

113TH CONGRESS
1ST SESSION

S. 1439

To amend title XVIII of the Social Security Act to provide for advanced illness care coordination services for Medicare beneficiaries, and for other purposes.

IN THE SENATE OF THE UNITED STATES

AUGUST 1, 2013

Mr. WARNER (for himself and Mr. ISAKSON) introduced the following bill;
which was read twice and referred to the Committee on Finance

A BILL

To amend title XVIII of the Social Security Act to provide for advanced illness care coordination services for Medicare beneficiaries, 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 “Care Planning Act of 2013”.

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

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings.
- Sec. 3. Improvement of advanced illness planning and coordination.
- Sec. 4. Quality measurement development.

- Sec. 5. Inclusion of advance care planning materials in the Medicare & You handbook.
- Sec. 6. Care Planning Advisory Board.
- Sec. 7. Improvement of policies related to the use and portability of advance directives.
- Sec. 8. Additional requirements for facilities.
- Sec. 9. Grants for increasing public awareness of advance care planning and advanced illness care.
- Sec. 10. HHS study and report on the storage of advance directives.
- Sec. 11. GAO study and report on the provisions of, and amendments made by, this Act.
- Sec. 12. Consultation with the Care Planning Advisory Board.
- Sec. 13. Rule of construction.

1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

3 (1) The population of the United States is esti-
4 mated to age rapidly, with the number of people over
5 the age of 65 set to double to more than
6 72,000,000, or 1 in 5 Americans, over the next two
7 decades.

8 (2) Americans today are living longer and
9 healthier lives than ever before in the history of the
10 United States yet are also facing increased incidence
11 of multiple serious conditions as aging progresses.

12 (3) Americans with advanced illness face a com-
13 plicated and fragmented system of care delivery that
14 puts them at risk for repeat hospitalizations, adverse
15 drug reactions, and conflicting medical advice that
16 may be overwhelming to individuals and families.

17 (4) The progression of advanced illness leads to
18 the need for increasingly intensive decision support,

1 health care services, and support from family care-
2 givers.

3 (5) The complexity of care needed by individ-
4 uals with advanced illness may result in uncoordi-
5 nated care, adverse health outcomes, frustration,
6 wasted time, and undue emotional burdens on indi-
7 viduals and their family caregivers.

8 (6) Numerous private sector leaders, including
9 hospitals, health systems, home health agencies, hos-
10 pice programs, long-term care providers, employers,
11 and other entities, have put in place innovative solu-
12 tions to provide more comprehensive and coordinated
13 care for Americans living with advanced illness.

14 (7) Hospice programs, as one of the longest
15 standing Medicare care coordination benefits that
16 offer a comprehensive set of services via an inter-
17 disciplinary team working to provide person- and
18 family-centered care to the frailest and most vulner-
19 able individuals in our communities, can serve as a
20 model for advanced illness care delivery.

21 (8) Palliative care programs that serve patients
22 beginning at diagnosis with advanced illness and
23 provide care designed to reduce the symptom burden
24 of illness can serve as a model for interdisciplinary

1 team care planning based on the individual's goals
2 of care.

3 (9) The Government of the United States, as
4 the Nation's largest purchaser of health care serv-
5 ices, must learn from these innovators and encour-
6 age health care providers to furnish more supportive
7 and comprehensive advanced illness care to improve
8 the efficacy and quality of health care delivered for
9 generations of Americans to come.

10 (10) Health care providers who serve individ-
11 uals with advanced illness face complicated care sys-
12 tems and legal concerns that may result in over- or
13 under-treatment of individuals with advanced illness.

14 (11) Individuals have the well-established right
15 to accept or reject medical treatment that is offered,
16 as well as the well-established right to document
17 their preferences for how treatment decisions should
18 be made if, at some point in the future, they lose the
19 ability to make health care decisions.

20 (12) Too often, individuals with advanced ill-
21 ness do not understand the conditions they are fac-
22 ing or their treatment options, and they do not re-
23 ceive the information or support they need to evalu-
24 ate treatment options in light of their personal goals
25 and values and to document treatment plans in a

1 manner that allows providers and facilities to follow
2 their plans.

3 (13) Providing quality services and planning
4 support to individuals with advanced illness will pro-
5 tect and preserve their dignity.

6 **SEC. 3. IMPROVEMENT OF ADVANCED ILLNESS PLANNING**
7 **AND COORDINATION.**

8 (a) **MEDICARE COVERAGE OF PLANNING SERV-**
9 **ICES.—**

10 (1) **COVERAGE.**—Section 1861(s)(2) of the So-
11 cial Security Act (42 U.S.C. 1395x(s)(2)) is amend-
12 ed—

13 (A) in subparagraph (EE), by striking
14 “and” at the end;

15 (B) in subparagraph (FF), by inserting
16 “and” at the end; and

17 (C) by inserting after subparagraph (FF)
18 the following new paragraph:

19 “(GG) planning services (as defined in
20 subsection (iii));”.

21 (2) **SERVICES DESCRIBED.**—Section 1861 of
22 the Social Security Act (42 U.S.C. 1395x) is amend-
23 ed by adding at the end the following new sub-
24 section:

1 “Planning Services

2 “(iii)(1)(A) The term ‘planning services’ means a vol-
3 untary decisionmaking process that includes the elements
4 described in paragraph (2) and is furnished to a planning
5 services eligible individual by an applicable provider
6 through an interdisciplinary team.

7 “(B) Planning services may only be furnished to a
8 planning services eligible individual under this title once
9 in each 12-month period.

10 “(2)(A) The elements described in this paragraph are
11 the following:

12 “(i) One or more face-to-face encounters be-
13 tween one or more members of the interdisciplinary
14 team and the individual and, at the individual’s dis-
15 cretion, family caregivers, or, for an individual who
16 lacks decisionmaking capacity under State law, the
17 individual’s legally authorized representative.

18 “(ii) The provision of information about the
19 typical trajectory of illnesses or conditions that af-
20 fect the individual, including foreseeable care deci-
21 sions that may need to be made at a future time
22 when the individual is likely to be unable to make
23 decisions due to temporary or permanent cognitive
24 incapacity.

1 “(iii) Assisting the individual in defining and
2 articulating goals of care, values, and preferences.

3 “(iv) Providing the individual with (and dis-
4 cussing) information about the benefits and burdens
5 of a relevant range of treatment options available to
6 the individual, including disease modifying or poten-
7 tially curative treatment, palliative care, which may
8 be provided alone or in conjunction with disease
9 modifying treatment, and, when the individual may
10 be currently eligible or may become eligible for hos-
11 pice care due to disease progression, hospice care.
12 An applicable provider shall present and discuss rel-
13 evant treatment options that may help the individual
14 to achieve goals of care and may not exclude options
15 based on an individual’s age, disability status, or the
16 presence of advanced illness unless, in the provider’s
17 clinical judgment, a treatment option will not
18 achieve the outcome sought by the individual.

19 “(v) Assisting the individual in evaluating treat-
20 ment options and approaches to care to identify
21 those that most closely align with the individual’s
22 goals of care, values, and preferences.

23 “(vi) Preparing, and sharing with relevant pro-
24 viders, documentation—

1 “(I) that states the individual’s goals of
2 care, preferences, and values, preferred deci-
3 sionmaking strategies, and a plan of care that
4 is concrete, achievable, and actionable; and

5 “(II) that is in a paper or electronic for-
6 mat, on State or locally recognized forms that
7 are used for the purpose of assuring that pro-
8 viders can follow the plan across care settings,
9 such as advance directives or portable treat-
10 ment orders.

11 “(vii) Referrals to providers, including medical
12 and social service providers, who deliver care con-
13 sistent with the plan.

14 “(viii) Providing culturally and educationally
15 appropriate training for the individual and family
16 caregivers to support their ability to carry out the
17 plan.

18 “(B) Even when the individual’s decisional capacity
19 is impaired and another person or entity, such as an ap-
20 pointed agent, proxy, or surrogate, is exercising legal au-
21 thority under State law governing decisionmaking on be-
22 half of incapacitated individuals, the interdisciplinary
23 team shall make a reasonable attempt to include the indi-
24 vidual in the planning process.

1 “(3) For purposes of this subsection, the term ‘plan-
2 ning services eligible individual’ means an individual that
3 meets at least one of the following criteria:

4 “(A) The individual is diagnosed with meta-
5 static or locally advanced cancer.

6 “(B) The individual is diagnosed with Alz-
7 heimer’s disease or another progressive dementia.

8 “(C) The individual is diagnosed with late-stage
9 neuromuscular disease.

10 “(D) The individual is diagnosed with late-stage
11 diabetes.

12 “(E) The individual is diagnosed with late-stage
13 kidney, liver, heart, gastrointestinal, cerebrovascular,
14 or lung disease.

15 “(F) The individual needs assistance with two
16 or more activities of daily living (defined as bathing,
17 dressing, eating, getting out of bed or a chair, mobil-
18 ity, and toileting) that are caused by one or more
19 progressive illnesses.

20 “(G) The individual meets other criteria deter-
21 mined appropriate by the Secretary, including cri-
22 teria that are designed to identify individuals with a
23 need for planning services due to advancing illness
24 or risk of decline in cognitive function over time.

1 “(4) For purposes of this subsection, the term ‘appli-
2 cable provider’ means a hospice program (as defined in
3 section 1861(dd)(2)) or other provider of services (as de-
4 fined in section 1861(u)) or supplier (as defined in section
5 1861(d)) that—

6 “(A) furnishes planning services through an
7 interdisciplinary team; and

8 “(B) meets such other requirements the Sec-
9 retary may determine to be appropriate.

10 “(5)(A) For purposes of this subsection, the term
11 ‘interdisciplinary team’ means a group that—

12 “(i) includes—

13 “(I) a core team of a physician or an ad-
14 vance practice registered nurse, a social worker,
15 a nurse; and, subject to subparagraph (B), a
16 chaplain, a minister, or the individual’s per-
17 sonal religious or spiritual advisor; and

18 “(II) when necessary to meet an individ-
19 ual’s planning needs, other professionals, which
20 may include a pharmacist, a licensed clinical so-
21 cial worker, and a psychologist, either as ongo-
22 ing team members or who may be brought in as
23 needed to address the individual’s planning
24 needs; and

1 “(ii) meets requirements that may be estab-
2 lished by the Secretary.

3 “(B) An applicable provider furnishing planning serv-
4 ices to a planning services eligible individual shall offer
5 to the individual (or the individual’s legally authorized rep-
6 resentative when the individual has been found to lack
7 decisional capacity) the opportunity to select either a
8 chaplain affiliated with the provider, a minister, or per-
9 sonal religious or spiritual advisor who can help to rep-
10 resent the individual’s goals, values, and preferences to
11 serve as a core team member at the individual’s (or legally
12 authorized representative’s) request.

13 “(C) The requirements established by the Secretary
14 under subparagraph (A)(ii) shall include a requirement
15 that interdisciplinary team members (except for the
16 individuals’s chosen minister or personal religious or spir-
17 itual advisor) have training and experience in delivering
18 person-directed planning services and in team-based deliv-
19 ery of services for individuals with dementing illness and
20 individuals with advanced illness.”.

21 (3) PAYMENT UNDER PHYSICIAN FEE SCHED-
22 ULE.—Section 1848(j)(3) of the Social Security Act
23 (42 U.S.C. 1395w-4(j)(3)) is amended by inserting
24 “(2)(GG),” after “(2)(FF) (including administration
25 of the health risk assessment),”.

1 (4) FREQUENCY LIMITATION.—Section 1862(a)
2 of the Social Security Act (42 U.S.C. 1395y(a)) is
3 amended—

4 (A) in paragraph (1)—

5 (i) in subparagraph (O), by striking
6 “and” at the end;

7 (ii) in subparagraph (P) by striking
8 the semicolon at the end and inserting “,
9 and”; and

10 (iii) by adding at the end the fol-
11 lowing new subparagraph:

12 “(Q) in the case of planning services (as
13 defined in section 1861(iii)(1)), which are fur-
14 nished more frequently than is covered under
15 subparagraph (B) of such section;”; and

16 (B) in paragraph (7), by striking “or (P)”
17 and inserting “(P), or (Q)”.

18 (5) EFFECTIVE DATE.—The amendments made
19 by this subsection shall apply to services furnished
20 on or after January 1, 2015.

21 (b) MEDICAID COVERAGE OF PLANNING SERV-
22 ICES.—

23 (1) IN GENERAL.—Section 1905(a) of the So-
24 cial Security Act (42 U.S.C. 1396d(a)) is amend-
25 ed—

1 (A) by redesignating paragraph (29) as
2 paragraph (30);

3 (B) in paragraph (28), by striking at the
4 end “and”; and

5 (C) by inserting after paragraph (28) the
6 following new paragraph:

7 “(29) planning services (as defined in section
8 1861(iii)); and”.

9 (2) CONFORMING AMENDMENT.—Section
10 1902(a)(10)(A) of the Social Security Act (42
11 U.S.C. 1396a(a)(10)(A)) is amended by striking
12 “and (28)” and inserting “, (28), and (29)”.

13 (3) EFFECTIVE DATE.—

14 (A) IN GENERAL.—Except as provided in
15 subparagraph (B), the amendments made by
16 paragraphs (1) and (2) take effect on January
17 1, 2015.

18 (B) EXTENSION OF EFFECTIVE DATE FOR
19 STATE LAW AMENDMENT.—In the case of a
20 State plan under title XIX of the Social Secu-
21 rity Act (42 U.S.C. 1396 et seq.) which the
22 Secretary determines requires State legislation
23 in order for the plan to meet the additional re-
24 quirements imposed by the amendments made
25 by paragraphs (1) and (2), the State plan shall

1 not be regarded as failing to comply with the
 2 requirements of such title solely on the basis of
 3 its failure to meet these additional requirements
 4 before the first day of the first calendar quarter
 5 beginning after the close of the first regular
 6 session of the State legislature that begins after
 7 the date of the enactment of this Act. For pur-
 8 poses of the previous sentence, in the case of a
 9 State that has a 2-year legislative session, each
 10 year of the session is considered to be a sepa-
 11 rate regular session of the State legislature.

12 (c) ADVANCED ILLNESS CARE COORDINATION SERV-
 13 ICES PROJECT.—Section 1115A(b)(2) of title XI of the
 14 Social Security Act (42 U.S.C. 1315a(b)(2)) is amended—

15 (1) in subparagraph (A), by adding at the end
 16 the following new sentence: “The models selected
 17 under this subparagraph shall include the model de-
 18 scribed in subparagraph (D) and such model shall be
 19 implemented by not later than December 31,
 20 2015.”; and

21 (2) by adding at the end the following new sub-
 22 paragraph:

23 “(D) ADVANCED ILLNESS CARE COORDINA-
 24 TION SERVICES MODEL.—

25 “(i) MODEL.—

1 “(I) IN GENERAL.—The model
2 described in this subparagraph is a
3 model under which payments are
4 made to applicable providers that fur-
5 nish advanced illness care coordina-
6 tion services to eligible individuals.

7 “(II) REQUIREMENT.—At least
8 one applicable provider selected for
9 participation under the model shall be
10 a hospice program (as defined in sec-
11 tion 1861(dd)(2)).

12 “(ii) APPLICABLE PROVIDER.—In this
13 subparagraph, the term ‘applicable pro-
14 vider’ means a hospice program (as defined
15 in section 1861(dd)(2)) or other provider
16 of services (as defined in section 1861(u))
17 or supplier (as defined in section 1861(d))
18 that—

19 “(I) furnishes advanced illness
20 care coordination services through an
21 interdisciplinary team (as defined in
22 section 1861(iii)(5)); and

23 “(II) meets such other require-
24 ments the Secretary may determine to
25 be appropriate.

1 “(iii) ADVANCED ILLNESS CARE CO-
2 ORDINATION SERVICES.—In this subpara-
3 graph, the term ‘advanced illness care co-
4 ordination services’ means the following
5 services:

6 “(I) Planning services (as defined
7 in section 1861(iii)).

8 “(II) A multi-dimensional assess-
9 ment of the individual’s strengths and
10 limitations.

11 “(III) An assessment of the indi-
12 vidual’s formal and informal supports,
13 including family caregivers.

14 “(IV) Comprehensive medication
15 review and management (including, if
16 appropriate, counseling and self-man-
17 agement support).

18 “(V) In-home supportive services
19 for the eligible individual and family
20 caregivers consistent with the care
21 plan.

22 “(VI) 24-hour access to emer-
23 gency support in person or via tele-
24 phone or telemedicine with the indi-

1 vidual’s medical record and care plan
2 available to the responder.

3 “(VII) Coordination across
4 health care and social service systems,
5 including involvement of the inter-
6 disciplinary team to evaluate quality
7 and address concerns.

8 “(VIII) Such other services as
9 specified by the Secretary.

10 “(iv) ELIGIBLE INDIVIDUAL.—In this
11 subparagraph, the term ‘eligible individual’
12 means an individual who—

13 “(I) is entitled to, or enrolled for,
14 benefits under part A of title XVIII
15 and enrolled under part B of such
16 title, but not enrolled under part C of
17 such title; and

18 “(II) has the need for assistance
19 with two or more activities of daily
20 living (defined as bathing, dressing,
21 eating, getting out of bed or a chair,
22 mobility, and toileting) that are
23 caused by one or more progressive
24 conditions.”.

1 **SEC. 4. QUALITY MEASUREMENT DEVELOPMENT.**

2 (a) IN GENERAL.—Section 931(c)(2) of the Public
3 Health Service Act (42 U.S.C. 299b–31(c)(2)) is amend-
4 ed—

5 (1) by redesignating subparagraphs (I) and (J)
6 as subparagraphs (L) and (M), respectively; and

7 (2) by inserting after subparagraph (H) the fol-
8 lowing new subparagraphs:

9 “(I) the process of eliciting and docu-
10 menting patient (and, where relevant and ap-
11 propriate, family caregiver) goals, preferences,
12 and values from the patient or from a legally
13 authorized representative, including the articu-
14 lation of goals that accurately reflect how the
15 patient wants to live;

16 “(J) the effectiveness, patient-centeredness
17 (and, where relevant, family caregiver-
18 centeredness), and accuracy of care plans, in-
19 cluding documentation of individual goals, pref-
20 erences, and values;

21 “(K) agreement and consistency among—

22 “(i) the patient’s goals, values, and
23 preferences;

24 “(ii) any documented care plan;

25 “(iii) the treatment delivered; and

26 “(iv) outcomes of treatment;”.

1 (b) AUTHORIZATION OF APPROPRIATIONS.—There
2 are authorized to be appropriated to the Secretary of
3 Health and Human Services to carry out the amendments
4 made by this section, \$5,000,000 for fiscal year 2014.
5 Amounts appropriated under the preceding sentence shall
6 remain available until expended.

7 **SEC. 5. INCLUSION OF ADVANCE CARE PLANNING MATE-**
8 **RIALS IN THE MEDICARE & YOU HANDBOOK.**

9 (a) IN GENERAL.—Section 1804(a) of the Social Se-
10 curity Act (42 U.S.C. 1395b–2(a)) is amended—

11 (1) in paragraph (2), by striking “and” at the
12 end;

13 (2) in paragraph (3), by striking the period at
14 the end and inserting a semicolon; and

15 (3) by inserting after paragraph (3) the fol-
16 lowing new paragraphs:

17 “(4) information on—

18 “(A) care planning;

19 “(B) how individual goals, values, and
20 preferences should be considered in framing a
21 care plan; and

22 “(C) a range of approaches for treating
23 advanced illness, including disease modifying
24 options, palliative care that supports individuals
25 from the onset of advanced illness and can be

1 provided at the same time as all other care
2 types, and hospice care; and

3 “(5) information on documentation options for
4 care planning or advance care planning, including
5 advance directives and portable treatment orders.”.

6 (b) EFFECTIVE DATE.—The amendments made by
7 this section shall apply to notices distributed on or after
8 January 1, 2015.

9 **SEC. 6. CARE PLANNING ADVISORY BOARD.**

10 (a) ESTABLISHMENT.—The Secretary of Health and
11 Human Services shall establish the Care Planning Advi-
12 sory Board (in this section referred to as the “Advisory
13 Board”).

14 (b) MEMBERSHIP.—

15 (1) IN GENERAL.—The Advisory Board shall be
16 composed of 15 members, to be appointed not later
17 than 30 days after the date of the enactment of this
18 Act, as follows:

19 (A) The President of the United States
20 shall appoint 3 members.

21 (B) The majority leader of the Senate shall
22 appoint 3 members.

23 (C) The minority leader of the Senate shall
24 appoint 3 members.

1 (D) The Speaker of the House of Rep-
2 resentatives shall appoint 3 members.

3 (E) The minority leader of the House of
4 Representatives shall appoint 3 members.

5 (2) REPRESENTATION.—The membership of the
6 Advisory Board shall include individuals who (with a
7 preference for individuals who also are members of
8 the group they are appointed to represent)—

9 (A) represent the interests of—

10 (i) patient advocacy groups;

11 (ii) older adults;

12 (iii) individuals with cognitive or func-
13 tional limitations;

14 (iv) family caregivers for individuals
15 described in clause (ii) or (iii);

16 (v) palliative care and hospice pro-
17 viders;

18 (vi) researchers;

19 (vii) ethicists;

20 (viii) faith communities;

21 (ix) health care providers; and

22 (x) health care facilities;

23 (B) have demonstrated experience in deal-
24 ing with issues related to health care decision-
25 making and health care policy; and

1 (C) represent the health care interests and
2 needs of a variety of geographic areas and de-
3 mographic groups.

4 (c) DUTIES.—The Advisory Board shall advise the
5 Secretary on issues related to care planning, advanced ill-
6 ness coordination services, advance care planning, and
7 documentation options, including how to—

8 (1) assure that individuals with advanced illness
9 receive person- and family-centered care;

10 (2) assist individuals with advanced illness to
11 develop a treatment plan that is formed around their
12 goals, values, and preferences, that is informed by
13 research on disease trajectory, and that includes a
14 documented plan that is realistic, actionable, and
15 concrete, and that may include the use of advance
16 directives, portable treatment orders (where appro-
17 priate), or other forms used in the State or locality;

18 (3) develop and monitor a demonstration pro-
19 gram that includes an optimal service array to sup-
20 port individuals with advanced illness with services
21 designed to manage symptoms as illness progresses;

22 (4) provide health care that is consistent with
23 individuals' current treatment preferences or, for
24 those whose capacity to make decisions is impaired,
25 with the individuals' values and goals, and specific

1 directions documented in advance directives and
2 portable treatment orders;

3 (5) encourage provider participation in edu-
4 cational and training activities addressing care plan-
5 ning, advanced illness care, and advance care plan-
6 ning;

7 (6) develop quality measures, including process,
8 outcome, and experience measures, that applicable
9 providers should report for planning services (as de-
10 fined in section 1861(iii) of the Social Security Act,
11 as added by section 3);

12 (7) determine the appropriate role for discharge
13 planners in educating individuals and their families
14 about care planning services, advance care planning,
15 palliative care, hospice, advance directives, portable
16 treatment orders, and other relevant services, sup-
17 ports, planning tools, and documentation options;

18 (8) develop and promote best practices in com-
19 munications about advanced illness between pro-
20 viders, individuals, and family caregivers in different
21 settings, including acute care hospitals;

22 (9) evaluate the feasibility of replacing life ex-
23 pectancy in months with clinical criteria to deter-
24 mine eligibility for hospice care; and

1 (10) promote effective advance care planning
2 and effective and appropriate use of portable treat-
3 ment orders.

4 (d) APPLICATION OF FACA.—The Federal Advisory
5 Committee Act (5 U.S.C. App.) shall apply to the Advisory
6 Board.

7 (e) PAY AND REIMBURSEMENT.—

8 (1) NO COMPENSATION FOR MEMBERS OF ADVI-
9 SORY BOARD.—Except as provided in paragraph (2),
10 a member of the Advisory Board may not receive
11 pay, allowances, or benefits by reason of their serv-
12 ice on the Board.

13 (2) TRAVEL EXPENSES.—Each member shall
14 receive travel expenses, including per diem in lieu of
15 subsistence under subchapter I of chapter 57 of title
16 5, United States Code.

17 (f) REPORT.—Not later than 3 years after the estab-
18 lishment of the Advisory Board, the Advisory Board shall
19 submit to Congress a final report containing the findings
20 and conclusions of the Advisory Board, together with rec-
21 ommendations for such legislation and administrative ac-
22 tions as the Advisory Board considers appropriate.

23 (g) TERMINATION.—The Advisory Board shall termi-
24 nate 30 days after submitting the report under subsection
25 (f).

1 (h) AUTHORIZATION OF APPROPRIATIONS.—There
2 are authorized to be appropriated such sums as may be
3 necessary to carry out this section.

4 **SEC. 7. IMPROVEMENT OF POLICIES RELATED TO THE USE**
5 **AND PORTABILITY OF ADVANCE DIRECTIVES.**

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

8 (1) in paragraph (1)—

9 (A) in subparagraph (A)(i), by striking
10 “State law” and all that follows through “med-
11 ical care” and inserting “relevant State and
12 Federal law (whether statutory or as recognized
13 by the courts) to make decisions concerning
14 medical care”;

15 (B) by striking subparagraph (B);

16 (C) by redesignating subparagraphs (C),
17 (D), and (E) as subparagraphs (G), (H), and
18 (I), respectively;

19 (D) by inserting after subparagraph (A)
20 the following new subparagraphs:

21 “(B) to document in a prominent part of the
22 individual’s current medical record whether or not
23 the individual has an advance directive or portable
24 treatment order, to request a copy of the advance di-
25 rective or portable treatment order, as applicable,

1 and if received, to include the copy (or the content
2 of the document or documents) in a prominent part
3 of such record;

4 “(C) to provide each individual with the oppor-
5 tunity to discuss the information provided pursuant
6 to subparagraph (A) with an appropriately trained
7 employee or volunteer of the provider or organiza-
8 tion;

9 “(D) for an individual with decisional capacity
10 under State law, to follow the individual’s current
11 treatment instructions, as expressed in writing or
12 through verbal or nonverbal communications;

13 “(E) for an individual who lacks decisional ca-
14 pacity—

15 “(i) to ensure that treatment decisions are
16 made in accordance with current preferences,
17 values, and goals of the individual, when pos-
18 sible to ascertain and follow, and in accordance
19 with current advance directives and portable
20 treatment orders that are valid under State law
21 where the care is delivered, and instructions
22 provided by legally authorized representatives in
23 accordance with State and Federal law;

24 “(ii) in the absence of a current advance
25 directive or portable treatment order that is

1 valid under State law where the care is deliv-
2 ered, to deliver treatment based on credible evi-
3 dence of the individual’s treatment preferences,
4 goals, and values, such as a current advance di-
5 rective or portable treatment order executed in
6 another State or past statements about treat-
7 ment preferences; and

8 “(iii) to reconcile actual or suspected dis-
9 crepancies among advance directives, portable
10 treatment orders, and other evidence in accord-
11 ance with State law, and, where State law is si-
12 lent, to reconcile discrepancies in the manner
13 most likely to deliver treatment that is con-
14 sistent with the individual’s treatment pref-
15 erences, goals, and values;

16 “(F) that specify narrow, but potentially recur-
17 ring, conditions or circumstances under which an ad-
18 vance directive, portable treatment order, or treat-
19 ment directions from an individual or legally author-
20 ized representative would not be followed, such as—

21 “(i) where the validity or authenticity of a
22 document is in question;

23 “(ii) where there is evidence that an indi-
24 vidual’s preferences changed after the individual

1 documented preferences in an advance directive
2 or portable treatment order;

3 “(iii) where the treatment sought by the
4 individual is not medically indicated; and

5 “(iv) because of conscience objections in
6 accordance with paragraph (3);”;

7 (E) in subparagraph (H), as redesignated
8 by subparagraph (C), by striking “State law”
9 and all that follows through “respecting” and
10 inserting “this section and relevant State and
11 Federal law (whether statutory or as recognized
12 by the courts) respecting”;

13 (F) in subparagraph (I), as redesignated
14 by subparagraph (C), by inserting “and port-
15 able treatment orders” before the period at the
16 end;

17 (G) in the flush matter at the end, by
18 striking “(C)” and inserting “(G)”; and

19 (H) by adding at the end the following new
20 sentence: “Nothing in subparagraph (D) or (E)
21 shall be construed to apply to sterilization or
22 abortion.”;

23 (2) by redesignating paragraphs (3) and (4) as
24 paragraphs (4) and (5), respectively;

1 (3) by inserting after paragraph (2) the fol-
2 lowing new paragraph:

3 “(3) Nothing in this section shall be construed to pro-
4 hibit the application of a State law which allows for an
5 objection on the basis of conscience for any health care
6 provider or any agent of such provider which as a matter
7 of conscience cannot implement an advance directive.”;

8 (4) in paragraph (4), as redesignated by para-
9 graph (2)—

10 (A) by striking “written”;

11 (B) by striking “State law” and inserting
12 “State or Federal law”; and

13 (C) by striking “of the State”;

14 (5) by redesignating paragraph (5), as redesign-
15 nated by paragraph (2), as paragraph (6);

16 (6) by inserting after paragraph (4) the fol-
17 lowing new paragraph:

18 “(5) In this subsection, the term ‘portable treatment
19 order’ means a treatment order designed to document a
20 clinical process that includes shared, informed medical de-
21 cisionmaking, that reflects the individual’s goals of care
22 and values, and that is designed to apply across care set-
23 tings, including the home.”; and

1 (7) by inserting after paragraph (6), as redesignated by paragraph (6), the following new paragraph:
2
3

4 “(7) Nothing in this subsection shall permit the Secretary to seek civil penalties, including exclusion from participation in the program under this title or the program under title XIX, against an individual or entity if the individual or entity—
5
6
7
8

9 “(A) used reasonable efforts to deliver care that is consistent with an individual’s goals, preferences, and values when addressing decisionmaking for an individual who lacks decisional capacity; or
10
11
12

13 “(B) declined to furnish care in accordance with paragraph (3).”
14

15 (b) MEDICAID.—Section 1902(w) of the Social Security Act (42 U.S.C. 1396a(w)) is amended—
16

17 (1) in paragraph (1)—

18 (A) in subparagraph (A)(i), by striking “State law” and all that follows through “medical care” and inserting “relevant State and Federal law (whether statutory or as recognized by the courts) to make decisions concerning medical care”;
19
20
21
22
23

24 (B) by striking subparagraph (B);

1 (C) by redesignating subparagraphs (C),
2 (D), and (E) as subparagraphs (F), (G), and
3 (H), respectively;

4 (D) by inserting after subparagraph (A)
5 the following new subparagraphs:

6 “(B) to document in a prominent part of the
7 individual’s current medical record whether or not
8 the individual has an advance directive or portable
9 treatment order, to request a copy of the advance di-
10 rective and or portable treatment order, and if re-
11 ceived, to include the copy (or the content of the
12 document or documents) in a prominent part of such
13 record;

14 “(C) to provide each individual with the oppor-
15 tunity to discuss the information provided pursuant
16 to subparagraph (A) with an appropriately trained
17 personnel of the provider or organization;

18 “(D) for an individual with decisional capacity
19 under State law, to follow the individual’s current
20 treatment instructions, as expressed in writing or
21 through verbal or non-verbal communications;

22 “(E) for an individual who lacks decisional ca-
23 pacity—

24 “(i) to ensure that treatment decisions are
25 made in accordance with State law addressing

1 legally authorized representatives and advance
2 directives;

3 “(ii) in the absence of a current advance
4 directive or portable treatment order, to deliver
5 treatment based on credible evidence of the in-
6 dividual’s treatment preferences, goals, and val-
7 ues, such as an advance directive or portable
8 treatment order executed in another State or
9 past statements about treatment preferences;
10 and

11 “(iii) to reconcile actual or suspected dis-
12 crepancies among advance directives, portable
13 treatment orders, and other evidence in accord-
14 ance with State law, and, where State law is si-
15 lent, to reconcile discrepancies in the manner
16 most likely to deliver treatment that is con-
17 sistent with the individual’s treatment pref-
18 erences, goals, and values;

19 “(F) that specify narrow, but potentially recur-
20 ring, conditions or circumstances under which an ad-
21 vance directive, portable treatment order, or treat-
22 ment directions from an individual or legally author-
23 ized representative would not be followed, such as—

24 “(i) where the validity or authenticity of a
25 document is in question;

1 “(ii) where there is evidence that an indi-
2 vidual’s preferences changed after the individual
3 documented preferences in an advance directive
4 or portable treatment order;

5 “(iii) where the treatment sought by the
6 individual is not medically indicated; and

7 “(iv) because of conscience objections in
8 accordance with paragraph (3);”;

9 (E) in subparagraph (H), as redesignated
10 by subparagraph (C), by striking “State law”
11 and all that follows through “respecting” and
12 inserting “this section and relevant State and
13 Federal law (whether statutory or as recognized
14 by the courts) respecting”;

15 (F) in subparagraph (I), as redesignated
16 by subparagraph (C), by inserting “and port-
17 able treatment orders” before the period at the
18 end;

19 (G) in the flush matter at the end, by
20 striking “(C)” and inserting “(G)”; and

21 (H) by adding at the end the following new
22 sentence: “Nothing in subparagraph (D) or (E)
23 shall be construed to apply to sterilization or
24 abortion.”; and

25 (2) in paragraph (4)—

1 (A) by striking “written”;

2 (B) by striking “State law” and inserting
3 “State or Federal law”; and

4 (C) by striking “of the State”;

5 (3) by redesignating paragraph (5) as para-
6 graph (6);

7 (4) by inserting after paragraph (4) the fol-
8 lowing new paragraph:

9 “(5) In this subsection, the term ‘portable treatment
10 order’ means a treatment order designed to document a
11 clinical process that includes shared, informed medical de-
12 cisionmaking, that reflects the individual’s goals of care
13 and values, and that is designed to apply across care set-
14 tings, including the home.”; and

15 (5) by inserting after paragraph (6), as redesign-
16 ated by paragraph (3), the following new para-
17 graph:

18 “(7) Nothing in this subsection shall permit the Sec-
19 retary to seek civil penalties, including exclusion from par-
20 ticipation in the program under this title or the program
21 under title XVIII, against an individual or entity if the
22 individual or entity—

23 “(A) used reasonable efforts to deliver care that
24 is consistent with an individual’s goals, preferences,

1 and values when addressing decisionmaking for an
2 individual who lacks decisional capacity; or

3 “(B) declined to furnish care in accordance
4 with paragraph (3).”.

5 (c) CLARIFICATION WITH RESPECT TO ADVANCE DI-
6 RECTIVES.—Section 7 of the Assisted Suicide Funding
7 Restriction Act of 1997 (42 U.S.C. 14406) is amended—

8 (1) in paragraph (1), by striking “or” at the
9 end; and

10 (2) by striking paragraph (2) and inserting the
11 following:

12 “(2) to require any provider or organization, or
13 any employee of such a provider or organization, to
14 follow or be bound by a request from an individual
15 or legally authorized representative, an advance di-
16 rective, or a portable treatment order that directs
17 the purposeful causing of, or the purposeful assist-
18 ing in causing, the death of any individual, such as
19 by assisted suicide, euthanasia, or mercy killing; or

20 “(3) to allow discrimination against or imposi-
21 tion of penalties on any provider or organization, or
22 any employee of such a provider or organization,
23 that refuses, for any reason, including an objection
24 based on a religious, conscience, or moral objection,
25 to inform, counsel, or in any way participate in the

1 purposeful causing of, or the purposeful assisting in
2 causing, the death of any individual, such as by as-
3 sisted suicide, euthanasia, or mercy killing.”.

4 (d) EFFECTIVE DATES.—

5 (1) IN GENERAL.—Subject to paragraph (2),
6 the amendments made by subsections (a) and (b)
7 shall apply to provider agreements and contracts en-
8 tered into, renewed, or extended under title XVIII of
9 the Social Security Act (42 U.S.C. 1395 et seq.),
10 and to State plans under title XIX of such Act (42
11 U.S.C. 1396 et seq.), on or after such date as the
12 Secretary of Health and Human Services specifies,
13 but in no case may such date be later than 1 year
14 after the date of the enactment of this Act.

15 (2) EXTENSION OF EFFECTIVE DATE FOR
16 STATE LAW AMENDMENT.—In the case of a State
17 plan under title XIX of the Social Security Act (42
18 U.S.C. 1396 et seq.) which the Secretary of Health
19 and Human Services determines requires State legis-
20 lation in order for the plan to meet the additional
21 requirements imposed by the amendments made by
22 subsection (b), the State plan shall not be regarded
23 as failing to comply with the requirements of such
24 title solely on the basis of its failure to meet these
25 additional requirements before the first day of the

1 first calendar quarter beginning after the close of
2 the first regular session of the State legislature that
3 begins after the date of the enactment of this Act.
4 For purposes of the previous sentence, in the case
5 of a State that has a 2-year legislative session, each
6 year of the session is considered to be a separate
7 regular session of the State legislature.

8 **SEC. 8. ADDITIONAL REQUIREMENTS FOR FACILITIES.**

9 (a) REQUIREMENTS.—

10 (1) IN GENERAL.—Section 1866(a)(1) of the
11 Social Security Act (42 U.S.C. 1395cc(a)(1)) is
12 amended—

13 (A) in subparagraph (V), by striking
14 “and” at the end;

15 (B) in subparagraph (W), as added by sec-
16 tion 3005(1)(C) of the Patient Protection and
17 Affordable Care Act (Public Law 111–148), by
18 redesignating such subparagraph as subpara-
19 graph (X), moving such subparagraph to follow
20 subparagraph (V), moving such subparagraph 2
21 ems to the left, and striking the period at the
22 end and inserting a comma;

23 (C) in subparagraph (W), as added by sec-
24 tion 6406(b)(3) of the Patient Protection and
25 Affordable Care Act (Public Law 111–148), by

1 redesignating such subparagraph as subpara-
2 graph (Y), moving such subparagraph to follow
3 subparagraph (X), as added by subparagraph
4 (B), moving such subparagraph 2 ems to the
5 left, and striking the period at the end and in-
6 serting “, and”; and

7 (D) by inserting after subparagraph (Y)
8 the following new subparagraph:

9 “(Z) in the case of hospitals, skilled nursing fa-
10 cilities, home health agencies, and hospice programs,
11 to assure that appropriate documentation of care
12 plans made while the individual received care by or
13 through the provider (which may include advance di-
14 rectives, portable orders, or other locally appropriate
15 documents) be completed prior to discharge to allow
16 the plan to be carried out after discharge.”.

17 (2) EFFECTIVE DATE.—The amendments made
18 by this subsection shall apply to agreements entered
19 into or renewed on or after January 1, 2015.

20 (b) HHS STUDY AND REPORT.—

21 (1) STUDY.—The Secretary of Health and
22 Human Services shall conduct a study on the extent
23 to which hospitals, skilled nursing facilities, hospice
24 programs, home health agencies, and applicable pro-
25 viders of planning services under section 1861(iii) of

1 the Social Security Act, as added by section 3(a),
2 work with individuals to—

3 (A) engage in a care planning process;

4 (B) thoroughly and completely document
5 the care planning process in the medical record;

6 (C) complete documents necessary to sup-
7 port the treatment and care plan, such as port-
8 able treatment orders and advance directives;

9 (D) provide services and support that is
10 free from discrimination based on advanced
11 age, disability status, or advanced illness; and

12 (E) provide documentation necessary to
13 carry out the treatment plan to—

14 (i) subsequent providers or facilities;

15 and

16 (ii) the individual, their legally au-
17 thorized representatives, and, where appro-
18 priate and relevant, their family caregiver.

19 (2) REPORT.—Not later than January 1, 2018,
20 the Secretary of Health and Human Services shall
21 submit to Congress a report on the study conducted
22 under paragraph (1) together with recommendations
23 for such legislation and administrative action as the
24 Secretary determines to be appropriate.

1 **SEC. 9. GRANTS FOR INCREASING PUBLIC AWARENESS OF**
2 **ADVANCE CARE PLANNING AND ADVANCED**
3 **ILLNESS CARE.**

4 (a) MATERIAL AND RESOURCES DEVELOPMENT.—

5 (1) IN GENERAL.—The Secretary of Health and
6 Human Services (in this section referred to as the
7 “Secretary”) is authorized to award grants to enti-
8 ties described in subsection (d) to develop online
9 training modules, decision support tools, and in-
10 structional materials for individuals, family care-
11 givers, and health care providers that include—

12 (A) for healthy individuals, the importance
13 of—

14 (i) identifying an individual who will
15 make treatment decisions in the event of
16 future cognitive incapacity;

17 (ii) discussing values and goals rel-
18 evant to catastrophic injury or illness; and

19 (iii) completing an advance directive
20 that—

21 (I) appoints a surrogate; and

22 (II) documents goals and values
23 and other information that should be
24 considered in making treatment deci-
25 sions;

1 (B) for individuals with advanced illness,
2 the importance of—

3 (i) articulating goals of care;

4 (ii) understanding prognosis and typ-
5 ical disease trajectory;

6 (iii) evaluating treatment options in
7 light of goals of care;

8 (iv) developing a treatment plan; and

9 (v) documenting the treatment plan
10 on advance directives, portable treatment
11 orders, and other documentation forms
12 used in the locality where the plan is to be
13 executed;

14 (C) the role and effective use of State and
15 other advance directive forms and portable
16 treatment orders; and

17 (D) the range of services for individuals
18 facing advanced illness, including planning serv-
19 ices, palliative care, and hospice care.

20 (2) PERIOD.—Any grant awarded under para-
21 graph (1) shall be for a period of 3 years.

22 (b) ESTABLISHMENT AND MAINTENANCE OF WEB-
23 AND TELEPHONE-BASED RESOURCES.—

24 (1) IN GENERAL.—The Secretary is authorized
25 to award grants to entities described in subsection

1 (d) to establish and maintain a website and tele-
2 phone hotline to disseminate resources developed
3 under subsection (a) and materials designed by the
4 Department of Health and Human Services Center
5 for Faith-Based and Neighborhood Partnerships for
6 faith communities.

7 (2) PERIOD.—Any grant awarded under para-
8 graph (1) shall be for a period of 5 years.

9 (3) ABILITY TO SUSTAIN ACTIVITIES.—The
10 Secretary shall take into account the ability of an
11 entity to sustain the activities described in para-
12 graph (1) beyond the 5-year grant period in deter-
13 mining whether to award a grant under paragraph
14 (1) to the entity.

15 (c) NATIONAL PUBLIC EDUCATION CAMPAIGN.—

16 (1) IN GENERAL.—The Secretary is authorized
17 to award grants to entities described in subsection
18 (d) to conduct a national public education campaign
19 to raise public awareness of advance care planning
20 and advanced illness care, including the availability
21 of the resources created under subsections (a) and
22 (b).

23 (2) PERIOD.—Any grant awarded under para-
24 graph (1) shall be for a period of 5 years.

1 (d) ELIGIBLE ENTITIES.—Entities described in this
2 subsection are public or private entities (including States
3 or political subdivisions of a State, faith-based organiza-
4 tions, and religious educational institutions), or a consor-
5 tium of any such entities.

6 (e) AUTHORIZATION OF APPROPRIATIONS.—

7 (1) IN GENERAL.—There are authorized to be
8 appropriated to the Secretary—

9 (A) for purposes of making grants under
10 subsection (a), \$5,000,000 for fiscal year 2015,
11 to remain available until expended;

12 (B) for purposes of making grants under
13 subsection (b), \$5,000,000 for fiscal year 2015,
14 to remain available until expended; and

15 (C) for purposes of making grants under
16 subsection (c), \$5,000,000 for fiscal year 2015
17 to remain available until expended.

18 (2) LIMITATION.—None of the funds appro-
19 priated under paragraph (1) shall be used to—

20 (A) develop a model advance directive;

21 (B) develop or employ a dollars-per-quality
22 adjusted life year (or similar measure that dis-
23 counts the value of a life because of an individ-
24 ual's disability); or

1 (C) make a grant to a private entity that
2 advocates, promotes, or facilitates any item or
3 procedure for which funding is unavailable
4 under the Assisted Suicide Funding Restriction
5 Act of 1997 (Public Law 105–12).

6 **SEC. 10. HHS STUDY AND REPORT ON THE STORAGE OF AD-**
7 **VANCE DIRECTIVES.**

8 (a) STUDY.—The Secretary of Health and Human
9 Services shall conduct a study on State and regional activi-
10 ties with respect to storing completed advance directives
11 and portable treatment orders. Such study shall include
12 an analysis of the practicality and feasibility of estab-
13 lishing a national registry for completed advance directives
14 and portable treatment orders, taking into consideration
15 the constraints created by the privacy provisions enacted
16 as a result of the Health Insurance Portability and Ac-
17 countability Act of 1996 (Public Law 104–191).

18 (b) REPORT.—Not later than January 1, 2017, the
19 Secretary of Health and Human Services shall submit to
20 Congress a report on the study conducted under sub-
21 section (a) together with recommendations for such legis-
22 lation and administrative action as the Secretary deter-
23 mines to be appropriate.

1 **SEC. 11. GAO STUDY AND REPORT ON THE PROVISIONS OF,**
2 **AND AMENDMENTS MADE BY, THIS ACT.**

3 (a) STUDY.—The Comptroller General of the United
4 States (in this section referred to as the “Comptroller
5 General”) shall conduct a study on the provisions of, and
6 amendments made by, this Act, including the quality (such
7 as individual and family experience, individual under-
8 standing of treatment choices, and alignment among indi-
9 vidual goals, values, and preferences, the documented care
10 plan, treatment delivered, and treatment outcomes) associ-
11 ated with such provisions and such amendments.

12 (b) REPORT.—Not later than January 1, 2018, the
13 Comptroller General shall submit to Congress a report
14 containing the results of the study conducted under sub-
15 section (a), together with recommendations for such legis-
16 lation and administrative action as the Comptroller Gen-
17 eral determines appropriate.

18 **SEC. 12. CONSULTATION WITH THE CARE PLANNING ADVI-**
19 **SORY BOARD.**

20 The Secretary of Health and Human Services shall
21 consult with the Care Planning Advisory Board estab-
22 lished under section 6 in order to ensure that every activ-
23 ity carried out under the provisions of, and amendments
24 made by, this Act will help individuals to—

1 (1) receive education and care that is free from
2 discrimination based on advanced age, disability sta-
3 tus, or presence of advanced illness;

4 (2) develop plans and receive care that is con-
5 sistent with each individual's goals, values and pref-
6 erences; and

7 (3) receive an explanation of a range of per-
8 spectives on approaches for treating advanced ill-
9 ness, including disease modifying options, palliative
10 care that supports individuals from the onset of ad-
11 vanced illness and can be provided at the same time
12 as all other care types, and hospice care.

13 **SEC. 13. RULE OF CONSTRUCTION.**

14 Nothing in the provisions of, or the amendments
15 made by, this Act shall be construed to limit the restric-
16 tions of, or to authorize the use of Federal funds for any
17 service, material, or activity pertaining to an item or serv-
18 ice or procedure for which funds are unavailable under,
19 the Assisted Suicide Funding Restriction Act of 1997
20 (Public Law 105–12).

○