114TH CONGRESS
2D SESSION

S. 2961

To improve end-of-life care.

IN THE SENATE OF THE UNITED STATES

MAY 19, 2016

Mr. BLUMENTHAL (for himself and Mrs. CAPITO) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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A BILL

To improve end-of-life care.

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

SECTION 1. SHORT TITLE.

(a) SHORT TITLE.—This Act may be cited as the ''Compassionate Care Act''.

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

SEC. 2. DEFINITIONS.

In this Act:

(1) ADVANCE CARE PLANNING.—The term ''advance care planning'' means the process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders.

(2) ADVANCE DIRECTIVE.—The term ''advance directive'' means a written or otherwise recorded instruction, such as a living will or durable power of attorney for health care, recognized under the law of the State in which it was executed (whether statutory or as recognized by the courts of the State) and relating to the provision of such care when the individual is incapacitated.

(3) CHIP.—The term ''CHIP'' means the State Children's Health Insurance Program under

title XXI of the Social Security Act (42 U.S.C. 1397aa et seq.)

(4) END-OF-LIFE-CARE.—The term ''end-of-life care'' means all aspects of care of a patient with a potentially fatal condition, and includes care that is focused on preparations for an impending death.

(5) HEALTH CARE AGENT.—The term ''health care agent'' means the person, designated in a health care power of attorney, who is selected to make medical decisions on behalf of the person who executed such power of attorney, in the case of incapacity of such person who executed the power of attorney.

(6) HEALTH CARE POWER OF ATTORNEY.—The term ''health care power of attorney'' means a legal document that identifies the health care agent of the person executing such document.

(7) LIVING WILL.—The term ''living will'' means a written document or a video statement about the kinds of medical care or other care a person does or does not want under certain specific conditions, in the event that such person no longer is able to express those wishes.

(8) MEDICAID.—The term ''Medicaid'' means the program established under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.).

(9) MEDICARE.—The term ''Medicare'' means the program established under title XVIII of the Social Security Act (42 U.S.C. 1395 et seq.).

(10) ORDERS FOR LIFE-SUSTAINING TREATMENT.—The term ''orders for life-sustaining treatment'' means a set of portable medical orders (such as physician orders for life-sustaining treatment or similar portable medical orders) that address key medical decisions consistent with the patient's goals of care and results from a clinical process designed to facilitate shared, informed medical decision-making and communication between qualified health care professionals and patients with serious, progressive illness or frailty.

(11) QUALIFIED HEALTH CARE PROVIDER.—The term ''qualified health care provider'' means a medical doctor, doctor of osteopathy, nurse, physician assistant, nurse practitioner, social worker, home health aide, palliative care professional, or individual in a similar position, as designated by the Secretary.

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

TITLE I—ADVANCE CARE PLANNING

Subtitle A—Consumer Education

SEC. 101. ADVANCE CARE PLANNING GUIDELINES.

It is the sense of the Senate that, to the extent practicable, advance care planning should—

(1) occur with an individual and such individual's health care agent, primary clinician, other authorized decisionmaker, or members of the entire interdisciplinary health care team;

(2) be recorded and updated as needed; and

(3) allow for flexible decisionmaking in the context of the patient's medical situation, in accordance with guidelines provided by the Secretary.

SEC. 102. NATIONAL PUBLIC EDUCATION CAMPAIGN.

(a) NATIONAL PUBLIC EDUCATION CAMPAIGN.—

(1) IN GENERAL.—Not later than January 1, 2017, the Secretary, acting through the Director of the Centers for Disease Control and Prevention and in consultation with public and private entities, as the Secretary determines appropriate, shall, directly or through grants, contracts, or interagency agreements, develop and implement a national campaign

to inform the public of the importance of advance care planning and of an individual's right to direct and participate in health care decisions affecting such individual.

(2) CONTENT OF EDUCATIONAL CAMPAIGN.—The national public education campaign established under paragraph (1) may—

(A) employ the use of various media, including regularly televised public service announcements;

(B) provide culturally and linguistically appropriate information;

(C) be conducted continuously over a period of not less than 5 years;

(D) identify and promote the advance care planning information available on the Internet Websites of the Department of Health and Human Service's National Clearinghouse for Long-Term Care Information, the Administration for Children and Families, the Administration for Community Living, and the Centers for Medicare & Medicaid Services;

(E) address the importance of individuals speaking to family members, health care proxies, and qualified health care providers as part

of an ongoing dialogue regarding health care choices;

(F) address the need for individuals to communicate their health care goals and wishes through a variety of means, including the use of readily available legal and medical documents that express their health care decisions in the form of advance directives (including living wills, orders for life-sustaining treatment, and durable powers of attorney for health care);

(G) raise public awareness regarding the availability of hospice and palliative care and the quality of life benefits of early use of such services; and

(H) encourage individuals to speak with qualified health care professionals about their options and intentions for end-of-life care.

(3) EVALUATION.—Not later than July 1 2019, the Secretary shall report to the appropriate committees of Congress on the effectiveness of the public education campaign under this section, and include in such report any recommendations that the Secretary determines appropriate regarding the need for continuation of legislative or administrative changes

to facilitate changing public awareness, attitudes, and behaviors regarding advance care planning.

(b) REPEAL.—Section 4751(d) of the Omnibus Budget Reconciliation Act of 1990 (42 U.S.C. 1396a note; Public Law 101–508) is repealed.

Subtitle B—Provider Education

SEC. 111. PUBLIC PROVIDER ADVANCE CARE PLANNING WEBSITE.

(a) DEVELOPMENT.—Not later than January 1, 2018, the Secretary, acting through the Administrator of the Centers for Medicare & Medicaid Services and the Director of the Agency for Healthcare Research and Quality, shall establish an, or expand upon an existing, Internet Website for providers under Medicare, Medicaid, CHIP, the Indian Health Service (including contract providers), and other qualified health care providers on each individual's right to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and engage in advance care planning.

(b) MAINTENANCE.—The Internet Website described in subsection (a) shall be maintained and publicized by the Secretary on an ongoing basis.

(c) CONTENT.—The Internet Website may include content, tools, and resources necessary to do the following:

(1) Inform qualified health care providers about the advance directive requirements under the health care programs described in subsection (a) and other State and Federal laws and regulations related to advance care planning.

(2) Educate providers about advance care planning quality improvement activities.

(3) Provide assistance to qualified health care providers to—

(A) integrate advance care planning documents into electronic health records, including oral directives; and

(B) develop and disseminate advance care planning informational materials for patients.

(4) Inform qualified health care providers about advance care planning continuing education requirements and opportunities.

(5) Encourage qualified health care providers to discuss advance care planning with patients of all ages.

(6) Assist qualified health care providers' understanding of the continuum of end-of-life care services and supports available to patients, including palliative care and hospice.

(7) Inform qualified health care providers of best practices for discussing end-of-life care with dying patients and their loved ones.

SEC. 112. ADVANCE CARE CURRICULA PILOT PROGRAM.

(a) IN GENERAL.—The Secretary, in consultation with appropriate professional associations, shall establish a pilot program by which the Secretary awards grants to eligible entities that require a minimum amount of end-of-life training as a requirement for obtaining a degree from such entity.

(b) ELIGIBILITY.—To be eligible to participate in the pilot program under this section, an entity shall—

(1) be a school of medicine, school of osteopathic medicine, a physician assistant education program (as defined in section 799B(3) of the Public Health Service Act (42 U.S.C. 295p(3))), a school of allied health (as defined in section 799B(4) of the Public Health Service Act(42 U.S.C. 295p(4))), a school of nursing, a school of social work, a graduate medical education program accredited by the Accreditation Council for Graduate Medical Education or the American Osteopathic Association, or other school, as the Secretary determines appropriate;

(2) be staffed by teaching health professionals who have experience or training in palliative medicine;

(3) provide training in palliative medicine through a variety of service rotations, such as consultation services, acute care services, extended care facilities, ambulatory care and comprehensive evaluation units, hospice, home health, and community care programs;

(4) develop specific performance-based measures to evaluate the competency of trainees; and

(5) ensure that by not later than the end of the 2-year period beginning on the date of enactment of this Act, professionals who are applicable faculty at the entity, or others as determined appropriate by the Secretary, shall be offered retraining in hospice and palliative medicine.

(c) TRAINING.—Eligible entities participating in the pilot program under this section shall require minimum training for trainees that includes—

(1) training in how to discuss and help patients and their loved ones with advance care planning;

(2) with respect to trainees who will work with children, specialized pediatric training;

(3) training in the continuum of end-of-life services and supports, including palliative care and hospice;

(4) training in how to discuss end-of-life care with dying patients and their loved ones;

(5) medical and legal issues training associated with end of life care;

(6) training in cultural competency; and

(7) in the case of a graduate medical education program accredited by the Accreditation Council for Graduate Medical Education or the American Osteopathic Association, a longitudinal component of at least 6 months.

(d) REPORTS.—Each recipient of a grant under this section shall report to the Secretary on the outcomes of the program within 18 months of receipt of the final allotment of grant funds. Not later than 1 year after receipt of all such reports, the Secretary shall submit to Congress a report compiling such results from all grant recipients.

SEC. 113. DEVELOPMENT OF CORE END-OF-LIFE CARE QUALITY MEASURES ACROSS EACH RELEVANT PROVIDER SETTING.

(a) IN GENERAL.—The Secretary, acting through the Administrator of the Agency for Healthcare Research and Quality (in this section referred to as the ''Adminis-

trator'') and in consultation with the Administrator of the Centers for Medicare & Medicaid Services, shall require the development of specific end-of-life quality measures for each relevant qualified health care provider setting, as identified by the Administrator, in accordance with the requirements of subsection (b).

(b) REQUIREMENTS.—For purposes of subsection (a), the requirements specified in this subsection are the following:

(1) Selection of the specific measure or measures for an identified provider setting shall be based on an assessment of what is likely to have the greatest positive impact on quality of end-of-life care in that setting, and made in consultation with affected providers, patients, and private organizations, that have developed such measures.

(2) The measures may be structure-oriented, process-oriented, or outcome-oriented, as determined appropriate by the Administrator, and shall be patient-oriented.

(3) The Administrator shall ensure that reporting requirements related to such measures are imposed consistently with other applicable laws and regulations, and in a manner that takes into account existing measures, the needs of patient populations,

the specific services provided, and the potential administrative burden to providers.

(4) Not later than—

(A) April 1, 2017, the Secretary shall disseminate the reporting requirements to all affected providers and provide for a 60-day period for public comment; and

(B) April 1, 2018, initial reporting by health care providers relating to the measures shall begin.

SEC. 114. CONTINUING EDUCATION FOR QUALIFIED HEALTH CARE PROVIDERS.

(a) IN GENERAL.—Not later than January 1, 2018, the Secretary, acting through the Director of Health Resources and Services Administration, shall approve existing and develop, in consultation with qualified health care providers, other professionals as the Secretary determines appropriate, and State boards of medicine and nursing, new curricula on advance care planning and end-of-life care for continuing education that States may adopt for qualified health care providers.

(b) CONTENT.—The continuing education curriculum developed under subsection (a) shall, at a minimum, include—

(1) a description of the meaning and importance of advance care planning;

(2) a description of advance care planning documents, including living wills and durable powers of attorney, and the use of such directives;

(3) the appropriate use of orders for scope of treatment;

(4) counseling skills for when and how to introduce and engage in advance care planning with patients and their loved ones;

(5) palliative care principles and approaches to care;

(6) the continuum of end-of-life services and supports, including palliative care and hospice; and

(7) the importance of introducing palliative care and hospice early in illness in order to improve quality of life.

TITLE II—REPORTS, RESEARCH, AND EVALUATIONS

SEC. 201. DEMONSTRATION PROJECTS FOR USE OF TELEMEDICINE SERVICES IN ADVANCE CARE PLANNING.

(a) IN GENERAL.—Not later than July 1, 2019, the Secretary shall establish a demonstration program to reimburse eligible entities for costs associated with the use

of telemedicine services (including equipment and connection costs) to provide advance care planning through telemedicine consultations with geographically distant providers and their patients.

(b) DURATION.—The demonstration project under this section shall be conducted for at least a 3-year period.

(c) REPORT.—Not later than March 15, 2017, the Secretary shall, using quantitative and qualitative research methods, submit a report to Congress on the status of telemedicine programs, including information that identifies—

(1) the telehealth services for which payment can be made, as of the date of the enactment of this Act, under the fee-for-service program under parts A and B of title XVIII of the Social Security Act;

(2) the telehealth services for which payment can be made, as of such date, under private health insurance plans;

(3) with respect to services identified under paragraph (2) but not under paragraph (1), ways in which payment for such services might be incorporated into such fee-for-service program (including any recommendations for ways to accomplish this incorporation); and

(4) any legal or regulatory challenges to expanding telehealth services, and any promising solutions to such challenges.

(d) DEFINITIONS.—For purposes of this section:

(1) The term ''eligible entity'' means an academic medical center, a medical school, a State health department, a State medical association, a multi-State taskforce, a hospital, a home health agency, or a health system or coalition of stakeholders capable of administering a program for orders regarding life-sustaining treatment for a State or locality.

(2) The term ''geographically distant'' has the meaning given that term by the Secretary for purposes of conducting the demonstration program established under this section.

(3) The term ''telemedicine services'' means a service or consultation provided via telecommunication equipment that allows an eligible entity to exchange or discuss medical information with a patient (including the family caregiver of the patient if the patient agrees) or a qualified health care provider at a separate location through real-time videoconferencing, or a similar format, for the purpose of providing health care diagnosis and treatment.

(e) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to the Secretary such sums as may be necessary to carry out this section. Any funds made available under this section shall be used to supplement, not supplant, other Federal, State, and local funding provided for telemedicine services.

SEC. 202. STUDY AND REPORT BY THE SECRETARY REGARDING THE ESTABLISHMENT AND IMPLEMENTATION OF A NATIONAL UNIFORM POLICY ON ADVANCE DIRECTIVES.

(a) STUDY.—

(1) IN GENERAL.—The Secretary, acting through the Office of the Assistant Secretary for Planning and Evaluation, shall conduct a study to evaluate the barriers to establishing and implementing a national uniform policy on advance directives and what needs to be done to overcome those barriers.

(2) MATTERS STUDIED.—The matters studied by the Secretary under paragraph (1) may 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 one health care setting to another;

(C) the feasibility of establishing an optional, national advance directive form deemed valid by any health care entity or qualified health care provider participating in Medicare, Medicaid, or CHIP, regardless of State law; and

(D) State variations in advance directive laws that are relevant to the establishment and implementation of a national uniform policy of advance directives.

(b) REPORT TO CONGRESS.—Not later than 2 years after the date of enactment of this Act, the Secretary 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 shall consult with the Uniform Law Commissioners, and other interested parties.

SEC. 203. GAO STUDY AND REPORT ON ESTABLISHMENT OF NATIONAL ADVANCE DIRECTIVE REGISTRY; OTHER STUDIES.

(a) STUDY AND REPORT ON ESTABLISHMENT OF NATIONAL ADVANCE DIRECTIVE REGISTRY.—

(1) STUDY.—The Comptroller General of the United States shall conduct a study on the feasibility of a national registry for advance directives, taking into consideration the constraints created by the privacy provisions enacted as a result of the Health Insurance Portability and Accountability Act of 1996 (Public Law 104–191).

(2) REPORT.—Not later than 18 months after the date of enactment of this Act, the Comptroller General of the United States shall submit to Congress a report on the study conducted under subsection (a) together with recommendations for such legislation and administrative action as the Comptroller General of the United States determines to be appropriate.

(b) ONC STUDY.—The National Coordinator of the Office of the National Coordinator for Health Information Technology shall conduct a study on the feasibility and impact on advance care planning of requiring that electronic health record vendors seeking certification have a prominent and easily visible field for storing and sharing

advance care planning documents and related clinical notes.

(c) ADDITIONAL STUDY.—The Comptroller General of the United States shall conduct a study and submit a report to Congress on the incidence of health care, tests, surgeries, drugs, and other services paid provided by qualified health care providers and paid for by the Federal Government or the patient and that were unwanted by the patient or family of the patient.

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