

Public Law 102-507
102d Congress

An Act

To amend the Alzheimer's Disease and Related Dementias Services Research Act of 1986 to reauthorize the Act, and for other purposes.

Oct. 24, 1992
[S. 1577]

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

SECTION 1. SHORT TITLE.

This Act may be cited as the "Alzheimer's Disease Research, Training, and Education Amendments of 1992".

SEC. 2. SHORT TITLE OF ACT.

(a) **IN GENERAL.**—Section 901 of the Alzheimer's Disease and Related Dementias Services Research Act of 1986 (42 U.S.C. 11201 note) is amended by striking "Services Research Act of 1986" and inserting "Research Act of 1992".

(b) **CONFORMING AMENDMENT.**—The Alzheimer's Disease and Related Dementias Research Act of 1992 (42 U.S.C. 11201 et seq.) is amended in the heading for title IX by striking "**SERVICES**".

SEC. 3. REFERENCES.

Except as otherwise specifically provided, whenever in this Act an amendment or repeal is expressed in terms of an amendment to, or a repeal of, a section or other provision, the reference shall be considered to be made to a section or other provision of the Alzheimer's Disease and Related Dementias Research Act of 1992 (42 U.S.C. 11201 et seq.).

SEC. 4. FINDINGS.

Section 902 (42 U.S.C. 11201) is amended—

(1) by redesignating paragraphs (7) through (12) as paragraphs (9) through (14);

(2) by striking paragraphs (4), (5), and (6); and

(3) by inserting after paragraph (3) the following new paragraphs:

"(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 break-

Alzheimer's
Disease
Research,
Training, and
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Amendments of
1992.
Health and
health care.
42 USC 11201
note.

through 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.”.

SEC. 5. COUNCIL ON ALZHEIMER'S DISEASE.

(2) ESTABLISHMENT.—Section 911 (42 U.S.C. 11211) is amended—

(1) in subsection (a)—

(A) in paragraph (2), by striking “Surgeon General of the United States” and inserting “Surgeon General of the Public Health Service”;

(B) in paragraph (6), by striking “and Communicative Diseases” and inserting “Disorders”;

(C) by striking paragraphs (10), (11), and (12); and

(D) by adding at the end the following new paragraphs:

“(10) the Administrator of the Agency for Health Care Policy and Research;

“(11) the Administrator of the Health Resources and Services Administration;

“(12) the Director of the National Center for Nursing Research;

“(13) the Chief Medical Director of the Department of Veterans Affairs;

“(14) the Director of the National Center for Health Statistics; and

“(15) such additional members as the Secretary of Health and Human Services (hereinafter referred to as the ‘Secretary’) considers appropriate.”;

(2) by striking subsection (b) and inserting the following new subsection:

“(b) The Assistant Secretary for Health shall serve as the Chairman of the Council.”; and

(3) in subsection (d), by striking “twice” and inserting “once”.

(b) FUNCTIONS.—Section 912 (42 U.S.C. 11212) is amended—

(1) in subsection (a)—

(A) by adding “and” at the end of paragraph (3);

(B) by striking “; and” at the end of paragraph (4) and inserting a period; and

(C) by striking paragraph (5); and

(2) by striking subsection (b) and inserting the following new subsection:

“(b)(1) The Chairman of the Council shall submit to the committees listed in paragraph (2) an annual report containing information on—

“(A) progress made by research, sponsored by the Federal Government, on Alzheimer's disease and related dementias; and

“(B) new directions that the Council considers potentially important in research on Alzheimer's disease and related dementias.

Reports.

"(2) The Chairman of the Council shall submit the report described in paragraph (1) to—

"(A) the Committee on Energy and Commerce of the House of Representatives;

"(B) the Committee on Ways and Means of the House of Representatives;

"(C) the Committee on Veterans' Affairs of the House of Representatives;

"(D) the Committee on Appropriations of the House of Representatives;

"(E) the Committee on Labor and Human Resources of the Senate;

"(F) the Committee on Finance of the Senate;

"(G) the Committee on Veterans' Affairs of the Senate; and

"(H) the Committee on Appropriations of the Senate."

SEC. 6. ADVISORY PANEL ON ALZHEIMER'S DISEASE.

(a) ESTABLISHMENT.—Section 921 (42 U.S.C. 11221) is amended—

(1) in subsection (a)(2), by striking "the Director of the National Center for Health Services Research and Health Care Technology Assessment" and inserting "the Administrator of the Agency for Health Care Policy and Research";

(2) in subsection (d), to read as follows:

"(d)(1)(A) Except as provided in subparagraph (B), members of the Panel appointed under subsection (a)(1) shall each serve for a term of 3 years.

"(B) Of the members appointed under subsection (a)(1) that are serving on the Panel on the day before the date of the enactment of this subsection—

"(i) five shall serve for a term that expires on such date;

"(ii) five shall serve for a term that expires 1 year after such date; and

"(iii) five shall serve for a term that expires 2 years after such date.

"(2) A vacancy on the Panel shall be filled in the same manner as the original appointment was made, and not later than 90 days after the date on which the vacancy first arises. A vacancy on the Panel shall not affect the powers of the Panel."

(3) in subsection (f), by striking "twice" and inserting "once";

(4) in subsection (h), by striking "of \$100 per day" and inserting "at the daily equivalent of the maximum rate specified for GS-15 of the General Schedule under section 5332 of title 5, United States Code,"; and

(5) by adding at the end the following new subsection:

"(i) Notwithstanding section 14 of the Federal Advisory Committee Act (5 U.S.C. App.), on September 30, 1996, the Panel shall be abolished and all programs established under this part shall terminate."

Termination
date.

(b) AUTHORIZATION OF APPROPRIATIONS.—Section 923 (42 U.S.C. 11223) is amended to read as follows:

"SEC. 923. AUTHORIZATION OF APPROPRIATIONS.

"There are authorized to be appropriated to carry out this part such sums as may be necessary for each of the fiscal years 1992 through 1996."

SEC. 7. RESEARCH RELATING TO SERVICES FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS AND FAMILIES OF THE INDIVIDUALS.

(a) RESPONSIBILITIES OF THE NATIONAL INSTITUTE OF MENTAL HEALTH.—

(1) GRANTS.—Section 931 (42 U.S.C. 11251) is amended—

(A) by striking subsections (b)(2) and (c);

(B) in subsection (a), by inserting “and specialized care” after “services”; and

(C) in subsection (b)(1)—

(i) by striking “Within 6 months” and all that follows through “plan shall” and inserting “The Director of the National Institute of Mental Health shall”;

(ii) in subparagraph (A)—

(I) by striking “provide for” and inserting “ensure that the research conducted under subsection (a) includes”;

(II) by striking clause (iii) and inserting the following new clause:

“(iii) 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.”;

(III) in clause (iv), by inserting “the evaluation of best practices for the development of” before “appropriate”; and

(IV) in clauses (v) and (vii), by striking “and nursing home services” and inserting “nursing home services, and other residential services and care”; and

(iii) in subparagraph (B), by striking “research carried out under the plan” and inserting “the research”.

(2) CONFORMING AMENDMENTS.—Section 931(b) (42 U.S.C. 11251(b)) is amended—

(A) by striking “(1)”;

(B) by redesignating subparagraphs (A) and (B) as paragraphs (1) and (2), respectively;

(C) in paragraph (1) (as redesignated by subparagraph (B) of this paragraph), by redesignating clauses (i) through (vii) as subparagraphs (A) through (G), respectively; and

(D) in paragraph (1)(C) (as so redesignated, and as amended by paragraph (1)(C)(ii)(II) of this subsection), by redesignating subclauses (I) through (IV) as clauses (i) through (iv), respectively.

(3) AUTHORIZATION OF APPROPRIATIONS.—Section 933 (42 U.S.C. 11253) is amended to read as follows:

"SEC 933. AUTHORIZATION OF APPROPRIATIONS.

"There are authorized to be appropriated to carry out this subpart such sums as may be necessary for each of the fiscal years 1992 through 1996."

(b) RESPONSIBILITIES OF THE AGENCY FOR HEALTH CARE POLICY AND RESEARCH.—

(1) RESEARCH PROGRAM AND PLAN.—Subpart 2 of part D (42 U.S.C. 11261 et seq.) is amended—

(A) in the heading for the subpart, by striking "National Center" and all that follows and inserting the following: "Agency for Health Care Policy and Research"; and

(B) by striking section 934 and inserting the following new section:

"SEC 934. RESEARCH PROGRAM.

42 USC 11261.

"(a) GRANTS FOR RESEARCH.—The Administrator of the Agency for Health Care Policy and Research shall conduct, or make grants for the conduct of, research relevant to appropriate services for individuals with Alzheimer's disease and related dementias and for their families.

"(b) RESEARCH SUBJECTS.—The Administrator of the Agency for Health Care Policy and Research shall ensure that research conducted under subsection (a) shall include research—

"(1) concerning improving the organization, delivery, and financing of services for individuals with Alzheimer's disease and related dementias and for their families, including research on—

"(A) the design, staffing, and operation of special care units for the individuals in institutional settings, as well as individuals in institutional settings, as well as individuals in home care, day care, and respite care; and

"(B) the exploration and enhancement of services such as home care, day care, and respite care, that provide alternatives to institutional care;

"(2) concerning the costs incurred by individuals with Alzheimer's disease and related dementias and by their families in obtaining services, particularly services that are essential to the individuals and that are not generally required by other patients under long-term care programs;

"(3) concerning the costs, cost-effectiveness, and effectiveness of various interventions to provide services for individuals with Alzheimer's disease and related dementias and for their families;

"(4) conducted in consultation with the Director of the National Institute on Aging and the Commissioner of the Administration on Aging, concerning the role of physicians in caring for persons with Alzheimer's disease and related dementias and for their families, including the role of a physician in connecting such persons with appropriate health care and supportive services, including those supported through State and area agencies on aging designated under section 305(a) (1) and (2)(A) of the Older Americans Act of 1965 (42 U.S.C. 3025(a)(1) and (2)(A)); and

"(5) conducted in consultation with the Director of the National Institute on Aging and the Commissioner of the Administration on Aging, concerning legal and ethical issues,

including issues associated with special care units, facing individuals with Alzheimer's disease and related dementias and facing their families.”.

(2) **AUTHORIZATION OF APPROPRIATIONS.**—Section 936 (42 U.S.C. 11263) is amended to read as follows:

“SEC. 936. AUTHORIZATION OF APPROPRIATIONS.

“There are authorized to be appropriated to carry out this subpart such sums as may be necessary for each of the fiscal years 1992 through 1996.”.

SEC. 8. TRAINING AND EDUCATIONAL ACTIVITIES.

(a) **ACTIVITIES.**—Section 962 (42 U.S.C. 11292) is amended to read as follows:

“SEC. 962. EDUCATION OF THE PUBLIC, INDIVIDUALS WITH ALZHEIMER'S DISEASE AND THEIR FAMILIES, AND HEALTH AND LONG-TERM CARE PROVIDERS.

“(a) TRAINING MODELS GRANTS.—

“(1) GRANTS.—The Director of the National Institute on Aging may award grants to eligible entities to assist the entities in developing and evaluating model training programs—

“(A) for—

“(i) health care professionals, including mental health professionals;

“(ii) health care paraprofessionals;

“(iii) personnel, including information and referral, case management, and in-home services personnel (including personnel receiving support under the Older Americans Act of 1965 (42 U.S.C. 3001 et seq.)), providing supportive services to the elderly and the families of the elderly;

“(iv) family caregivers providing care and treatment for individuals with Alzheimer's disease and related disorders; and

“(v) personnel of local organizations (including community groups, business and labor groups, and religious, educational, and charitable organizations) that have traditionally not been involved in planning and developing long-term care services; and

“(B) with attention to such variables as—

“(i) curricula development for training and continuing education programs;

“(ii) care setting; and

“(iii) intervention technique.

“(2) ELIGIBLE ENTITY.—To be eligible to receive grants under this subsection, an entity shall be—

“(A) an educational institution providing training and education in medicine, psychology, nursing, social work, gerontology, or health care administration;

“(B) an educational institution providing preparatory training and education of personnel for nursing homes, hospitals, and home or community settings; or

“(C) an Alzheimer's Disease Research Center described in section 445(a) of the Public Health Service Act.

“(b) EDUCATIONAL GRANTS.—The Director of the National Institute on Aging is authorized to make grants to public and nonprofit private entities to assist such entities in establishing

programs, for educating health care providers and the families of individuals with Alzheimer's disease or related disorders, regarding—

“(1) caring for individuals with such diseases or disorders; and

“(2) the availability in the community of public and private sources of assistance, including financial assistance, for caring for such individuals.

“(c) AWARD OF GRANTS.—In awarding grants under this section, the Director of the National Institute on Aging shall—

“(1) award the grants on the basis of merit;

“(2) award the grants in a manner that will ensure access to the programs described in subsections (a) and (b) by rural, minority, and underserved populations throughout the country; and

“(3) ensure that the grants are distributed among the principal geographic regions of the United States.

“(d) APPLICATION.—To be eligible to receive a grant under this section, an entity shall submit an application to the Director of the National Institute on Aging at such time, in such manner, and containing or accompanied by such information, as the Director may reasonably require, including, at a minimum, an assurance that the entity will coordinate programs provided under this section with the State agency designated under section 305(a)(1) of the Older Americans Act of 1965, in the State in which the entity will provide such programs.

“(e) COORDINATION.—The Director of the National Institute on Aging shall coordinate the award of grants under this section with the heads of other appropriate agencies, including the Commissioner of the Administration on Aging.”

(b) AUTHORIZATION OF APPROPRIATIONS.—Section 964 of such Act (42 U.S.C. 11294) is amended—

(1) by inserting “(a)” after “964.”;

(2) in subsection (a), as designated by paragraph (1) of this section, by striking “this part” and inserting “sections 961 and 963”; and

(3) by adding at the end the following new subsection:

“(b) There are authorized to be appropriated such sums as may be necessary for each of the fiscal years 1992 through 1996, to carry out section 962.”

SEC. 9. GRANTS FOR PROMOTING INDEPENDENCE AND PREVENTING SECONDARY DISABILITIES IN PERSONS WITH ALZHEIMER'S DISEASE.

Section 445C of the Public Health Service Act (42 U.S.C. 285e-5) is amended by adding at the end the following new subsection:

“(d) the Director of the Institute may develop, or make grants to develop—

“(1) model techniques to—

“(A) promote greater independence, including enhanced independence in performing activities of daily living and instrumental activities of daily living, for persons with Alzheimer's disease and related disorders; and

“(B) prevent or reduce the severity of secondary disabilities, including confusional episodes, falls, bladder and bowel incontinence, and adverse effects of prescription and over-the-counter medications, in such persons; and

"(2) model curricula for health care professionals, health care paraprofessionals, and family caregivers, for training and application in the use of such techniques."

Approved October 24, 1992.

LEGISLATIVE HISTORY—S. 1577:

SENATE REPORTS: No. 102-242 (Comm. on Labor and Human Resources).

CONGRESSIONAL RECORD:

Vol. 137 (1991): Nov. 26, considered and passed Senate.

Vol. 138 (1992): Oct. 5, considered and passed House, amended.

Oct. 7, Senate concurred in House amendment.