

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.

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## 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

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## 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.”.

8 (2) Deaths from Alzheimer’s disease increased  
9 55 percent between 1999 and 2014 in the United  
10 States, according to data from the Centers for Dis-  
11 ease Control and Prevention.

12 (3) More than 5,000,000 people in the United  
13 States are living with Alzheimer’s disease and, with-  
14 out significant efforts to change the current trajec-  
15 tory, as many as 16,000,000 people in the United  
16 States will have Alzheimer’s disease by 2050. This  
17 explosive growth will cause costs associated with Alz-  
18 heimer’s disease to increase from an estimated  
19 \$259,000,000,000 in 2017 to more than  
20 \$1,100,000,000,000 in 2050 (in 2017 dollars).

21 (4) Among individuals living with Alzheimer’s  
22 disease and other dementias, evidence indicates as  
23 many as 50 percent have not been diagnosed.  
24 Among individuals diagnosed with Alzheimer’s dis-  
25 ease, only 33 percent are aware of the diagnosis.  
26 Early detection and diagnosis of Alzheimer’s disease

1 and other dementias allow people to access available  
2 treatments, build a care team, participate in support  
3 services, and enroll in clinical trials. Early detection  
4 can help physicians better manage a patient's co-  
5 morbid conditions and avoid prescribing medications  
6 that may worsen cognition or function.

7 (5) Among individuals living with Alzheimer's  
8 disease and other dementias, 25.3 percent experience  
9 a preventable hospitalization, and such preventable  
10 hospitalizations cost the Medicare program nearly  
11 \$2,600,000,000 in 2013.

12 (6) African Americans are about 2 times more  
13 likely than White Americans to have Alzheimer's dis-  
14 ease and other dementias. Hispanics are about one  
15 and one-half times more likely than White Ameri-  
16 cans to have Alzheimer's disease and other demen-  
17 tias.

18 (7) In 2016, 15,900,000 family members and  
19 friends provided 18,200,000,000 hours of unpaid  
20 care to individuals with Alzheimer's disease and  
21 other dementias, at an economic value of over  
22 \$230,000,000,000. The physical and emotional im-  
23 pact of caregiving of individuals with Alzheimer's  
24 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**  
15 **AGING PROGRAM.**

16 Part P of title III of the Public Health Service Act  
17 (42 U.S.C. 280g et seq.) is amended by adding at the end  
18 the following:

19 **“SEC. 399V-7. PROMOTION OF PUBLIC HEALTH KNOWL-**  
20 **EDGE AND AWARENESS OF ALZHEIMER’S DIS-**  
21 **EASE, COGNITIVE DECLINE, AND BRAIN**  
22 **HEALTH UNDER THE ALZHEIMER’S DISEASE**  
23 **AND HEALTHY AGING PROGRAM.**

24 “(a) DEFINITIONS.—In the section:

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 (c), (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-

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

5           “(B) advance the efforts of public health  
6           officials referred to in subparagraph (A) in ap-  
7           plying evidence-based systems change, commu-  
8           nications, and programmatic interventions for  
9           populations with cognitive impairment, includ-  
10          ing Alzheimer’s disease, and caregivers for such  
11          populations; and

12          “(C) expand public-private partnerships  
13          engaged in activities related to cognitive impair-  
14          ment and associated health disparities with  
15          demonstrated success or innovative programs  
16          (as determined by the Secretary).

17          “(2) REQUIREMENTS.—To be eligible to receive  
18          a cooperative agreement under this subsection, an  
19          entity shall submit to the Secretary an application  
20          containing such agreements and information as the  
21          Secretary may require, including an agreement that  
22          the center to be established or supported under the  
23          cooperative agreement will operate in accordance  
24          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           capacity 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

1 departments to receive a cooperative agreement  
2 under paragraph (1)(B), the Secretary shall al-  
3 locate any amounts reserved for such agree-  
4 ments to additional cooperative agreements  
5 under paragraph (1)(A).

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

13 “(A) how the applicant proposes to develop  
14 or expand, programs to educate individuals  
15 through partnership engagement, workforce de-  
16 velopment, guidance and support for pro-  
17 grammatic efforts, strategic communication,  
18 and evaluation with respect to Alzheimer’s dis-  
19 ease, and in the case of a cooperative agree-  
20 ment under paragraph (1)(B), how the appli-  
21 cant proposes to implement the most current  
22 version of the ‘Healthy Brain Initiative: Public  
23 Health Road Map’ of the Centers for Disease  
24 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:

4           “(A) The analysis and timely public re-  
5 porting of data on the State and national levels  
6 regarding cognitive decline, including Alz-  
7 heimer’s disease, caregiving, and health dispari-  
8 ties experienced by individuals with cognitive  
9 decline and their caregivers.

10           “(B) The monitoring of objectives on de-  
11 mentia, including Alzheimer’s disease, and  
12 caregiving in the program of the Secretary re-  
13 garding health-status goals for 2020 (commonly  
14 referred to as the ‘Healthy People 2020 re-  
15 port’), and the development and monitoring of  
16 such objectives in future Healthy People reports  
17 of the Department of Health and Human Serv-  
18 ices.

19           “(2) ELIGIBILITY.—To be eligible to receive a  
20 cooperative agreement under this subsection, an en-  
21 tity shall be a public or nonprofit private entity, in-  
22 cluding institutions of higher education, and submit  
23 to the Secretary an application at such time, in such  
24 manner, and containing such information as the Sec-  
25 retary 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.”.

○