

National Alzheimer's Project Act

[Public Law 111–375]

[As Amended Through P.L. 118–93, Enacted October 1, 2024]

【Currency: This publication is a compilation of the text of Public Law 111–375. It was last amended by the public law listed in the As Amended Through note above and below at the bottom of each page of the pdf version and reflects current law through the date of the enactment of the public law listed at <https://www.govinfo.gov/app/collection/comps/>】

【Note: While this publication does not represent an official version of any Federal statute, substantial efforts have been made to ensure the accuracy of its contents. The official version of Federal law is found in the United States Statutes at Large and in the United States Code. The legal effect to be given to the Statutes at Large and the United States Code is established by statute (1 U.S.C. 112, 204).】

AN ACT To establish the National Alzheimer's Project.

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

SECTION 1. [42 U.S.C. 11201 note] SHORT TITLE.

This Act may be cited as the “National Alzheimer's Project Act”.

SEC. 2. [42 U.S.C. 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 on, 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) promotion of healthy aging and reduction and mitigation of risk factors for Alzheimer's;

(B) early diagnosis of Alzheimer's disease; and

(C) coordination of the care and treatment of citizens with Alzheimer's;

(5) ensure the inclusion of ethnic and racial populations and other underserved populations, including individuals with developmental disabilities such as Down syndrome, 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;

(6) provide information on, and promote the adoption of, healthy behaviors that may reduce the risk of cognitive decline and promote and protect cognitive health; and

(7) 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, across public and private sectors, in preparing for the escalating burden of Alzheimer's, including both implementation steps and recommendations for priority actions based on the assessment, including consideration of public-private collaborations, as appropriate.

(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.

(xi) A designee of the Department of Justice.

(xii) A designee of the Federal Emergency Management Agency.

(xiii) A designee of the Social Security Administration.

(xiv) 2 or more other designees, as determined by the Secretary of Health and Human Services, at least one of whom has expertise in risk factors associated

with the development or the progression of Alzheimer's.

(B) NON-FEDERAL MEMBERS.—In addition to the members outlined in subparagraph (A), the Advisory Council shall include 15 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) 3 researchers with Alzheimer's-related expertise in basic, translational, clinical, or drug development science, including at least one researcher with demonstrated experience in recruitment and retention of underrepresented groups into research or clinical trials related to dementia;
- (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;
- (vii) 1 individual with a diagnosis of Alzheimer's disease; and
- (viii) 1 representative from a historically underserved population whose lifetime risk for developing Alzheimer's is markedly higher than that of other populations.

(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) annual evaluations of all federally funded efforts in Alzheimer's research, risk reduction, public health, clinical care, and institutional-, home-, and community-based programs and their outcomes;

(B) recommendations for priority actions to expand, eliminate, coordinate, or condense programs based on the program's performance, mission, and purpose;

(C) 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 reduce disparities; and

(D) annual evaluations 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, 2035.

(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—

(A) an evaluation;¹ of all federally funded efforts in Alzheimer's research, clinical care, and institutional-, home-, and community-based programs and their outcomes; and

(B) a summary of the Secretary's process for identifying and updating what conditions constitute Alzheimer's disease;

(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 and reduce disparities;

(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) PROFESSIONAL JUDGMENT BUDGET.—For fiscal year 2024 and each subsequent fiscal year, 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, an annual budget estimate for the initiatives of the National Institutes of Health pursuant to the reports and recommendations made under this Act, including an estimate of the number and type of personnel needs for the National Institutes of Health.

¹ The semicolon in subparagraph (A) before "of all federally funded" is so in law. See amendment made by section 2(4)(A)(ii) of Public Law 118–92.

(i) SUNSET.—The Project shall expire on December 31, 2035.