided to, and of the outcomes for, medicare beneficiaries, medicaid beneficiaries, and SCHIP beneficiaries, and the families of such beneficiaries, that are enrolled in the program being evaluated.

(xii) An analysis of any ethical, cultural, or legal concerns—

(I) regarding the program being evaluated; and

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

(xiii) An analysis of any changes to regulations or of any additional funding that would result in more efficient procedures or improved outcomes under the program being evaluated.

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

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

(e) REPORTS TO CONGRESS.—

(1) ANNUAL REPORTS BY SECRETARY.—

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

(B) SUMMARY OF RECENT STUDIES.—A report submitted under subparagraph (A) shall include a summary of any recent studies and advice from experts in the health care field regarding the ethical, cultural, and legal issues that may arise when attempting to improve the health care system to meet the needs of individuals with serious and eventually terminal conditions.

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

year anniversary of the date the Secretary implements the demonstration project shall include recommendations regarding whether such demonstration project should be continued beyond the period described in subsection (a)(3) and whether broad replication of any of the programs conducted under the demonstration project should be initiated.

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

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

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

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

(ii) recommendations for such legislation and administrative actions as the Board considers appropriate.

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

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

(g) DEFINITIONS.—In this section:

(1) DEMONSTRATION PROJECT.—The term ''demonstration project'' means the demonstration project conducted under this section.

(2) MEDICAID BENEFICIARIES.—The term ''medicaid beneficiaries'' means individuals who are enrolled in the State medicaid program.

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

(4) MEDICARE BENEFICIARIES.—The term ''medicare beneficiaries'' means individuals who are entitled to benefits under part A or enrolled for benefits under part B of the medicare program.

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

(6) SCHIP BENEFICIARY.—The term ''SCHIP beneficiary'' means an individual who is enrolled in SCHIP.

(7) SCHIP.—The term ''SCHIP'' means the State children's health insurance program under title XXI of the Social Security Act (42 U.S.C. 1397aa et seq.).

(8) SECRETARY.—The term ''Secretary'' means the Secretary of Health and Human Services.

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

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

(b) STRUCTURE AND MEMBERSHIP.—

(1) IN GENERAL.—The Board shall be composed of 15 members who shall be appointed by the Secretary of Health and Human Services (in this section referred to as the ''Secretary'').

(2) REQUIRED REPRESENTATION.—The Secretary shall ensure that the following groups, organizations, and associations are represented in the membership of the Board:

(A) An end-of-life consumer advocacy organization.

(B) A senior citizen advocacy organization.

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

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

(E) A hospice or palliative care provider organization.

(F) A hospice or palliative care representative that serves the veterans population.

(G) A physician-based medical association.

(H) A physician-based pediatric medical association.

(I) A home health-based nurses association.

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

(K) A children-based or family-based hospice resource group.

(L) A cancer pain management resource group.

(M) A cancer research and policy advocacy group.

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

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

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

(4) PROHIBITION.—No individual who is a Federal officer or employee may serve as a member of the Board.

(5) TERMS OF APPOINTMENT.—Each member of the Board shall serve for a term determined appropriate by the Secretary.

(6) CHAIRPERSON.—The Secretary shall designate a member of the Board as chairperson.

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

(d) DUTIES.—

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

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

(A) CONSULTING.—The Board shall consult with the Secretary regarding—

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

(ii) conducting the study and submitting the report under section 3; and

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

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

(e) MEMBERS TO SERVE WITHOUT COMPENSATION.—

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

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

(f) STAFF.—

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

be necessary to enable the Board to perform its duties. The employment of an executive director shall be subject to confirmation by the Board.

(2) COMPENSATION.—The chairperson of the Board may fix the compensation of the executive director and other personnel without regard to chapter 51 and subchapter III of chapter 53 of title 5, United States Code, relating to classification of positions and General Schedule pay rates, except that the rate of pay for the executive director and other personnel may not exceed the rate payable for level V of the Executive Schedule under section 5316 of such title.

(3) PERSONNEL AS FEDERAL EMPLOYEES.—

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

(B) MEMBERS OF BOARD.—Subparagraph (A) shall not be construed to apply to members of the Board.

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

Board without additional reimbursement (other than the employee' regular compensation), and such detail shall be without interruption or loss of civil service status or privilege.

(h) PROCUREMENT OF TEMPORARY AND INTERMITTENT SERVICES.—The chairperson of the Board may procure temporary and intermittent services under section 3109(b) of title 5, United States Code, at rates for individuals which do not exceed the daily equivalent of the annual rate of basic pay prescribed for level V of the Executive Schedule under section 5316 of such title.

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

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

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

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