103D CONGRESS
2D SESSION

S. 2556

To provide for the portability of validly executed advance directives, to provide patients with a better understanding of their health care choices and to promote study of the quality of care for the gravely or terminally ill or injured, and for other purposes.

IN THE SENATE OF THE UNITED STATES

OCTOBER 8 (legislative day, SEPTEMBER 12), 1994

Mr. DANFORTH introduced the following bill; which was read twice and referred to the Committee on Finance

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A BILL

To provide for the portability of validly executed advance directives, to provide patients with a better understanding of their health care choices and to promote study of the quality of care for the gravely or terminally ill or injured, 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. PORTABILITY OF ADVANCE DIRECTIVES.

(a) IN GENERAL.—An advance directive validly executed outside the State in which such directive is presented must be given effect to the same extent as an ad-

vance directive validly executed under the law of the State in which presented.

(b) NO INFERENCE.—Nothing in this section may be construed to authorize the administration, withholding, or withdrawal of health care otherwise prohibited by the laws of the State.

(c) PREEMPTION.—The provisions of this section shall preempt any State law to the extent such law is inconsistent with such provisions. The provisions of this section 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.

(d) EFFECTIVE DATE.—This section shall take effect on the date that is 6 months after the date of enactment of this Act.

SEC. 2. AMENDMENTS TO RULES UNDER MEDICARE AND MEDICAID.

(a) MEDICARE.—Section 1866(f)(1) of the Social Security Act (42 U.S.C. 1395cc(f)(1)) is amended—

(1) in subparagraph (A), by striking ''and'' at the end of clause (i), by redesignating clause (ii) as clause (iii), and by inserting after clause (i) the following new clause:

''(ii) the result under such State law if the individual is incapacitated in the absence of an advance directive, and'';

(2) in subparagraph (B), by inserting ''and to include the content of such directive if the individual so desires'' before the semicolon;

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

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

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

''(F) to provide for effective communication between the individual (or surrogate decision maker when appropriate) and the appropriate provider regarding all relevant aspects of health care decisions affecting the individual, including obtaining informed consent, individual prognosis and treatment decisions, and the formulation of advance directives.''.

(b) MEDICAID.—Section 1902(a) (42 U.S.C. 1396a(a)) is amended by inserting in paragraph 58, ''and what occurs in the absence of an advance directive'' after ''subsection (w) of this section.'' Section 1902(w)(1) of the

Social Security Act (42 U.S.C. 1396a(w)(1)) is amended—

(1) in subparagraph (A), by striking ''and'' at the end of clause (i), by redesignating clause (ii) as clause (iii), and by inserting after clause (i) the following new clause:

''(ii) the result under such State law if the individual is incapacitated in the absence of an advance directive, and'';

(2) in subparagraph (B), by inserting ''and to include the content of such directive if the individual so desires'' before the semicolon;

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

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

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

''(F) to provide for effective communication between the individual (or surrogate decision maker when appropriate) and the appropriate provider regarding all relevant aspects of health care decisions affecting the individual, including obtaining informed consent, individual prognosis and treatment

decisions, and the formulation of advance directives.''.

(c) APPLICATION TO KIDNEY DIALYSIS CENTERS OF PROVISIONS RELATING TO ADVANCE DIRECTIVES.—

(1) MEDICARE.—Section 1866(a)(1)(Q) of the Social Security Act (42 U.S.C. 1395cc(a)(1)(Q)) is amended by striking ''and hospice programs'' and inserting ''hospice programs, and kidney dialysis centers''.

(2) MEDICAID.—Section 1902(a)(57) of such Act (42 U.S.C. 1396(a)(57)) is amended by striking ''hospice program'' and inserting ''hospice program, kidney dialysis center''.

(d) EFFECTIVE DATE.—The amendments made by this section shall take effect on and after the date which is 1 year after the date of the enactment of this Act.

SEC. 3. STUDY OF ISSUES RELATED TO END OF LIFE CARE.

(a) STUDY.—

(1) IN GENERAL.—Within 6 months after the date of the enactment of this Act, the Secretary shall enter into an agreement with the Institute of Medicine of the National Academy of Sciences (or with another nonprofit, nongovernmental organization or consortium of institutions if the Institute declines to perform the study) to investigate and re-

port on issues relating to care at the end of life, including how to determine the application of medically necessary or appropriate care for gravely or terminally ill or injured persons of all ages.

(2) SPECIFIC ISSUES.—The study described in paragraph (1) shall specifically include an examination of the following issues:

(A) The epidemiology of dying.

(B) Conditions that promote or impede appropriate care (such as professional training and beliefs, financing and organization of services, patient and public knowledge and attitudes).

(C) Concerns of health care practitioners and providers, medical educators, the religious and medical ethics communities, the general public, and others responsible for public and private decisions about the organization, financing, and quality of health care in the United States.

(D) Measures to evaluate systems of care on the quality of care they provide for gravely or terminally ill or injured patients.

(E) Methods of communication and health care decisionmaking among providers, patients, and surrogates.

(F) Priorities for research on the issues described in the preceding subparagraphs.

(b) REPORT.—The Institute of Medicine (or the organization conducting the study under this section) shall submit to the Secretary and the Congress a report on the study described in subsection (a) within 27 months after the date of the enactment of this Act.

(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated such sums as are necessary to carry out the purposes of this section.

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