

(8) the responsibility for care of individuals with Alzheimer's disease and related dementias falls primarily on their families, and the care is financially and emotionally devastating;

(9) attempts to reduce the emotional and financial burden of caring for dementia patients is impeded by a lack of knowledge about such patients, how to care for such patients, the costs associated with such care, the effectiveness of various modes of care, the quality and type of care necessary at various stages of the disease, and other appropriate services that are needed to provide quality care;

(10) the results of the little research that has been undertaken concerning dementia has been inadequate or the results have not been widely disseminated;

(11) more knowledge is needed concerning—

(A) the epidemiology of, and the identification of risk factors for, Alzheimer's disease and related dementias;

(B) the development of methods for early diagnosis, functional assessment, and psychological evaluation of individuals with Alzheimer's disease for the purpose of monitoring the course of the disease and developing strategies for improving the quality of life for such individuals;

(C) the understanding of the optimal range and cost-effectiveness of community and institutional services for individuals with Alzheimer's disease and related dementias and their families, particularly with respect to the design, delivery, staffing, and mix of such services and the coordination of such services with other services, and with respect to the relationship of formal to informal support services;

(D) the understanding of optimal methods to combine formal support services provided by health care professionals with informal support services provided by family, friends, and neighbors of individuals with Alzheimer's disease, and the identification of ways family caregivers can be sustained through interventions to reduce psychological and social problems and physical problems induced by stress;

(E) existing data that are relevant to Alzheimer's disease and related dementias; and

(F) the costs incurred in caring for individuals with Alzheimer's disease and related dementias;

(12) it is imperative to provide appropriate coordination of the efforts of the Federal Government in the provision of services for individuals with Alzheimer's disease and related dementias;

(13) it is important to increase the understanding of Alzheimer's disease and related dementias by the diverse range of personnel involved in the care of individuals with such disease and dementias; and

(14) it is imperative that the Social Security Administration be provided information pertaining to Alzheimer's disease and related dementias, particularly for personnel in such Administration involved in the establishment and updating of criteria for determining whether an individual is under a disability for

purposes of titles II and XVI of the Social Security Act [42 U.S.C. 401 et seq., 1381 et seq.].

(Pub. L. 99-660, title IX, §902, Nov. 14, 1986, 100 Stat. 3802; Pub. L. 102-507, §4, Oct. 24, 1992, 106 Stat. 3281.)

REFERENCES IN TEXT

The Social Security Act, referred to in par. (14), is act Aug. 14, 1935, ch. 531, 49 Stat. 620, as amended. Titles II and XVI of the Act are classified generally to subchapters II (§401 et seq.) and XVI (§1381 et seq.), respectively, of chapter 7 of this title. For complete classification of this Act to the Code, see section 1305 of this title and Tables.

AMENDMENTS

1992—Pars. (4) to (14). Pub. L. 102-507 added pars. (4) to (8), redesignated former pars. (7) to (12) as (9) to (14), 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 (referred 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.