II

106TH CONGRESS
1ST SESSION

S. 628

To amend titles XVIII and XIX of the Social Security Act to expand and clarify 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

MARCH 16, 1999

Mr. ROCKEFELLER (for himself, Ms. COLLINS, Mr. COCHRAN, Mr. CONRAD, Mr. WYDEN, and Mr. JEFFORDS) 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 expand and clarify 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 1999".

(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, acting through the Administrator of the Health Care Financing Administration, the Director of the National Institutes of Health, and the Administrator of the Agency for Health Care Policy and Research, shall develop outcome standards and measures to evaluate the performance of health care programs and projects that provide end-of-life care to individuals and the quality of such care.

(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 a report to Congress concerning the outcome standards and measures developed under subsection (a).

SEC. 3. STUDY AND RECOMMENDATIONS TO CONGRESS ON ISSUES RELATING TO ADVANCE DIRECTIVE EXPANSION.

(a) STUDY.—The Secretary of Health and Human Services shall conduct a thorough study regarding the implementation of the amendments made by section 5.

(b) REPORT.—Not later than 18 months after the date of enactment of this Act, the Secretary of Health and Human Services shall submit a report to Congress that contains a detailed statement of the findings and conclusions of the Secretary regarding the study conducted pursuant to subsection (a), together with the Secretary's recommendations for such legislation and administrative actions as the Secretary considers appropriate.

SEC. 4. STUDY AND LEGISLATIVE PROPOSAL TO CONGRESS.

(a) STUDY.—

(1) IN GENERAL.—The Secretary of Health and Human Services shall conduct a thorough study of all matters relating to the creation 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) the election or refusal of life-sustaining treatment;

(B) the provision of adequate palliative care including pain management;

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

(D) immunity for health care providers that follow the instructions in an individual's advance directive;

(E) exemptions for health care providers from following the instructions in an individual's advance directive;

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

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

(H) the criteria for determining that an individual is in terminal status; and

(I) surrogate decision making regarding end of life care.

(b) REPORT TO CONGRESS.—Not later than 18 months after the date of enactment of this Act, the Sec-

retary of Health and Human Services shall submit a report to Congress that contains a detailed description of the results of the study conducted pursuant to subsection (a).

(c) CONSULTATION.—In conducting the study and developing the report under this section, the Secretary of Health and Human Services shall consult with physicians and other health care provider groups, consumer groups, the Uniform Law Commissioners, and other interested parties.

SEC. 5. EXPANSION 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;

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

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

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

''(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.''; and

(2) by adding at the end the following:

''(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) Nothing in this paragraph shall be construed to authorize the administration, withholding, or withdrawal of health care unless it is consistent with the laws of the State in which an advance directive is presented.

''(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.''.

(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;

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

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

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

''(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.''; and

(2) by adding at the end the following:

''(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) Nothing in this paragraph shall be construed to authorize the administration, withholding, or withdrawal of health care otherwise prohibited by the laws of the State in which an advance directive is presented.

''(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) 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 the 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 the 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. 6. NATIONAL INFORMATION HOTLINE FOR END–OF–LIFE DECISIONMAKING.

The Secretary of Health and Human Services, acting through the Administrator of the Health Care Financing Administration, shall establish and 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, 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)), and end-of-life decisionmaking.

SEC. 7. EVALUATION OF AND DEMONSTRATION PROJECTS FOR INNOVATIVE AND NEW APPROACHES TO END–OF–LIFE CARE FOR MEDICARE BENEFICIARIES.

(a) DEFINITIONS.—In this section:

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

(2) 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.).

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

(b) EVALUATION OF EXISTING PROGRAMS.—

(1) IN GENERAL.—The Secretary, acting through the Administrator of the Health Care Financing Administration, shall conduct ongoing eval-

uations of innovative health care programs that provide end-of-life care to medicare beneficiaries who are seriously ill or who suffer from a medical condition that is likely to be fatal.

(2) REQUIREMENTS.—Evaluations conducted under this subsection shall include the following:

(A) Evidence that the evaluated program implements practices or procedures that result in improved patient outcomes, resource utilization, or both.

(B) A definition of the population served by the program and a determination as to how accurately that population reflects the total medicare beneficiaries in the area who are in need of services offered by the program.

(C) A description of the eligibility requirements and enrollment procedures for the program.

(D) A detailed description of the services provided to medicare beneficiaries served by the program and the utilization rates for such services.

(E) A description of the structure for the provision of specific services.

(F) A detailed accounting of the costs of providing specific services under the program.

(G) A description of any procedures for offering medicare beneficiaries a choice of services and how the program responds to the preferences of the medicare beneficiaries served by the program.

(H) An assessment of the quality of care and of the outcomes for medicare beneficiaries and the families of such beneficiaries served by the program.

(I) An assessment of any ethical, cultural, or legal concerns regarding the evaluated program and with the replication of such program in other settings.

(J) Identification of any changes to regulations, or of any additional funding, that would result in more efficient procedures or improved outcomes, for the program.

(3) EXTERNAL EVALUATORS.—The Secretary shall contract with 1 or more external evaluators to coordinate and conduct the evaluations required under this subsection and under subsection (c)(4).

(4) USE OF OUTCOME MEASURES AND STANDARDS.—An evaluation conducted under this sub-

section and subsection (c)(4) shall use the outcome standards and measures required to be developed under section 2 as soon as those standards and measures are available.

(c) DEMONSTRATION PROJECTS.—

(1) AUTHORITY.—The Secretary, acting through the Administrator of the Health Care Financing Administration, shall conduct demonstration projects to develop new and innovative approaches to providing end-of-life care to medicare beneficiaries who are seriously ill or who suffer from a medical condition that is likely to be fatal.

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

(3) SELECTION CRITERIA.—

(A) IN GENERAL.—In selecting entities to conduct demonstration projects under this subsection, the Secretary shall select entities that will allow for demonstration projects to be conducted in a variety of States, in an array of care settings, and that reflect—

(i) a balance between urban and rural settings;

(ii) cultural diversity; and

(iii) various modes of medical care and insurance, such as fee-for-service, preferred provider organizations, health maintenance organizations, hospice care, home care services, long-term care, and integrated delivery systems.

(B) PREFERENCES.—The Secretary shall give preference to applications for demonstration projects that—

(i) will serve medicare beneficiaries who are dying of illnesses that are most prevalent under the medicare program, including cancer, heart failure, chronic obstructive respiratory disease, dementia, stroke, and progressive multifactorial frailty associated with advanced age; and

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

(4) EVALUATIONS.—Each demonstration project conducted under this subsection shall be evaluated at such regular intervals as the Secretary determines are appropriate. An evaluation of a

project conducted under this subsection shall include the items described in subsection (b)(2) and the following:

(A) A comparison of the quality of care and of the outcomes for medicare beneficiaries and the families of such beneficiaries served by the demonstration project to the quality of care and outcomes for such individuals that would have resulted if care had been provided under existing delivery systems.

(B) An analysis of how ongoing measures of quality and accountability for improvement and excellence could be incorporated into the demonstration project.

(C) A comparison of the costs of the care provided to medicare beneficiaries under the demonstration project to the costs of that care if it had been provided under the medicare program.

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

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

(d) ANNUAL REPORTS TO CONGRESS.—

(1) 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 quality of end-of-life care under the medicare program, together with any suggestions for legislation to improve the quality of such care under that program.

(2) SUMMARY OF RECENT STUDIES.—A report submitted under this subsection 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 fatal illnesses.

(3) CONTINUATION OR REPLICATION OF DEMONSTRATION PROJECTS.—Beginning 3 years after the date of enactment of this Act, the report required under this subsection shall include recommendations regarding whether the demonstration projects conducted under subsection (c) should be

continued and whether broad replication of any of those projects should be initiated.

(e) FUNDING.—The Secretary shall provide for the transfer from the Federal Hospital Insurance Trust Fund established under section 1817 of the Social Security Act (42 U.S.C. 1395i) of such sums as are necessary for the costs of conducting evaluations under subsection (b), conducting demonstration projects under subsection (c), and preparing and submitting the annual reports required under subsection (d). Amounts may be transferred under the preceding sentence without regard to amounts appropriated in advance in appropriations Acts.

SEC. 8. MEDICARE COVERAGE OF SELF-ADMINISTERED MEDICATION FOR CERTAIN PATIENTS WITH CHRONIC PAIN.

(a) IN GENERAL.—Section 1861(s)(2) of the Social Security Act (42 U.S.C. 1395x(s)(2)) is amended—

(1) in subparagraph (S), by striking ''and'' at the end;

(2) in subparagraph (T), by striking the period at the end and inserting ''; and''; and

(3) by inserting after subparagraph (T) the following:

''(U) self-administered drugs which may be dispensed only upon prescription and which are pre-

scribed for the relief of chronic pain in patients with a life-threatening disease or condition;''.

(b) EFFECTIVE DATE.—The amendments made by subsection (a) shall apply to items and services furnished on or after January 1, 2000.

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