118TH CONGRESS
2d Session
HOUSE OF REPRESENTATIVES
REPORT
118–526

NAPA REAUTHORIZATION ACT

MAY 24, 2024.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mrs. RODGERS of Washington, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 619]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 619) to extend the National Alzheimer's Project, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

CONTENTS

The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "NAPA Reauthorization Act".

SEC. 2. EXTENSION OF NATIONAL ALZHEIMER'S PROJECT.

(a) PURPOSE OF PROJECT.—Section 2(c) of the National Alzheimer's Project Act (42 U.S.C. 11225(c)) is amended—

(1) in paragraph (2), by striking "and coordination of" and inserting "on, and coordination of,";

(2) in paragraph (4)—

(A) by redesignating subparagraphs (A) and (B) as subparagraphs (B) and (C), respectively; and

(B) by inserting before subparagraph (B), as so redesignated, the following:

"(A) promotion of healthy aging and reduction and mitigation of risk factors for Alzheimer's;";

(3) in paragraph (5)—

(A) by inserting "and other underserved populations, including individuals with developmental disabilities such as Down syndrome," after "populations"; and

(B) by striking "; and" and inserting a semicolon;

(4) by redesignating paragraph (6) as paragraph (7); and

(5) by inserting after paragraph (5) the following:

"(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".

(b) NATIONAL PLAN.—Section 2(d)(2) of the National Alzheimer's Project Act (42 U.S.C. 11225(d)(2)) is amended—

(1) by inserting ", across public and private sectors," after "Nation's progress"; and

(2) by inserting ", including consideration of public-private collaborations, as appropriate" before the period at the end.

(c) ADVISORY COUNCIL.—Section 2(e) of the National Alzheimer's Project Act (42 U.S.C. 11225(e)) is amended—

(1) in paragraph (2)—

(A) in subparagraph (A), by adding at the end the following:

"(xi) A designee of the Department of Justice.

"(xii) A designee of the Social Security Administration.

"(xiii) A designee of the Federal Emergency Management Agency.

"(xiv) 2 or more other designees of the Department 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 disease, as determined by the Secretary of Health and Human Services."; and

(B) in subparagraph (B)—

(i) in the matter preceding clause (i), by striking "12" and inserting "14";

(ii) in clause (v)—

(I) by striking "2 researchers" and inserting "3 researchers"; and

(II) by striking "; and" and inserting ", including at least one researcher with demonstrated experience in recruitment and retention of underrepresented groups into research or clinical trials related to dementia;";

(iii) in clause (vi), by striking the period at the end and inserting "; and"; and

(iv) by adding at the end the following:

"(vii) 1 individual with a diagnosis of Alzheimer's disease.";

(2) in paragraph (5)—

(A) in subparagraph (A)—

(i) by striking "an initial evaluation" and inserting "annual evaluations"; and

(ii) by striking "research, clinical" and inserting "research, risk reduction, public health, clinical";

(B) in subparagraph (B), by striking "initial" and inserting "annual";

(C) in subparagraph (C)—

(i) in the matter preceding clause (i), by striking "initial" and inserting "annual"; and

(ii) in clause (ii), by inserting "and reduce disparities" before the semicolon at the end; and

(D) in subparagraph (D), by striking "annually thereafter, an evaluation" and inserting "annual evaluations"; and

(3) in paragraph (6), by striking "2025" and inserting "2035".

(d) ANNUAL REPORT.—Section 2(g) of the National Alzheimer's Project Act (42 U.S.C. 11225(g)) is amended—

(1) in paragraph (1)—

(A) by striking "that includes an evaluation" and inserting the following: "that includes—

"(A) an evaluation";

(B) in subparagraph (A) (as so designated), by adding "and" at the end; and

(C) by adding at the end the following:

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

(2) in paragraph (3)(A)(ii), by inserting "and reduce disparities" before the semicolon at the end.

(e) SUNSET.—Section 2(h) of the National Alzheimer's Project Act (42 U.S.C. 11225(h)) is amended by striking "2025" and inserting "2035".

PURPOSE AND SUMMARY

H.R. 619 reauthorizes the National Alzheimer's Project through 2035, while making changes to the project to support efforts to address Alzheimer's disease and related dementias. This bill promotes healthy aging by reducing risk factors associated with cognitive decline. In addition, this bill expands membership of the Advisory Council on Alzheimer's Research, Care, and Services to include individuals diagnosed with Alzheimer's disease, researchers with specific clinical trial experience, and representatives from certain federal agencies.

BACKGROUND AND NEED FOR LEGISLATION

The NAPA Reauthorization Act maintains the framework for the national strategic plan to prevent and treat Alzheimer's disease, while including key provisions that seek to improve the support that patients and caregivers receive. About 1 in 9 people aged 65 and older (10.7 percent) has Alzheimer's, and 1 in 3 seniors dies with Alzheimer's or another dementia.[1] Sixty percent of health care workers believe the U.S. health care system is not effectively helping patients and their families navigate dementia care.[2]

COMMITTEE ACTION

On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 619. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:

- Andy Shih, Ph.D., Chief Science Officer, Autism Speaks;
- Corey Feist, J.D., M.B.A., Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
- Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
- Gordon Tomaselli, M.D., Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;
- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and

[1] Alzheimer's Association, "Alzheimer's Disease Facts and Figures", 2024. https://www.alz.org/alzheimers-dementia/facts-figures.

[2] *Id*.

• Christina Annunziata, M.D., Ph.D., Senior Vice President of Extramural Discovery Science, American Cancer Society.

On March 12, 2024, the Subcommittee on Health met in open markup session and forwarded H.R. 619, as amended, to the full Committee by a record vote of 26 yeas and 0 nays.

On March 20, 2024, the full Committee on Energy and Commerce met in open markup session and ordered H.R. 619, as amended, favorably reported to the House by a record vote of 43 yeas and 0 nays.

COMMITTEE VOTES

Clause 3(b) of rule XIII requires the Committee to list the record votes on the motion to report legislation and amendments thereto. The following reflects the record votes taken during the Committee consideration:

COMMITTEE ON ENERGY AND COMMERCE
118TH CONGRESS
ROLL CALL VOTE # 5

BILL: H.R. 619, NAPA Reauthorization Act

AMENDMENT: A motion by Chair Rodgers to order H.R. 619 favorably reported to the House, as amended. (Final Passage)

DISPOSITION: AGREED TO, by a roll call vote of 43 yeas to 0 nays.

REPRESENTATIVE	YEAS	NAYS	PRESENT	REPRESENTATIVE	YEAS	NAYS	PRESENT
Rep. Rodgers	X			Rep. Pallone	X		
Rep. Burgess	X			Rep. Eshoo	X		
Rep. Latta	X			Rep. DeGette	X		
Rep. Guthrie	X			Rep. Schakowsky	X		
Rep. Griffith	X			Rep. Matsui	X		
Rep. Bilirakis	X			Rep. Castor	X		
Rep. Bucshon	X			Rep. Sarbanes	X		
Rep. Hudson				Rep. Tonko	X		
Rep. Walberg	X			Rep. Clarke	X		
Rep. Carter				Rep. Cárdenas	X		
Rep. Duncan	X			Rep. Ruiz	X		
Rep. Palmer	X			Rep. Peters	X		
Rep. Dunn	X			Rep. Dingell	X		
Rep. Curtis				Rep. Veasey	X		
Rep. Lesko	X			Rep. Kuster	X		
Rep. Pence	X			Rep. Kelly			
Rep. Crenshaw	X			Rep. Barragán	X		
Rep. Joyce	X			Rep. Blunt Rochester			
Rep. Armstrong	X			Rep. Soto	X		
Rep. Weber				Rep. Craig	X		
Rep. Allen	X			Rep. Schrier	X		
Rep. Balderson	X			Rep. Trahan	X		
Rep. Fulcher	X			Rep. Fletcher	X		
Rep. Pfluger							
Rep. Harshbarger	X						
Rep. Miller-Meeks							
Rep. Cammack	X						
Rep. Obernolte	X						

03/20/2024

OVERSIGHT FINDINGS AND RECOMMENDATIONS

Pursuant to clause 2(b)(1) of rule X and clause 3(c)(1) of rule XIII, the Committee held a hearing and made findings that are reflected in this report.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to clause 3(c)(2) of rule XIII, the Committee finds that H.R. 619 would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII, at the time this report was filed, the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974 was not available.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to reauthorize the National Alzheimer's Project though 2035 and to make certain modifications to the Project structure, including the Project's purpose and the composition of the Advisory Council on Alzheimer's Research, Care and Services by expanding the membership and its reporting requirements.

DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 619 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111–139 or the most recent Catalog of Federal Domestic Assistance.

RELATED COMMITTEE AND SUBCOMMITTEE HEARINGS

Pursuant to clause 3(c)(6) of rule XIII, the following related hearing was used to develop or consider H.R. 619:

- On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 619. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:
  - Andy Shih, PhD, Chief Science Officer, Autism Speaks;
  - Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
  - Joanne Pike, DrPH, President and CEO, Alzheimer's Association;

- Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;
- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974. At the time this report was filed, the estimate was not available.

EARMARK, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 619 contains no earmarks, limited tax benefits, or limited tariff benefits.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 provides that the Act may be cited as the "NAPA Reauthorization Act".

Section 2. Extension of National Alzheimer's Project

Section 2 amends Section 2 of the National Alzheimer's Project Act by extending the program through 2035, as well as including preventative approaches within the purpose of the project and making certain modifications to the Advisory Council on Alzheimer's Research, Care, and Services.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics,

and existing law in which no change is proposed is shown in roman):

NATIONAL ALZHEIMER'S PROJECT ACT

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SEC. 2. 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] *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;

[(A)] *(B)* early diagnosis of Alzheimer's disease; and

[(B)] *(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[; and]*;*

(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

[(6)] *(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 Social Security Administration.

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

(xiv) 2 or more other designees of the Department 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 disease, as determined by the Secretary of Health and Human Services.

(B) NON-FEDERAL MEMBERS.—In addition to the members outlined in subparagraph (A), the Advisory Council shall include [12] *14* 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] *3 researchers* with Alzheimer's-related expertise in basic, translational, clinical, or drug development science[; and], *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[.]*; and*

(vii) 1 individual with a diagnosis of Alzheimer's disease.

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

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

(C) [initial] *annual* 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) [annually thereafter, an evaluation] *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, [2025] *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 an evaluation] *that includes—*

(A) an evaluation 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) SUNSET.—The Project shall expire on December 31, **[**2025**]** *2035*.

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