

115TH CONGRESS 1ST SESSION

H. R. 4256

To amend the Public Health Service Act to authorize the expansion of activities related to Alzheimer's disease, cognitive decline, and brain health under the Alzheimer's Disease and Healthy Aging Program, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 6, 2017

Mr. Guthrie (for himself, Mr. Tonko, Ms. Maxine Waters of California, and Mr. Smith of New Jersey) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to authorize the expansion of activities related to Alzheimer's disease, cognitive decline, and brain health under the Alzheimer's Disease and Healthy Aging Program, and for other purposes.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Building Our Largest
- 5 Dementia Infrastructure for Alzheimer's Act" or the
- 6 "BOLD Infrastructure for Alzheimer's Act".

1 SEC. 2. FINDINGS.

- 2 Congress finds as follows:
- 3 (1) According to former Surgeon General and 4 Director of the Centers for Disease Control and Pre-5 vention, Dr. David Satcher, "Alzheimer's is the most 6 under-recognized threat to public health in the 21st 7 century.".
 - (2) Deaths from Alzheimer's disease increased 55 percent between 1999 and 2014 in the United States, according to data from the Centers for Disease Control and Prevention.
 - (3) More than 5,000,000 people in the United States are living with Alzheimer's disease and, without significant efforts to change the current trajectory, as many as 16,000,000 people in the United States will have Alzheimer's disease by 2050. This explosive growth will cause costs associated with Alzheimer's disease to increase from an estimated \$259,000,000,000 in 2017 to more than \$1,100,000,000,000,000 in 2050 (in 2017 dollars).
 - (4) Among individuals living with Alzheimer's disease and other dementias, evidence indicates as many as 50 percent have not been diagnosed. Among individuals diagnosed with Alzheimer's disease, only 33 percent are aware of the diagnosis. Early detection and diagnosis of Alzheimer's disease

- and other dementias allow people to access available treatments, build a care team, participate in support services, and enroll in clinical trials. Early detection can help physicians better manage a patient's comorbid conditions and avoid prescribing medications that may worsen cognition or function.
 - (5) Among individuals living with Alzheimer's disease and other dementias, 25.3 percent experience a preventable hospitalization, and such preventable hospitalizations cost the Medicare program nearly \$2,600,000,000 in 2013.
 - (6) African Americans are about 2 times more likely than White Americans to have Alzheimer's disease and other dementias. Hispanics are about one and one-half times more likely than White Americans to have Alzheimer's disease and other dementias.
 - (7) In 2016, 15,900,000 family members and friends provided 18,200,000,000 hours of unpaid care to individuals with Alzheimer's disease and other dementias, at an economic value of over \$230,000,000,000. The physical and emotional impact of caregiving of individuals with Alzheimer's disease and other dementia resulted in an estimated

1	\$10,900,000,000 in increased caregiver health costs
2	in 2016.
3	(8) Strategy 4.B of the "National Plan to Ad-
4	dress Alzheimer's Disease: 2017 Update" of the Of-
5	fice of the Assistant Secretary for Planning and
6	Evaluation of the Department of Health and Human
7	Services is to "work with State, Tribal, and local
8	governments to improve coordination and identify
9	model initiatives to advance Alzheimer's disease
10	awareness and readiness across the Government.".
11	SEC. 3. PROMOTION OF PUBLIC HEALTH KNOWLEDGE AND
12	AWARENESS OF ALZHEIMER'S DISEASE, COG-
13	NITIVE DECLINE, AND BRAIN HEALTH UNDER
14	THE ALZHEIMER'S DISEASE AND HEALTHY
1 1	
	AGING PROGRAM.
15	AGING PROGRAM. Part P of title III of the Public Health Service Act
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115 116 117 118 119 220	Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.) is amended by adding at the end the following: "SEC. 399V-7. PROMOTION OF PUBLIC HEALTH KNOWL-
15 16 17 18	Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.) is amended by adding at the end the following: "SEC. 399V-7. PROMOTION OF PUBLIC HEALTH KNOWLEDGE AND AWARENESS OF ALZHEIMER'S DIS-
15 16 17 18 19 20 21	Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.) is amended by adding at the end the following: "SEC. 399V-7. PROMOTION OF PUBLIC HEALTH KNOWLEDGE AND AWARENESS OF ALZHEIMER'S DISEASE, COGNITIVE DECLINE, AND BRAIN

1	"(1) Alzheimer's disease.—The term 'Alz-
2	heimer's disease' means Alzheimer's disease and re-
3	lated dementias.
4	"(2) Indian tribe; tribal organization.—
5	The terms 'Indian tribe' and 'tribal organization'
6	have the meanings given such terms in section 4 of
7	the Indian Health Care Improvement Act.
8	"(b) Expansion of Activities Under the Alz-
9	HEIMER'S DISEASE AND HEALTHY AGING PROGRAM.—In
10	addition to activities conducted by the Secretary under the
11	Alzheimer's Disease and Healthy Aging Program of the
12	Centers for Disease Control and Prevention, the Sec-
13	retary, acting through the Director of the Centers for Dis-
14	ease Control and Prevention, subject to appropriations
15	under subsection (g), shall award cooperative agreements
16	under subsections (e), (d), and (e).
17	"(c) Centers of Excellence in Public Health
18	Practice.—
19	"(1) In General.—The Secretary shall award
20	cooperative agreements to eligible entities for the es-
21	tablishment or support of national or regional cen-
22	ters of excellence in public health practice in Alz-
23	heimer's disease to—
24	"(A) advance the education of public
25	health officials of States, of political subdivi-

sions of States, and of Indian tribes or tribal organizations, health care professionals, and the public on Alzheimer's disease, cognitive decline, brain health, and associated health disparities;

- "(B) advance the efforts of public health officials referred to in subparagraph (A) in applying evidence-based systems change, communications, and programmatic interventions for populations with cognitive impairment, including Alzheimer's disease, and caregivers for such populations; and
- "(C) expand public-private partnerships engaged in activities related to cognitive impairment and associated health disparities with demonstrated success or innovative programs (as determined by the Secretary).
- "(2) Requirements.—To be eligible to receive a cooperative agreement under this subsection, an entity shall submit to the Secretary an application containing such agreements and information as the Secretary may require, including an agreement that the center to be established or supported under the cooperative agreement will operate in accordance with the following:

1	"(A) The center will examine, evaluate, in-
2	crease, and promote evidence-based and effec-
3	tive Alzheimer's disease and caregiving-related
4	interventions for health and social services pro-
5	fessionals, underserved populations, families
6	and the public, after consultation with relevant
7	State and local public health officials, private-
8	sector Alzheimer's disease researchers, and ad-
9	vocates for individuals with Alzheimer's disease
10	"(B) The center will prioritize its activities
11	on the following:
12	"(i) Expanding efforts to educate
13	State, local, and tribal officials and public
14	health professionals in applying established
15	data and evidence-based best practices to
16	address Alzheimer's disease.
17	"(ii) Supporting public health officials
18	of States, of political subdivisions of
19	States, and of Indian tribes or tribal orga-
20	nizations in implementing the most current
21	version of the 'Healthy Brain Initiative
22	Public Health Road Map' of the Centers
23	for Disease Control and Prevention.
24	"(iii) Supporting early detection and
25	diagnosis of Alzheimer's disease.

1	"(iv) Reducing the risk of potentially
2	avoidable hospitalizations of individuals
3	with Alzheimer's disease.
4	"(v) Reducing the risk of cognitive de-
5	cline and cognitive impairment, including
6	Alzheimer's disease.
7	"(vi) Enhancing support to meet the
8	needs of caregivers of individuals with Alz-
9	heimer's disease.
10	"(vii) Reducing health disparities re-
11	lated to the care and support of individuals
12	with cognitive decline and Alzheimer's dis-
13	ease.
14	"(viii) Supporting care planning and
15	management for individuals with Alz-
16	heimer's disease.
17	"(3) Considerations.—In awarding coopera-
18	tive agreements under this subsection, the Secretary
19	shall consider, among other factors, whether the en-
20	tity—
21	"(A) has access to rural areas or other un-
22	derserved populations;
23	"(B) is located in an area where the aggre-
24	gate success rate for applications for National

1	Institutes of Health funding has been histori-
2	cally low;
3	"(C) is able to build on an existing infra-
4	structure of service and public health research;
5	"(D) has experience with providing care,
6	caregiver support, and research related to Alz-
7	heimer's disease; and
8	"(E) is integrated into existing local gov-
9	ernment and public health infrastructures.
10	"(4) Distribution of Awards.—In awarding
11	cooperative agreements under this subsection, the
12	Secretary, to the extent practicable, shall ensure eq-
13	uitable distribution of awards based on geographic
14	area, including consideration of rural areas, and the
15	burden of the disease on sub-populations.
16	"(d) Cooperative Agreements to Public
17	HEALTH DEPARTMENTS.—
18	"(1) In general.—The Secretary shall award
19	cooperative agreements to health departments of
20	States, of political subdivisions of States, and of In-
21	dian tribes and tribal organizations to promote cog-
22	nitive functioning, address cognitive impairment for
23	individuals living in such communities, help meet the
24	needs of caregivers, and address unique aspects of
25	Alzheimer's disease as follows:

1	"(A) The Secretary shall award core ca-
2	pacity cooperative agreements to such health
3	departments to support the development and
4	implementation of systems change, communica-
5	tions, and programmatic interventions with re-
6	spect to Alzheimer's disease, including activities
7	involving—
8	"(i) educating and informing the pub-
9	lic based on established public health re-
10	search and data;
11	"(ii) supporting early detection and
12	diagnosis;
13	"(iii) reducing the risk of potentially
14	avoidable hospitalizations;
15	"(iv) reducing the risk of cognitive de-
16	cline and cognitive impairment;
17	"(v) enhancing support to meet the
18	needs of caregivers;
19	"(vi) supporting care planning and
20	management; or
21	"(vii) supporting the actions set forth
22	in the most current version of the 'Healthy
23	Brain Initiative: Public Health Road Map'
24	of the Centers for Disease Control and
25	Prevention.

1	"(B) The Secretary shall award not less
2	than 5 enhanced activity cooperative agree-
3	ments to such health departments to carry out
4	activities related to Alzheimer's disease, includ-
5	ing through public-private partnerships with or-
6	ganizations or other agencies, such as large em-
7	ployers, public housing agencies, large health
8	care systems, and parks and recreation depart-
9	ments, that include—
10	"(i) expanding implementation of pro-
11	grams described in paragraph (2)(A) to
12	reach larger segments of the population;
13	and
14	"(ii) implementing the reports de-
15	scribed in subparagraph (A)(vii).
16	"(2) Other considerations.—
17	"(A) Preference.—In awarding coopera-
18	tive agreements under paragraph (1), the Sec-
19	retary shall give preference to applications that
20	focus on addressing health disparities, including
21	populations and geographic areas that are most
22	in need of intervention.
23	"(B) CLARIFICATION ON ENHANCED AC-
24	TIVITY COOPERATIVE AGREEMENTS.—If the
25	Secretary is unable to identify 5 eligible health

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departments to receive a cooperative agreement under paragraph (1)(B), the Secretary shall allocate any amounts reserved for such agreements to additional cooperative agreements under paragraph (1)(A).

"(3) ELIGIBILITY.—To be eligible to receive a cooperative agreement under paragraph (1), a State, political subdivision of a State, Indian tribe, or tribal organization shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including a plan that describes—

"(A) how the applicant proposes to develop or expand, programs to educate individuals through partnership engagement, workforce development, guidance and support for programmatic efforts, strategic communication, and evaluation with respect to Alzheimer's disease, and in the case of a cooperative agreement under paragraph (1)(B), how the applicant proposes to implement the most current version of the 'Healthy Brain Initiative: Public Health Road Map' of the Centers for Disease Control and Prevention;

1	"(B) the manner in which the applicant
2	will coordinate with appropriate State and local
3	authorities as well as, in the case of a coopera-
4	tive agreement under paragraph (1)(B), rel-
5	evant public and private organizations or agen-
6	cies; and
7	"(C) the manner in which the applicant
8	will evaluate the effectiveness of any program
9	carried out under the cooperative agreement.
10	"(4) Use of funds.—A health department
11	awarded a cooperative agreement under paragraph
12	(1) shall use amounts received under such coopera-
13	tive agreement to—
14	"(A) develop, implement, disseminate,
15	evaluate, and if applicable, expand programs to
16	educate individuals on matters related to Alz-
17	heimer's disease described in paragraph (1)(A);
18	and
19	"(B) in the case of a cooperative agree-
20	ment under paragraph (1)(B), implement the
21	most current version of the 'Healthy Brain Ini-
22	tiative: Public Health Road Map' of the Centers
23	for Disease Control and Prevention and evalu-
24	ate its implementation.
25	"(5) Matching requirement.—

1	"(A) In general.—Except as may be pro-
2	vided in subparagraph (B), each health depart-
3	ment that is awarded a cooperative agreement
4	under paragraph (1) shall provide, from non-
5	Federal sources, an amount equal to 15 percent
6	of the amount provided under such agreement
7	(which may be provided in cash or in-kind) to
8	carry out the activities supported by the cooper-
9	ative agreement.
10	"(B) WAIVER AUTHORITY.—The Secretary
11	may waive all or part of the matching require-
12	ment described in subparagraph (A) for any fis-
13	cal year for—
14	"(i) a health department, if the Sec-
15	retary determines that applying such
16	matching requirement to the health depart-
17	ment would result in serious hardship or
18	an inability to carry out the purposes of
19	the cooperative agreement awarded to such
20	health department; or
21	"(ii) a rural or frontier region.
22	"(e) Cooperative Agreements for Analysis and
23	REPORTING OF DATA REGARDING COGNITIVE DECLINE
24	AND CAREGIVING.—

- 1 "(1) IN GENERAL.—The Secretary may award 2 cooperative agreements to eligible entities for the fol-3 lowing activities:
 - "(A) The analysis and timely public reporting of data on the State and national levels regarding cognitive decline, including Alzheimer's disease, caregiving, and health disparities experienced by individuals with cognitive decline and their caregivers.
 - "(B) The monitoring of objectives on dementia, including Alzheimer's disease, and caregiving in the program of the Secretary regarding health-status goals for 2020 (commonly referred to as the 'Healthy People 2020 report'), and the development and monitoring of such objectives in future Healthy People reports of the Department of Health and Human Services.
 - "(2) ELIGIBILITY.—To be eligible to receive a cooperative agreement under this subsection, an entity shall be a public or nonprofit private entity, including institutions of higher education, and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

1	"(3) Surveillance.—The analysis, timely
2	public reporting, and dissemination of data regard-
3	ing cognitive decline, cognitive impairment, caregiv-
4	ing, and health disparities on the State and national
5	levels under a cooperative agreement under this sub-
6	section may be carried out by eligible entities using
7	data sources such as the following:
8	"(A) The Behavioral Risk Factor Surveil-
9	lance System.
10	"(B) The National Health and Nutrition
11	Examination Survey.
12	"(C) The National Health Interview Sur-
13	vey.
14	"(f) DATA COLLECTION.—The Secretary shall collect
15	data on cognitive decline, cognitive impairment, caregiv-
16	ing, and health disparities on the State and national levels,
17	using the surveillance systems described in subparagraphs
18	(A) through (C) of subsection (e)(3).
19	"(g) Nonduplication of Effort.—The Secretary
20	shall ensure that activities under any cooperative agree-
21	ment awarded under this section do not unnecessarily du-
22	plicate efforts of other agencies and offices within the De-
23	partment of Health and Human Services related to—

1	"(1) activities of centers of excellence in public
2	health practice with respect to Alzheimer's disease
3	described in subsection (c);
4	"(2) activities of public health departments with
5	respect to Alzheimer's disease described in sub-
6	section (d); or
7	"(3) the analysis and public reporting of sur-
8	veillance data on cognitive decline, caregiving, and
9	health disparities of individuals with Alzheimer's dis-
10	ease under subsection (e).
11	"(h) Authorization of Appropriations.—For
12	each of fiscal years 2018 through 2025, there are author-
13	ized to be appropriated \$12,000,000 for purposes of car-
14	rying out subsection (c), \$20,000,000 for purposes of car-
15	rying out subsection (d), and \$5,000,000 for purposes of
16	carrying out subsections (e) and (f). Funds appropriated
17	under this subsection shall remain available until ex-
18	pended.".