Sec.

11252. Dissemination.

11253. Authorization of appropriations.

PART 2—RESPONSIBILITIES OF AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

11261. Research program.

11262. Dissemination.

11263. Authorization of appropriations.

PART 3—RESPONSIBILITIES OF THE CENTERS FOR MEDICARE & MEDICAID SERVICES

11271. Research program and plan.

11272. Dissemination.

11273. Authorization of appropriations.

11281 to 11283. Repealed or Transferred.

## SUBCHAPTER V—EDUCATIONAL ACTIVITIES

11291. Providing information for personnel of Social Security Administration.

11292. Education of public, individuals with Alzheimer's disease and their families, and health and long-term care providers.

11293. Education programs for safety and transportation personnel.

11294. Authorization of appropriations.

#### CODIFICATION

Pub. L. 102-507, §2(b), Oct. 24, 1992, 106 Stat. 3281, struck out "SERVICES" before "RESEARCH" in chapter heading.

## SUBCHAPTER I—GENERAL PROVISIONS

### §11201. Findings

The Congress finds that-

- (1) best estimates indicate that between 2,000,000 and 3,000,000 Americans presently have Alzheimer's disease or related dementias;
- (2) estimates of the number of individuals afflicted with Alzheimer's disease and related dementias are unreliable because current diagnostic procedures lack accuracy and sensitivity and because there is a need for epidemiological data on incidence and prevalence of such disease and dementias:
- (3) studies estimate that between one-half and two-thirds of patients in nursing homes meet the clinical and mental status criteria for dementia:
- (4) 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;
- (5) progress in the neurosciences and behavioral sciences has demonstrated the interdependence and mutual reinforcement of basic science, clinical research, and services research for Alzheimer's disease and related dementias:
- (6) programs initiated as part of the Decade of the Brain are likely to provide significant progress in understanding the fundamental mechanisms underlying the causes of, and treatments for, Alzheimer's disease and related dementias;
- (7) 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 immediate future that would eliminate or substantially reduce—

- (A) the number of individuals with the disease and dementias; or
- (B) the difficulties of caring for the individuals:
- (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 per-

taining 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,  $\S901$ , Nov. 14, 1986, 100 Stat. 3802, as amended by Pub. L. 102–507,  $\S2(a)$ , 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,  $\S912$ , Nov. 14, 1986, 100 Stat. 3804; Pub. L. 100–607, title I,  $\S142(c)(1)(E)$ , Nov. 4, 1988, 102 Stat. 3057; Pub. L. 102–507,  $\S5(b)$ , 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.

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;

(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—