

respectively, and struck out former pars. (4) to (6) which read as follows:

“(4) the care for individuals with Alzheimer’s disease and related dementias falls primarily on their families, and such care is very often financially and emotionally devastating;

“(5) the cost of caring for individuals with Alzheimer’s disease and related dementias is great, and conservative estimates range between \$38,000,000,000 and \$42,000,000,000 per year solely for direct costs;

“(6) although substantial progress has been made in recent years in identifying possible leads to the causes of Alzheimer’s disease and related dementias and more progress can be expected in the near future, there is little likelihood of a breakthrough in the foreseeable future which would eliminate or substantially reduce the number of individuals with such disease and dementias or the difficulties of caring for such individuals;”.

#### SHORT TITLE OF 2011 AMENDMENT

Pub. L. 111-375, §1, Jan. 4, 2011, 124 Stat. 4100, provided that: “This Act [enacting subchapter III-A of this chapter] may be cited as the ‘National Alzheimer’s Project Act.’”

#### SHORT TITLE OF 1992 AMENDMENT

Pub. L. 102-507, §1, Oct. 24, 1992, 106 Stat. 3281, provided that: “This Act [enacting section 11261 of this title, amending this section and sections 285e-5, 11211, 11212, 11221, 11223, 11251, 11253, 11263, 11292, and 11294 of this title, repealing section 11261 of this title, and amending provisions set out as a note under this section] may be cited as the ‘Alzheimer’s Disease Research, Training, and Education Amendments of 1992.’”

#### SHORT TITLE

Pub. L. 99-660, title IX, §901, Nov. 14, 1986, 100 Stat. 3802, as amended by Pub. L. 102-507, §2(a), Oct. 24, 1992, 106 Stat. 3281, provided that: “This title [enacting this chapter] may be cited as the ‘Alzheimer’s Disease and Related Dementias Research Act of 1992.’”

### SUBCHAPTER II—COUNCIL ON ALZHEIMER’S DISEASE

#### §§ 11211, 11212. Repealed. Pub. L. 105-362, title VI, § 601(a)(2)(E), Nov. 10, 1998, 112 Stat. 3286

Section 11211, Pub. L. 99-660, title IX, §911, Nov. 14, 1986, 100 Stat. 3804; Pub. L. 102-54, §13(q)(14)(A), June 13, 1991, 105 Stat. 282; Pub. L. 102-507, §5(2)[(a)], Oct. 24, 1992, 106 Stat. 3282; Pub. L. 103-171, §3(b)(3), Dec. 2, 1993, 107 Stat. 1991, related to establishment of Council on Alzheimer’s Disease in the Department of Health and Human Services.

Section 11212, Pub. L. 99-660, title IX, §912, Nov. 14, 1986, 100 Stat. 3804; Pub. L. 100-607, title I, §142(c)(1)(E), Nov. 4, 1988, 102 Stat. 3057; Pub. L. 102-507, §5(b), Oct. 24, 1992, 106 Stat. 3282, related to functions of Council on Alzheimer’s Disease.

### SUBCHAPTER III—ADVISORY PANEL ON ALZHEIMER’S DISEASE

#### §§ 11221 to 11223. Omitted

#### CODIFICATION

Sections 11221 to 11223, which provided for the establishment of the Advisory Panel on Alzheimer’s Disease, were omitted pursuant to section 11221(i), which provided that the Panel and all programs established under this subchapter shall terminate on Sept. 30, 1996. See section 11225 of this title.

Section 11221, Pub. L. 99-660, title IX, §921, Nov. 14, 1986, 100 Stat. 3806; Pub. L. 102-507, §6(a), Oct. 24, 1992, 106 Stat. 3283; Pub. L. 103-171, §3(b)(3), Dec. 2, 1993, 107 Stat. 1991; Pub. L. 106-129, §2(b)(2), Dec. 6, 1999, 113 Stat. 1670, established the Advisory Panel on Alzheimer’s Disease within the Department of Health and Human Services.

Section 11222, Pub. L. 99-660, title IX, §922, Nov. 14, 1986, 100 Stat. 3807, related to the functions of Panel.

Section 11223, Pub. L. 99-660, title IX, §923, Nov. 14, 1986, 100 Stat. 3807; Pub. L. 102-507, §6(b), Oct. 24, 1992, 106 Stat. 3283, authorized appropriations to carry out this subchapter.

### SUBCHAPTER III-A—NATIONAL ALZHEIMER’S PROJECT

#### § 11225. The National Alzheimer’s Project

##### (a) Definition of Alzheimer’s

In this Act, the term “Alzheimer’s” means Alzheimer’s disease and related dementias.

##### (b) Establishment

There is established in the Office of the Secretary of Health and Human Services the National Alzheimer’s Project (referred to in this Act as the “Project”).

##### (c) Purpose of the Project

The Secretary of Health and Human Services, or the Secretary’s designee, shall—

(1) be responsible for the creation and maintenance of an integrated national plan to overcome Alzheimer’s;

(2) provide information and coordination of Alzheimer’s research and services across all Federal agencies;

(3) accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer’s;

(4) improve the—

(A) early diagnosis of Alzheimer’s disease; and

(B) coordination of the care and treatment of citizens with Alzheimer’s;

(5) ensure the inclusion of ethnic and racial populations at higher risk for Alzheimer’s or least likely to receive care, in clinical, research, and service efforts with the purpose of decreasing health disparities in Alzheimer’s; and

(6) coordinate with international bodies to integrate and inform the fight against Alzheimer’s globally.

##### (d) Duties of the Secretary

###### (1) In general

The Secretary of Health and Human Services, or the Secretary’s designee, shall—

(A) oversee the creation and updating of the national plan described in paragraph (2); and

(B) use discretionary authority to evaluate all Federal programs around Alzheimer’s, including budget requests and approvals.

###### (2) National plan

The Secretary of Health and Human Services, or the Secretary’s designee, shall carry out an annual assessment of the Nation’s progress in preparing for the escalating burden of Alzheimer’s, including both implementation steps and recommendations for priority actions based on the assessment.

##### (e) Advisory Council

###### (1) In general

There is established an Advisory Council on Alzheimer’s Research, Care, and Services (re-

ferred to in this Act as the “Advisory Council”).

**(2) Membership**

**(A) Federal members**

The Advisory Council shall be comprised of the following experts:

- (i) A designee of the Centers for Disease Control and Prevention.
- (ii) A designee of the Administration on Aging.
- (iii) A designee of the Centers for Medicare & Medicaid Services.
- (iv) A designee of the Indian Health Service.
- (v) A designee of the Office of the Director of the National Institutes of Health.
- (vi) The Surgeon General.
- (vii) A designee of the National Science Foundation.
- (viii) A designee of the Department of Veterans Affairs.
- (ix) A designee of the Food and Drug Administration.
- (x) A designee of the Agency for Healthcare Research and Quality.

**(B) Non-Federal members**

In addition to the members outlined in subparagraph (A), the Advisory Council shall include 12 expert members from outside the Federal Government, which shall include—

- (i) 2 Alzheimer’s patient advocates;
- (ii) 2 Alzheimer’s caregivers;
- (iii) 2 health care providers;
- (iv) 2 representatives of State health departments;
- (v) 2 researchers with Alzheimer’s-related expertise in basic, translational, clinical, or drug development science; and
- (vi) 2 voluntary health association representatives, including a national Alzheimer’s disease organization that has demonstrated experience in research, care, and patient services, and a State-based advocacy organization that provides services to families and professionals, including information and referral, support groups, care consultation, education, and safety services.

**(3) Meetings**

The Advisory Council shall meet quarterly and such meetings shall be open to the public.

**(4) Advice**

The Advisory Council shall advise the Secretary of Health and Human Services, or the Secretary’s designee.

**(5) Annual report**

The Advisory Council shall provide to the Secretary of Health and Human Services, or the Secretary’s designee and Congress—

- (A) an initial evaluation of all federally funded efforts in Alzheimer’s research, clinical care, and institutional-, home-, and community-based programs and their outcomes;
- (B) initial recommendations for priority actions to expand, eliminate, coordinate, or condense programs based on the program’s performance, mission, and purpose;

(C) initial recommendations to—

- (i) reduce the financial impact of Alzheimer’s on—
  - (I) Medicare and other federally funded programs; and
  - (II) families living with Alzheimer’s disease; and
- (ii) improve health outcomes; and

(D) annually thereafter, an evaluation of the implementation, including outcomes, of the recommendations, including priorities if necessary, through an updated national plan under subsection (d)(2).

**(6) Termination**

The Advisory Council shall terminate on December 31, 2025.

**(f) Data sharing**

Agencies both within the Department of Health and Human Services and outside of the Department that have data relating to Alzheimer’s shall share such data with the Secretary of Health and Human Services, or the Secretary’s designee, to enable the Secretary, or the Secretary’s designee, to complete the report described in subsection (g).

**(g) Annual report**

The Secretary of Health and Human Services, or the Secretary’s designee, shall submit to Congress—

- (1) an annual report that includes an evaluation of all federally funded efforts in Alzheimer’s research, clinical care, and institutional-, home-, and community-based programs and their outcomes;
- (2) an evaluation of all federally funded programs based on program performance, mission, and purpose related to Alzheimer’s disease;
- (3) recommendations for—

(A) priority actions based on the evaluation conducted by the Secretary and the Advisory Council to—

- (i) reduce the financial impact of Alzheimer’s on—
  - (I) Medicare and other federally funded programs; and
  - (II) families living with Alzheimer’s disease; and
- (ii) improve health outcomes;

(B) implementation steps; and

(C) priority actions to improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based programs of Alzheimer’s disease for individuals with Alzheimer’s disease and their caregivers; and

(4) an annually updated national plan.

**(h) Sunset**

The Project shall expire on December 31, 2025. (Pub. L. 111-375, §2, Jan. 4, 2011, 124 Stat. 4100.)

REFERENCES IN TEXT

This Act, referred to in subsecs. (a), (b), and (e)(1), is Pub. L. 111-375, Jan. 4, 2011, 124 Stat. 4100, known as the National Alzheimer’s Project Act, which enacted this subchapter and provisions set out as a note under sec-

tion 11201 of this title. For complete classification of this Act to the Code, see Short Title of 2010 Amendment note set out under section 11201 of this title and Tables.

CODIFICATION

Section was enacted as part of the National Alzheimer's Project Act, and not as part of the Alzheimer's Disease and Related Dementias Research Act of 1992 which comprises this chapter.

ANNUAL BUDGET ESTIMATE

Pub. L. 113-235, div. G, title II, §230, Dec. 16, 2014, 128 Stat. 2492, provided that: "Hereafter, for each fiscal year through fiscal year 2025, the Director of the National Institutes of Health shall prepare and submit directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council on Alzheimer's Research, Care, and Services, an annual budget estimate (including an estimate of the number and type of personnel needs for the Institutes) for the initiatives of the National Institutes of Health pursuant to the National Alzheimer's Plan, as required under section 2(d)(2) of Public Law 111-375 [42 U.S.C. 11225(d)(2)]."

SUBCHAPTER IV—RESEARCH RELATING TO SERVICES FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS AND THEIR FAMILIES

CODIFICATION

Pub. L. 100-607, title I, §142(c)(1)(B), (D), (2)(C), Nov. 4, 1988, 102 Stat. 3057, redesignated former subchapter V as IV and struck out heading for subchapter IV "AWARDS FOR LEADERSHIP AND EXCELLENCE IN ALZHEIMER'S DISEASE AND RELATED DEMENTIAS", consisting of sections 11231 and 11232, and struck out heading for part 1 "RESPONSIBILITIES OF NATIONAL INSTITUTE ON AGING", consisting of sections 11241 to 11243.

**§ 11231. Transferred**

Section, Pub. L. 99-660, title IX, §931, Nov. 14, 1986, 100 Stat. 3807, which provided for awards for biomedical research on Alzheimer's disease and related dementias, was redesignated section 445B of the Public Health Service Act by Pub. L. 100-607, title I, §142(a), Nov. 4, 1988, 102 Stat. 3057, and is classified to section 285e-4 of this title.

**§ 11232. Repealed. Pub. L. 100-607, title I, § 142(c)(1)(A), Nov. 4, 1988, 102 Stat. 3057**

Section, Pub. L. 99-660, title IX, §932, Nov. 14, 1986, 100 Stat. 3808, authorized appropriations for fiscal years 1988 through 1991 to carry out program of awards for research on Alzheimer's disease and related dementias.

**§§ 11241, 11242. Transferred**

Section 11241, Pub. L. 99-660, title IX, §941, Nov. 14, 1986, 100 Stat. 3808, which provided for Director of National Institute on Aging to conduct, or make grants for conduct of, research on services for individuals with Alzheimer's disease and related dementias and their families, was redesignated section 445C of the Public Health Service Act by Pub. L. 100-607, title I, §142(a), Nov. 4, 1988, 102 Stat. 3057, and is classified to section 285e-5 of this title.

Section 11242, Pub. L. 99-660, title IX, §942, Nov. 14, 1986, 100 Stat. 3809, which provided for Director to disseminate results of such research to professional entities and the public, was redesignated section 445D of the Public Health Service Act by Pub. L. 100-607, title I, §142(a), Nov. 4, 1988, 102 Stat. 3057, and is classified to section 285e-6 of this title.

**§ 11243. Repealed. Pub. L. 100-607, title I, § 142(c)(2)(A), Nov. 4, 1988, 102 Stat. 3057**

Section, Pub. L. 99-660, title IX, §943, Nov. 14, 1986, 100 Stat. 3809, authorized appropriations for fiscal years 1988 through 1991 to carry out programs of National Institute on Aging in research on services for individuals with Alzheimer's disease and related dementias and their families.

PART 1—RESPONSIBILITIES OF NATIONAL INSTITUTE OF MENTAL HEALTH

CODIFICATION

Pub. L. 100-607, title I, §142(c)(2)(C), (D), Nov. 4, 1988, 102 Stat. 3057, redesignated part 2 as 1 and struck out former part 1 heading "RESPONSIBILITIES OF NATIONAL INSTITUTE ON AGING".

**§ 11251. Research program and plan**

**(a) Grants for research**

The Director of the National Institute of Mental Health shall conduct, or make grants for the conduct of, research relevant to appropriate services and specialized care for individuals with Alzheimer's disease and related dementias and their families.

**(b) Preparation of plan; contents; revision**

The Director of the National Institute of Mental Health shall—

(1) ensure that the research conducted under subsection (a) includes research concerning—

(A) mental health services and treatment modalities relevant to the mental, behavioral, and psychological problems associated with Alzheimer's disease and related dementias;

(B) the most effective methods for providing comprehensive multidimensional assessments to obtain information about the current functioning of, and needs for the care of, individuals with Alzheimer's disease and related dementias;

(C) the optimal range, types, and cost-effectiveness of services and specialized care for individuals with Alzheimer's disease and related dementias and for their families, in community and residential settings (including home care, day care, and respite care), and in institutional settings, particularly with respect to—

(i) the design of the services and care;

(ii) appropriate staffing for the provision of the services and care;

(iii) the timing of the services and care during the progression of the disease or dementias; and

(iv) the appropriate mix and coordination of the services and specialized care;

(D) the efficacy of various special care units in the United States for individuals with Alzheimer's disease, including an assessment of the costs incurred in operating such units, the evaluation of best practices for the development of appropriate standards to be used by such units, and the measurement of patient outcomes in such units;

(E) methods to combine formal support services provided by health care professionals for individuals with Alzheimer's disease and related dementias with informal