



**HEALTHYBRAIN
INITIATIVE**

State and Local Public Health
Partnerships to Address Dementia:
The 2018-2023 Road Map



alzheimer's 
association®

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Healthy Brain Initiative: The Road Map for Indian Country

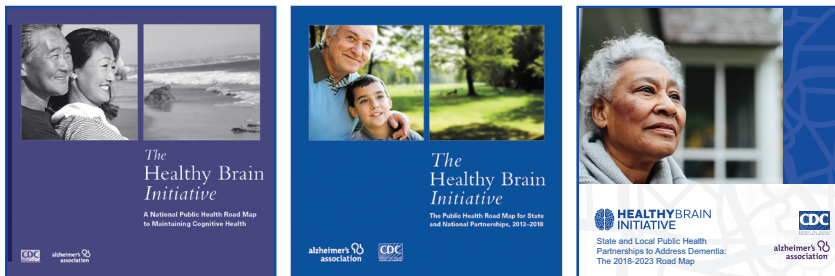
This Road Map focuses on issues pertinent to state and local public health agencies and their partners.

A companion Healthy Brain Initiative: The Road Map for Indian Country has been designed specifically for public health systems serving American Indians and Alaska Natives.

INTRODUCTION

The Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC) have developed the third in a series of Healthy Brain Initiative Road Maps to advance cognitive health as an integral component of public health (see Section IV). This Healthy Brain Initiative *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Twenty-five specific actions are proposed in four traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate. This “action agenda” speaks to critical issues of risk identification and risk reduction, diagnosis, education and training, caregivers, and evidence on impact of the disease. Twenty-one of the 25 actions are rooted in the second Road Map, *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.

Even as new initiatives are pursued, the need for continued attention to earlier identified priorities remains. Collectively, the action agenda provides a solid foundation for the public health community to anticipate and respond to the growing impact of Alzheimer’s and other dementias on every facet of society. The vision is for state and local public health agencies to continue strengthening their capacity, building strong state and local partnerships, and integrating cognitive health into ongoing public health efforts. Moving forward, changes to policies, systems, and environments should be considered to make progress in reducing risk for cognitive decline and optimizing the health, well-being, and functioning of people living with dementia and their caregivers. ●



The first Healthy Brain Initiative Road Map was published in 2007, *A National Public Health Road Map to Maintaining Cognitive Health*. Six years later, the second edition was released, *The Public Health Road Map for State and National Partnerships, 2013-2018*. This edition—*State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*—marks the third in this series.

ACTION AGENDA



EDUCATE & EMPOWER

E-1 Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis.

E-2 Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span.

E-3 Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.

E-4 Promote prevention of abuse, neglect, and exploitation of people with dementia.

E-5 Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.

E-6 Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia.

E-7 Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.



DEVELOP POLICIES & MOBILIZE PARTNERSHIPS

P-1 Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.

P-2 Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about brain health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces.

P-3 Support better informed decisions by educating policymakers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem.

P-4 Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes.

P-5 Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.

P-6 Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.



ASSURE A COMPETENT WORKFORCE

W-1 Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve.

W-2 Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.

W-3 Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.

W-4 Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.

W-5 Strengthen the competencies of professionals who deliver healthcare and other care services to people with dementia through interprofessional training and other strategies.

W-6 Educate healthcare professionals about the importance of treating co-morbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia.

W-7 Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.



MONITOR & EVALUATE

M-1 Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.

M-2 Support national data collection on dementia and caregiving.

M-3 Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.

M-4 Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.

M-5 Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.

This action agenda provides 25 ways that state and local public health agencies and their partners can pursue goals of the Healthy Brain Initiative.



GLOSSARY

ALZHEIMER'S DISEASE: an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

ALZHEIMER'S DEMENTIA: the dementia stage in the Alzheimer's continuum.

BRAIN HEALTH: a concept that involves making the most of the brain's capacity and helping to reduce some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.

CAREGIVER: spouses, partners, adult children, other relatives, and friends providing unpaid help to people living with dementia who have at least one limitation in their activities of daily living and reside in the community. Caregivers often assist with diverse activities of daily living such as personal care, household management, medication and healthcare management, and coordination of financial matters.

COGNITION: the mental functions involved in attention, thinking, understanding, learning, remembering, solving problems, and making decisions. Cognition is a fundamental aspect of an individual's ability to engage in activities, accomplish

goals, and successfully negotiate the world. It can be viewed along a continuum—from optimal functioning to mild cognitive impairment to Alzheimer's and severe dementia.

COGNITIVE IMPAIRMENT: trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.

DEMENTIA: the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities. These functions include memory, language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention. Alzheimer's is the most common cause of dementia. Other types include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

MILD COGNITIVE IMPAIRMENT: a slight but measurable decline in cognitive abilities that includes memory and thinking. A person with mild cognitive impairment is at an increased risk of developing Alzheimer's or another dementia.

SUBJECTIVE COGNITIVE DECLINE: self-reported confusion or memory loss that is happening more often or is getting worse.

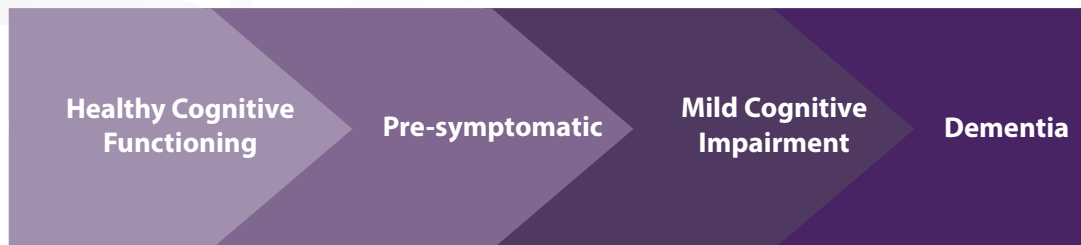


DEMENTIA: A LIFE COURSE APPROACH

Dementia is a general term used to describe symptoms characterized by the loss of cognitive function. Alzheimer's is the most common cause of dementia, accounting for 60–80% of dementia cases.¹ Other types include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Alzheimer's disease is a chronic condition that progressively damages and eventually destroys brain cells.

The course of Alzheimer's disease and other dementias should be viewed as a continuum across the life course (see Figure 1) that begins with **healthy cognitive functioning**. Over many years, physiological changes occur in the brain that are **pre-symptomatic** but eventually can result in **mild cognitive impairment**, when changes in memory or thinking become noticeable to persons affected, loved ones, colleagues, and friends. While a person with mild cognitive impairment is at greater risk of developing dementia, this is not inevitable. There is growing scientific evidence that healthy behaviors, which have been shown to prevent cancer, diabetes, and cardiovascular disease, also may reduce risk for cognitive decline and possibly dementia. A portion of people with mild cognitive impairment eventually develop dementia.

Figure 1. Life Course Perspective on Alzheimer's and Other Dementias



Dementia occurs along a continuum. While most older adults have healthy cognitive functioning, some will experience pre-symptomatic changes in the brain that may eventually lead to cognitive impairment or dementia. In dementia, symptoms become noticeable and the disruption to cognition and everyday life can range from mild to severe.

The symptoms of Alzheimer's and other dementias worsen over time, although the rate at which the disease progresses varies. In the **early stage of Alzheimer's dementia**, for example, a person may function independently, still drive, work, and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects. The **moderate stage of Alzheimer's dementia** is for some the longest stage and can last for many years. During the moderate stage, people may have greater difficulty performing tasks such as paying bills, but they may still remember significant details about their life. As this stage evolves, people may have more trouble communicating and experience mood or behavior changes. They may also have trouble with activities of

daily living such as managing medications, dressing, and bathing. In the **final or severe stage** of this disease, as more neurons involved in cognitive and physical functioning are damaged or destroyed, people lose the ability to respond to their environment, have a conversation and, eventually, control movement. They may become bed-bound and require around-the-clock care. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors. ●

ABOUT ALZHEIMER'S TERMINOLOGY

Traditionally, Alzheimer's disease has been synonymous with dementia. Healthcare providers often would not diagnose Alzheimer's unless a person had certain cognitive and behavioral symptoms associated with dementia. Diagnoses might be delayed for months or years as providers not only ruled out other potential sources of the symptoms but also observed whether dementia-associated symptoms worsened.

Now, researchers are adopting a diagnostic framework in which Alzheimer's disease is identified based on biological changes in the brain and body, even if no symptoms are present. This is because accumulating evidence suggests that dementia is just one stage in the continuum of the Alzheimer's disease process. The continuum begins with disease onset and the resulting biological changes that occur without any noticeable decline in cognitive functioning, before progressing over time to mild cognitive impairment with detectable symptoms. Then, at the dementia stage of the Alzheimer's continuum, symptoms related to cognitive decline and decline of physical function emerge and worsen, progressing from mild to severe.

This Road Map applies new terminology to align with current scientific understanding. "Alzheimer's disease" refers either to the underlying disease or the entire continuum of the disease. The terms "Alzheimer's dementia" or "dementia due to Alzheimer's" describe the dementia stage in the continuum. This terminology change is consistent with the 2018 research framework from the National Institute on Aging and

10 Early Signs and Symptoms of Alzheimer's Disease

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work, or at leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relations
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

the Alzheimer's Association that proposes a shift in terminology for research use.*

* Jack CR, Bennett DA, Blennow K, Carrillo MC, Dunn B, Haeberlein SB & Liu, E. (2018). NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 14(4), 535-562.



A GROWING CRISIS

A review of recent data reveals rapidly increasing trends in the number of people with dementia and associated healthcare costs. Accompanying these trends is the growing challenge to family and friends who are caring for others over extended periods of time.

Alzheimer's is increasingly understood as a disease that spans many years, with biological changes occurring decades prior to symptom onset.

- » Alzheimer's disease is the sixth leading cause of death in the U.S., and the fifth leading cause of death for those aged 65 and older.¹
- » Although deaths from other major causes have decreased significantly, records indicate that deaths from Alzheimer's disease have increased significantly.
- » Nearly six million Americans are living with Alzheimer's dementia.¹ By 2050, this number is projected to reach nearly 14 million.¹
- » Younger-onset (also known as early-onset) Alzheimer's dementia affects an estimated 200,000 people younger than age 65.¹
- » The science related to Alzheimer's and other dementias is rapidly evolving. Gaps remain, but best available evidence indicates that opportunities may exist to lessen the burden of the disease on the U.S. population.

Older adults with Alzheimer’s and other dementias are more likely than other older adults to have multiple chronic conditions.

- » More than 95% of people with dementia have one or more other chronic conditions.²
- » Alzheimer’s complicates the management of these other conditions, resulting in increased hospitalizations and costs.³

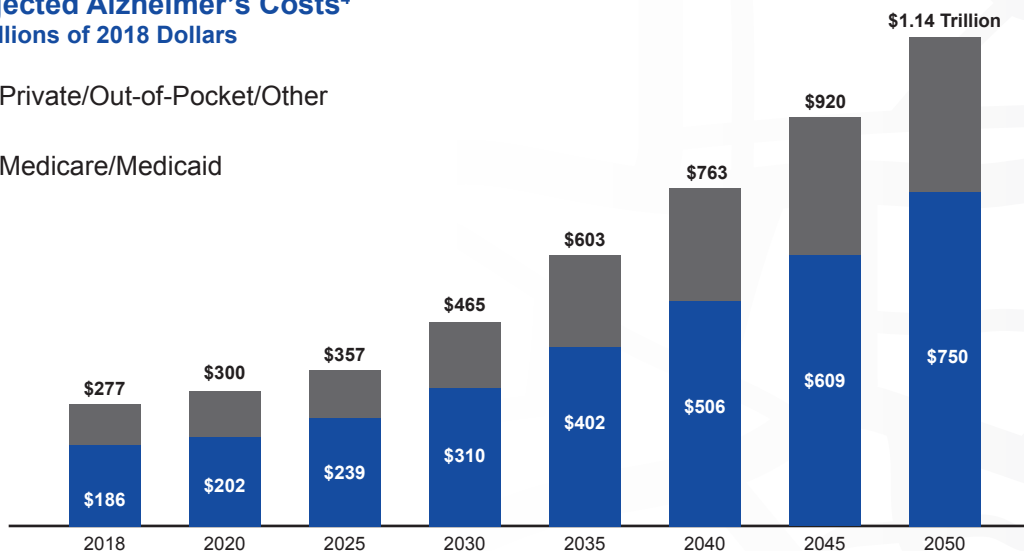
The cost of Alzheimer’s and other dementias is high and continues to rise.

- » Alzheimer’s is the most expensive disease in America, with costs exceeding a quarter of a trillion dollars annually.¹
- » By 2050, Alzheimer’s and other dementias will cost \$1.1 trillion (in 2018 dollars).¹

- » One in five Medicare dollars is spent on the care of people with Alzheimer’s. In 2050, it is projected to be one in every three dollars.¹
- » Average per-person Medicare spending for those with Alzheimer’s and other dementias is more than three times higher than average per-person spending across all other older adults. Medicaid payments are 23 times higher.¹
- » In 2015, there were 1,471 emergency department visits for every 1,000 Medicare beneficiaries with dementia.¹
- » In 2018, the direct costs to American society of caring for those with Alzheimer’s is estimated at \$277 billion.¹

**Projected Alzheimer’s Costs⁴
In Billions of 2018 Dollars**

- Private/Out-of-Pocket/Other
- Medicare/Medicaid



While caring for someone with Alzheimer’s and other dementias can be a rewarding experience, it can also be demanding and challenging.

- » In 2017, 16 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer’s and other dementias, at an economic value of more than \$232 billion.¹
- » The tasks required of caregivers for people with dementia can be particularly personal and burdensome. Nearly half provide help getting in and out of bed. Compared with caregivers for people with non-dementia conditions, they are much more likely to assist with bathing or showering and to deal with incontinence.¹
- » Caregivers for people with Alzheimer’s and other dementias are two and a half times more likely than caregivers for people with other conditions to help with emotional or mental challenges and nearly four times as likely to assist with behavioral issues.¹
- » About one in three Alzheimer’s caregivers report their health has gotten worse due to care responsibilities, compared with one out of five caregivers of other older adults.⁵
- » In all, the physical and emotional impact on caregivers for people with Alzheimer’s and other dementias resulted in an estimated \$11.4 billion in increased caregiver health costs in 2017.¹ ●

THE PUBLIC HEALTH ROLE

This crisis cannot be ignored. Public health has a critical role to play in promoting the cognitive functioning of adults across the life course and addressing soaring costs to healthcare, social, and economic systems. By applying its broad community-based approach (see Figure 2), public health can:

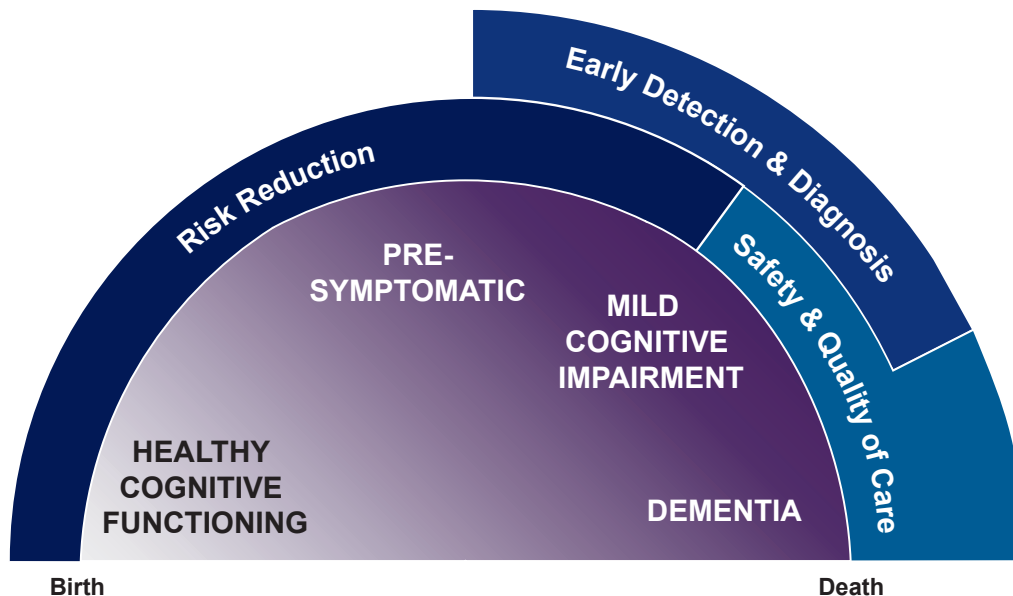
Accelerate risk reduction: Several modifiable risk factors for developing Alzheimer’s disease and other dementias have been identified. Expert panels have called attention to traumatic brain injury, smoking, diet, physical activity, cardiovascular risk, and other modifiable factors that also correspond with an overall healthy lifestyle and improved quality of life.

Advance early detection and diagnosis: The earlier dementia is diagnosed, the sooner care can be provided. A formal diagnosis allows people living with dementia to have access to available symptomatic treatments and interventions, build a care team, participate in support services, and potentially enroll in clinical trials. They and their caregivers can set systems in place to better manage medications, receive counseling, and address the challenges of other chronic conditions. Additional advantages include planning for future financial and legal needs and end of life choices.

Ensure safety and quality of care: The challenges of caring for persons with Alzheimer’s and other dementias can become difficult and overwhelming, especially when intensive care is needed for long periods of time. For many, however, caregiving is also a rewarding experience, bringing family members closer together in time of great need. Public health can play a central role in offering information, guidance, and supportive resources to caregivers to help them provide effective dementia care and attend to their

own well-being. In addition, public health can help improve the health and functioning of people living with dementia by assuring professionals delivering healthcare and other types of care services use evidence-based guidelines and have sufficient training. ●

Figure 2: Life Course Perspective on Alzheimer’s and Other Dementias and the Role of Public Health Across the Entire Population⁶



Throughout the dementia continuum (shown in purple), the public health community (shown in blue) can intervene by promoting health behaviors to reduce risk of cognitive decline, encourage early detection and diagnosis of cognitive impairment and dementia, ensure the safety of those with memory issues, and improve the quality of care for those impacted by dementia in their communities. These essential public health activities help reduce burden, improve health outcomes, and promote health and well-being among both people living with dementia and their caregivers.

II

USING THE ROAD MAP



The Road Map provides an action agenda for the public health community—especially at the state and local level—to respond to the growing dementia crisis through the traditional tools of public health. While the federal government plays a critical role in leading and funding efforts to address Alzheimer’s disease and other dementias, state and local agencies organize and provide public health services at the community level. Many Road Map actions are designed so that state and local agencies can incorporate cognitive health and caregiving issues into ongoing public health efforts. Other Road Map actions aim to help build public health capacity to lead policy, systems, and environmental changes, in part by leveraging strong partnerships.

The Road Map contains a flexible agenda of 25 actions that public health agencies and their partners can pursue over the next five years to address cognitive health and to meet the needs of caregivers. These actions align with Essential Services of Public Health: educate and empower the nation, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

To best use the Road Map, state and local public health agencies should view it as a guide to incorporating cognitive health into their work. Implementation of the Road Map will be most effective with participation by, and partnerships between, private, nonprofit, and governmental partners at the national, state, and local levels. Partners should cross multiple sectors and reach beyond the traditional boundaries of public health to include the aging network, employers, health systems, clinical and community providers, community service organizations, and faith-based and other spiritual groups. In addition, to stay grounded in day-to-day realities, people from diverse backgrounds and experiences with dementia should be involved at all stages of planning, implementation, and evaluation. This can include people living with dementia, their caregivers, and organizations that represent them. ●

Essential Services of Public Health

Educate and Empower

Public health informs, educates, and empowers people about health issues.

Develop Policies and Mobilize Partnerships

Public health develops policies and plans that support people and community health efforts. It also mobilizes community partnerships and action to identify and solve health problems.

Assure a Competent Workforce

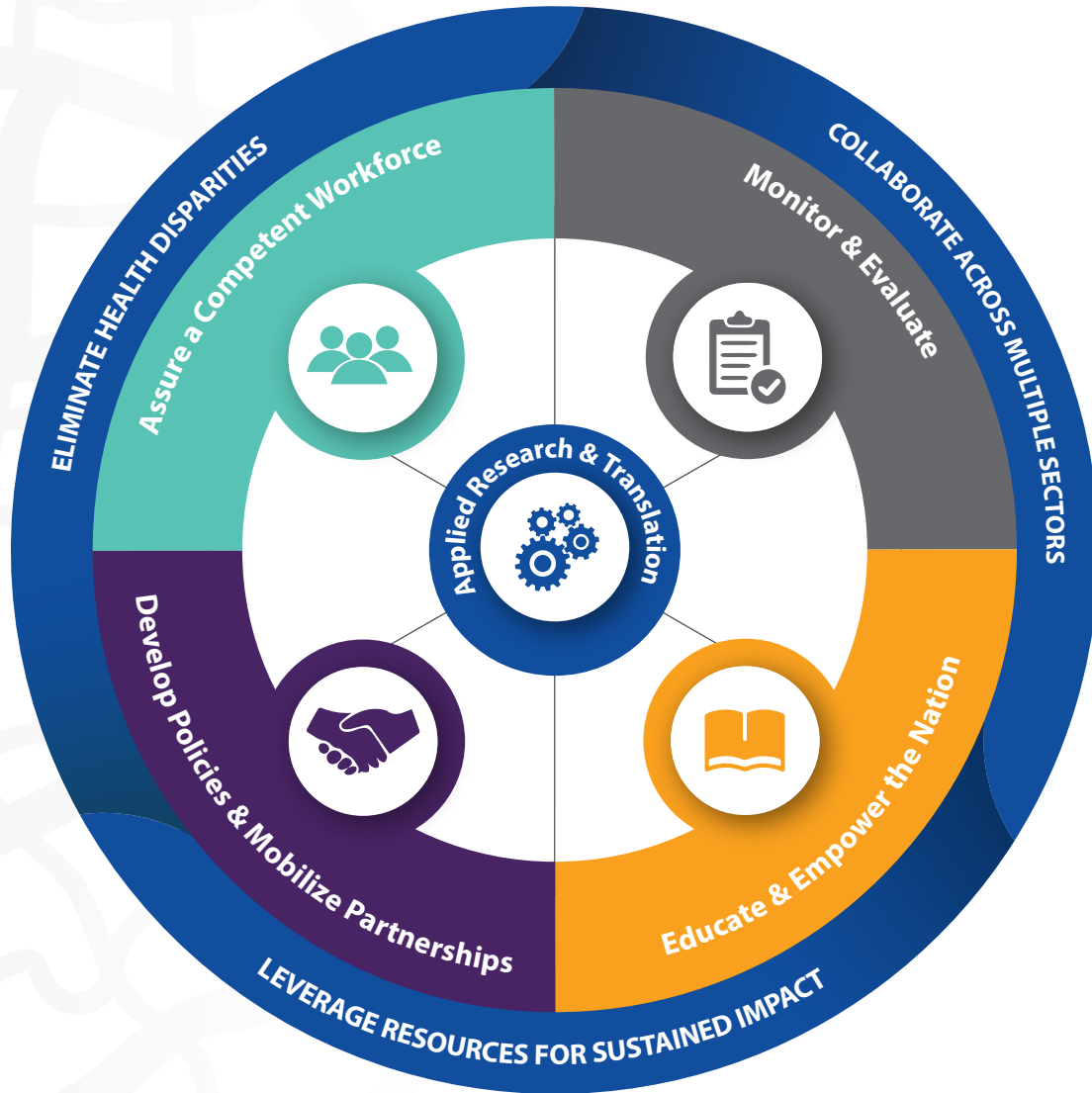
Public health assures that the public and personal healthcare workforce have essential competencies.

Monitor and Evaluate

Public health monitors health status to identify and solve community health problems and evaluates effectiveness, accessibility, and quality of personal and population-based health services.

Source: <https://www.cdc.gov/stitpublichealth/publichealthservices/essentialhealthservices.html>

Figure 3. Conceptual Framework for the Healthy Brain Initiative Road Map



State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map is informed by four Essential Services of Public Health—assure a competent workforce, monitor and evaluate, develop policies and mobilize partnerships, and educate and empower the nation. Action within each of these four domains is guided by three core principles to best eliminate health disparities, collaboration across multiple sectors, and the need to leverage resources for sustained impact.

Questions to Guide State and Local Public Health in Planning Road Map Actions

1. Which Road Map actions best fit state or local priorities, opportunities, and capabilities?
2. How can available data and other information be used to identify a reasonable and relevant set of actions?
3. How can identified actions best be integrated into existing initiatives? Are any new initiatives needed?
4. Who are potential partners? Can any current partnerships be leveraged to implement actions?
5. What are possible funding sources, and how can they be secured?
6. How will implementation and impact be evaluated? How and with whom will progress be shared?

CORE PRINCIPLES FOR THE ROAD MAP

Effectively addressing the rising number of people with Alzheimer's and other dementias will require diligent attention to three fundamental principles in planning and implementing Road Map actions (see Figure 3). These principles—eliminate health disparities, collaborate across multiple sectors, and leverage resources for sustained impact—are central to public health and have been noted by many other seminal reports.

Eliminate health disparities. Optimizing health for the U.S. population while also eliminating disparities remains an integral part of disease prevention and health promotion activities. Although significant strides have been made in the U.S. in the last two decades, disparities still exist.⁷ The 2011 National Prevention Strategy called for the elimination of health disparities and recommended focusing on those populations at most risk.⁸

The public health commitment to eliminating disparities is reflected in the *Healthy Aging in Action* report, which includes elimination of health disparities as a strategic direction. Prepared by the National Prevention, Health Promotion, and Public Health Council (National Prevention Council), the report calls on communities “to reduce health disparities by building community partnerships that create health parity; increasing access to preventive services; increasing the capacity of healthcare and prevention workers to address disparities; and implementing strategies that are culturally, linguistically, and age appropriate for people and their caregivers.”⁹ In a similar vein, many Alzheimer's state plans also call for reducing barriers and eliminating health disparities, and consider the effort central to accomplishing plan goals.

Major strides in improving the nation's health can best occur by focusing on communities at greatest risk and eliminating barriers to quality healthcare services.^{10,11}

Cognitive health is no exception. In implementing the actions in this Road Map, public health should consider concentrating resources on populations who are underserved, are more vulnerable, or suffer a disproportionate burden of disease.

Collaborate across multiple sectors. Implementation of the Road Map requires collaborations between the public health community and wide array of organizations at national, state, and local levels and in both public and private sectors. The need for and value of such cross-sector collaboration has gained increasing attention as an essential component of any strategy for improving health and well-being.¹² Yet much work remains to realize its potential.

The Robert Wood Johnson Foundation's *Culture of Health Action Framework*¹³ links cross-sector collaboration to making long-term gains in population health. Key factors for effective and sustained cross-sector collaborations are: the number, breadth, and quality of cross-sector partnerships; the adequacy of investment in these partnerships; and the adoption of policies needed to support them.¹⁴ Thus, a deliberate and coordinated approach to cognition and caregiving would cultivate partnerships that transcend traditional boundaries—especially between public health and aging networks, employers, health systems, clinical and community providers, community service organizations, and faith-based and other spiritual groups. Collaboration across programs focused on prevention and management of specific diseases

(such as cardiovascular health, infectious diseases, and other relevant conditions) can also be highly effective in achieving similar outcomes.

Leverage resources for sustained impact.

The challenges inherent in tackling dementia and improving cognitive health far exceed the capacity of the public health sector alone. True and sustained progress depends on building collaborative public and private sector partnerships to leverage resources toward accomplishing common Healthy Brain Initiative goals, promote widespread diffusion of an evidence-based model, or invest in capacity. Such resources can take many forms: *physical*, such as spaces, tools, and materials; *financial*, such as direct funding or discounts; *social*, such as networks of people or organizations, norms, shared understanding, and trust; and *intellectual*, such as data, skills, knowledge, time, and competencies of stakeholders. The National Academy of Medicine's *Vital Directions for Health and Health Care*¹⁵ calls for building collaborations to mobilize resources for health improvement. Expanding the range of existing and new resources not only has synergistic benefits but also supports scales that would be beyond the reach of a single organization and helps ensure sustainability. ●



Examples of Public Health Implementation of Road Map Actions

Chapter V contains recent examples of strategies used by state public health agencies to address cognitive health and caregiving. Many other examples and resources to help the public health community implement the Road Map are available at: alz.org/publichealth

DISPARITIES BY RACE/ETHNICITY AND GENDER

Disparities in the risk of developing Alzheimer's and other dementias are most prominent among African Americans, Hispanics, and women.

African Americans and Hispanics

- » One in seven African Americans aged 45 and older have subjective cognitive decline.¹⁶
- » Older African Americans are about two times more likely than older whites to have Alzheimer's or other dementias.¹
- » Older Hispanics are about one and one-half times more likely than older whites to have Alzheimer's or other dementias.¹

Variations in health, lifestyle, and socioeconomics likely account for most of the difference in risk by race and ethnicity. High blood pressure and diabetes, which are risk factors for dementia, are more prevalent in African American and Hispanic populations than in whites. Lower levels of education and greater levels of other socioeconomic characteristics and risk factors (such as poverty, adversity in early life, and access to quality care) among some racial and ethnic minorities may also contribute to increased risk. In addition, African Americans with subjective cognitive decline often have other health challenges that may complicate care, such as physical inactivity, tobacco use, and living alone.¹

Missed diagnoses of dementia are more common among African Americans than whites. While African Americans are two times more likely to have Alzheimer's or another dementia than whites, they are only 36% more likely to receive a diagnosis.¹⁷ Also, both African Americans and Hispanics with cognitive impairment are less likely than whites to say that a doctor has told them they have a "memory-related disease."¹⁸

Women

- » Almost two-thirds of older Americans with Alzheimer's dementia are women.¹
- » Among those aged 71 and older, 16% of women have Alzheimer's or other dementias, compared with 11% of men.¹⁹
- » At age 65, women without Alzheimer's have more than a one in five chance of developing Alzheimer's dementia during the remainder of their lives, compared with a one in nine chance for men.²⁰

These disparities may be primarily explained by the fact that women live longer, on average, than men. However, researchers are increasingly questioning whether there may be other reasons for the difference in the number of women compared with men who develop the disease. ●

III

THE ACTION AGENDA



This section presents actions that state and local public health agencies and their partners could pursue over the next five years to address cognitive health and meet the needs of caregivers. Actions are grouped by four Essential Services of Public Health:



E = EDUCATE & EMPOWER



P = DEVELOP POLICIES & MOBILIZE PARTNERSHIPS



W = ASSURE A COMPETENT WORKFORCE



M = MONITOR & EVALUATE

Actions are further divided by the desired outcome they share in common. Compelling data make the case for the urgency and importance of pursuing each group of actions. Text accompanying the actions offers insight into the roles that public health can play.



E = EDUCATE & EMPOWER

Outcome:

INFORMED PUBLIC

- E-1** Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis.
- E-2** Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span.
- E-3** Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.
- E-4** Promote prevention of abuse, neglect, and exploitation of people with dementia.

Public education is a fundamental public health role. Helping people take actions to promote cognitive health requires clear and consistent messages about what is known—and what is yet to be discovered. Target audiences include but are not limited to: older adults, adult children, employers, and people supporting an older neighbor or friend.

Sharing accurate information using culturally-appropriate health communications techniques would seek to:

- » Raise awareness about brain health and changes in cognition that merit a conversation with a healthcare professional;
- » Shift mindsets and normalize discussions about cognitive health in the routine delivery of healthcare to support early detection and modification of risk factors;
- » Improve access to available information, care planning, and community services to support physical and behavioral health as well as social, legal, financial, and spiritual needs; and
- » Reduce stigmas and myths surrounding the disease.



In South Carolina, an awareness campaign educated the public on brain health and risk reduction. Learn more on page 44.

Public health has strengths and capacities to advance awareness about the interplay between brain health and physical health. This could be done by linking dementia and cognitive decline risk messaging to health promotion activities in such areas as:

- » Tobacco prevention and control;
- » Cardiovascular health management;
- » Diabetes prevention and management;
- » Obesity prevention and control; and
- » Injury prevention.

Educating the public is also a needed component of preventing abuse, neglect, and exploitation (including financial exploitation) of people living with dementia. As cognitive impairment worsens, people can become increasingly vulnerable to falling victim to elder mistreatment. A person living with dementia may not recognize actions that could be harmful and have difficulty protecting themselves; in addition, communication problems can hinder reporting or seeking help. Cognitive impairment may also increase the risk of self-neglect for people living alone with dementia, especially as ability to perform activities of daily living gradually declines. Beyond public education, the public health community can actively strive to prevent abuse, neglect, and exploitation through partnerships with adult protective services, law enforcement, aging network service providers, and other community-based organizations as recommended in the *Elder Justice Roadmap*.²¹ ●

COMPELLING DATA

- » Nearly 90% of Americans say that if they were exhibiting confusion and memory loss, they would want to know if the cause of the symptoms was Alzheimer's disease. Yet, over half of the people aged 45 and older with subjective cognitive decline have not talked with a healthcare provider about their questions, concerns, and fears.¹
- » Evidence indicates that less than half of people with dementia have been diagnosed by a physician. Among older adults who have been diagnosed with dementia, only 35% are aware that they have the disease.²²
- » Nearly half of all caregivers (48%) who care for an older adult do so for someone with Alzheimer's and other dementias.¹



Outcome:

INFORMED PEOPLE WITH DEMENTIA AND CAREGIVERS

- E-5** Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.
- E-6** Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia.
- E-7** Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.

The challenges facing people with dementia and their caregivers can be daunting. Public health can help raise awareness about these challenges and the need to improve quality of life, safety, and well-being among people with dementia and their caregivers.

Public health can also facilitate access to affordable, evidence-informed services, programs, interventions, and supports to reduce stress and improve coping, self-efficacy, and overall health. Well-designed programs have been shown to benefit persons with dementia and caregivers, and should be readily accessible. Similarly, reliable information and tools that feature best practices should be widely distributed. Access to these programs and tools is particularly crucial for people with dementia who live alone.

Caregivers would benefit from compelling and easy-to-use content about how to enhance their own health while caring for their loved ones. Some of the many resources that public health can help expand, promote, or tailor to specific populations include:

- » Community-based programs for physical activity, chronic disease self-care, and caregiver education;
- » Peer support groups and social gatherings for people affected by dementia;
- » Online support and information resource centers;
- » Apps for caregivers and persons living with dementia and GPS tracking devices;



Efforts in Washington and Puerto Rico increased dementia awareness among traditionally underserved populations. Learn more on pages 45–46.

- » Home healthcare services and home modification programs;
- » Adult day care and respite care;
- » Advanced care and advanced financial planning;
- » Transportation services; and
- » Information and referral services. ●



Through community engagement and local partnerships across Maryland, the benefits of advance care planning were promoted. Learn more on page 47.

COMPELLING DATA

Among caregivers for people with Alzheimer’s and other dementias:

- » 86% have provided care for at least the past year, and well over half (57%) had provided care for four or more years.¹
- » Nearly one in four are “sandwich generation” caregivers—caring for both an older adult and a child.¹
- » 35% report that their health has gotten worse due to care responsibilities, compared to 19% of caregivers for older people without dementia.¹
- » Nearly 60% rate the emotional stress of caregiving as high or very high. As many as 40% report symptoms of depression.¹
- » The physical and emotional impact on caregivers for people with Alzheimer’s and other dementias resulted in an estimated \$11.4 billion in increased caregiver health costs in 2017.¹
- » Older adults with dementia are two to three times more likely to fall than older adults without dementia.²³



P = DEVELOP POLICIES & MOBILIZE PARTNERSHIPS

Outcome: **SCIENCE TRANSLATED INTO PRACTICE AND POLICIES**

- P-1** Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.
- P-2** Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about brain health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces.
- P-3** Support better informed decisions by educating policymakers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem.
- P-4** Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes.

The science of brain health and dementia will continue to evolve during the five-year time span of this Road Map. It is incumbent on public health to understand the implications of the best available evidence and to promote rapid integration into policies and practice. One tool for developing public health knowledge is the free curriculum for undergraduate courses in schools of public health, *A Public Health Approach to Alzheimer's and Other Dementias*, from CDC and the Alzheimer's Association.

An important opportunity for systemic change is influencing academic standards, through partnerships with local accrediting bodies, for future workforces of physicians, nurses, public health professionals, social workers, direct care workers, etc. Changes in science may necessitate ongoing education of policy and business leaders to update their understanding of the economic, public health, and social implications of dementia.

Planning and policy initiatives provide additional opportunities to integrate cognitive health and to engage additional state and local partners. In particular, the process of updating state Alzheimer's plans enables governmental and private sector partners to understand challenges encountered by people with dementia and caregivers especially in underserved communities, to examine potential policies in a concerted fashion, and to leverage partners' resources (tangible and intangible).

Another area for translating science into action is the use of quality measures to track progress. Measures specific to dementia have been developed by the Physician Consortium for Performance Improvement, the American Academy of Neurology, and the American Psychiatric Association Work Group. Further, the National Quality Forum and other experts may develop or endorse additional quality measures and measure concepts in the coming years.

The following programs and settings provide opportunities for state public health to use dementia-related measures:

- » State healthcare quality initiatives (e.g., Medicaid payment and encounter data sets, Medicaid adult core set);
- » Centers for Medicare & Medicaid Services (CMS) Quality Payment Program for the Merit-Based Incentive Payment System (MIPS);
- » State hospital and emergency department (ED) data sets;
- » Medicare Hospital Inpatient and Outpatient Quality Reporting Programs;
- » Physician Quality Reporting System (PQRS, now included in MIPS); and
- » Long-term care data sets (e.g. institutional and community-based services) and ambulatory care (e.g. home health, hospice). ●

COMPELLING DATA

The current public health and healthcare workforce had little or no formal preparation on dementia as a public health issue. In general, there is a lack of knowledge among healthcare workers on how to detect and diagnose the disease, how to interact with people with Alzheimer's, and how to help people with dementia and their caregivers navigate care and services.

- » Despite predominantly working with adults aged 55 and older, only 4% of social workers have specialized geriatric training.²⁴
- » Less than 1% of registered nurses, physician assistants, and pharmacists have specialized in geriatric care.²⁴
- » Less than 3% of medical students choose geriatric electives during their training, which means that most will enter the workforce with little exposure to the needs of older adults.²⁵

PUBLIC HEALTH ROLE IN DEMENTIA-FRIENDLY COMMUNITIES

The establishment of dementia-friendly communities is a growing movement in the U.S. and around the world. The movement mobilizes government, businesses, and civic groups to form a coalition and pledge to actively make changes to support people living with dementia and their caregivers. State and local public health organizations are uniquely positioned to become coalition partners and to help evaluate progress toward goals.

Currently, about 70% of people with Alzheimer's and other dementias live in community settings, with an estimated one-quarter of them living alone. A common preference for persons with dementia is to remain as engaged and independent for as long as possible. Supports that may help people living with dementia stay active and engaged can range from access to public transportation, interaction with service providers and friends that use effective communications techniques, as well as opportunities to be involved in community life. As cognitive and physical impairment progresses, high-quality healthcare and home- and community-based services become more important to well-being. Around-the-clock care may be necessary for people in the final stages of Alzheimer's dementia as they tend to become bed-bound.

To realize their potential, coalitions need a plan to change neighborhood environments and mobilize partners to adopt promising practices for supporting people affected by dementia. Insights from people

living with dementia and their caregivers are crucial to effective planning, and they can be compelling advocates for implementation. Plans should set measurable objectives and designate stakeholders responsible for achieving progress toward goals.

How can public health contribute to the dementia-friendly communities movement? The actions in this Road Map are ways public health and its partners can help ensure affected people have safe, supportive environments. Action P-5 calls on public health to “engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces.” Additional actions to support dementia-friendly communities include:

- » Educate the public (E-1, E-3);
- » Analyze the community support needs of people living with dementia and their caregivers (M-3, M-5);
- » Promote the use of evidence-informed practices and educational resources (E-6, E-7); and
- » Build the knowledge and skills of professionals who interact with people living with dementia and their caregivers (W-2, W-5, W-6). ●

TRANSLATING EVIDENCE THROUGH THE HEALTHY BRAIN RESEARCH NETWORK

The Healthy Brain Research Network (HBRN) is a thematic public health research network that brings together interdisciplinary expertise from six leading academic institutions across the United States: University of Washington (UW) (coordinating center); Oregon Health & Science University; University of Arizona; University of Illinois at Chicago; University of Pennsylvania; and University of South Carolina. CDC created the HBRN in 2014 to:

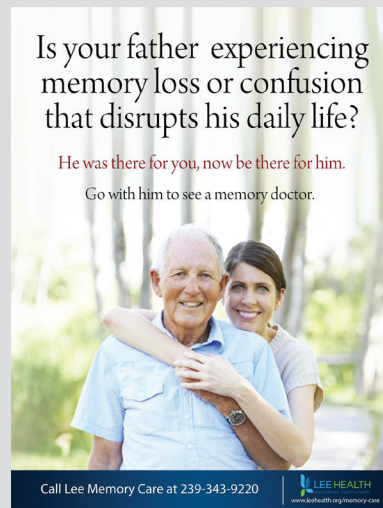
- » Establish and advance a public health research, translation, and dissemination agenda that promotes cognitive health and healthy aging, addresses cognitive impairment, and helps meet the needs of caregivers;
- » Build a strong evidence base for policy, communication, and programmatic interventions;
- » Collaborate with public health agencies and their partners to accelerate effective practices in states and communities; and
- » Build the capacity of public health professionals through training opportunities.

The HBRN plays an important role in translating evidence into policies and programs. As just one example, the HBRN center at the University of Pennsylvania initiated a project to increase early identification and intervention by targeting adult children concerned about their aging parents or older

relatives who need information about the next step. The HBRN developed and tested culturally-relevant messages for adult men and women from diverse racial and ethnic groups.^{26,27} HBRN centers collaborated in testing messages to increase

relevance and generalizability. The resulting research-tested messages encouraged adults to accompany their parents to healthcare appointments if they have concerns about their parents' memory.

Another important priority of the HBRN is workforce development. From 2014 to 2017, the network trained 33 scholars from undergraduate, graduate, and post-doctoral programs in nursing, medicine, public health, communications, and social work. The scholars were predominantly female (78%) and non-white (60%). The HBRN scholars reported increased knowledge about and commitment to cognitive health, and have contributed to the field by presenting at conferences, authoring scholarly publications, and serving on interdisciplinary research teams. ●





Outcome:
**SUPPORTIVE COMMUNITIES
AND WORKPLACES**

- P-5** Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.
- P-6** Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.

Most people with dementia (especially before the late stages) can remain involved in their communities—and, with appropriate support, they can have better outcomes and quality of life at lower costs than if they become isolated or institutionalized.²⁸ Unfortunately, many practicing healthcare professionals have received limited training on how to interact effectively with people living with Alzheimer’s and other dementias. The healthcare provider community also lacks knowledge about what small changes in daily practices a person with dementia can make to help them remain independent and engaged.^{29,30} Public health can address these challenges by going beyond healthcare and direct support systems to mobilize community action at all levels, beginning with insights from and action by people with dementia and their caregivers.

Specifically, the public health community can:

- » Assess community and workplace support needs of people with dementia and their caregivers;
- » Bring together multiple community players—local businesses, public service providers, area agencies on aging, community service organizations, faith-based and other spiritual groups, and community residents—to create new partnerships, develop action plans, and build support systems for people with Alzheimer’s and other dementias and caregivers;
- » Consider currently available tools and resources such as those developed by dementia-friendly community efforts; and

- » Promote the use of supportive practices and strategies, such as clearly marked signage, quiet public spaces during events, and supportive transportation options (volunteer driver programs, etc.) to take people to destinations in their communities.

To help ensure that local and state preparedness plans consider the particular vulnerabilities of this population, public health agencies can elicit insights from people with dementia, caregivers, and experts on cognitive impairment. Further, emergency responders and shelter staff could benefit from training about signs and symptoms of dementia, or conditions that can mimic cognitive impairment. ●



Across Colorado, first responders received training on ways to safely and compassionately serve people living with dementia. Learn more on page 48.

COMPELLING DATA

- » Approximately 70% of people with Alzheimer's and other dementias live in the community, with an estimated one-quarter living alone.¹
- » Only half of employers have policies that support caregivers: 53% offer flexible work hours/paid sick days, 32% offer paid family leave, 23% offer employee assistance programs, and 22% allow telecommuting.³¹
- » Caring for people with Alzheimer's can have a negative effect on employment, income, and financial security. Among caregivers for people with Alzheimer's and other dementias who are employed full or part time, 57% said they had to go in late, leave early, or take time off because of their caregiving responsibilities. In addition, 18% had to go from full to part time, 16% took a leave of absence, and 8% turned down a promotion due to the burden of caregiving.¹
- » Although a majority of people with Alzheimer's will wander at some point, as of 2015, only 10 states require training for law enforcement regarding dementia.³² Additionally, people with dementia are particularly vulnerable during natural disasters such as floods and hurricanes.^{33,34}

SPOTLIGHT

USING STATE PLANS ON ALZHEIMER'S AND OTHER DEMENTIAS

State and local dementia plans aim to build the infrastructure and accountability for policies, services, and programs to mitigate the burden of dementia. A comprehensive state plan helps to unite key stakeholders and public health partners—including people living with dementia and caregivers—around a range of issues. State plans often focus on:

- » Tailoring supports for people affected by dementia;
- » Using data and analyses to inform the state response and track progress on priorities;
- » Assuring quality of long-term care;
- » Providing home- and community-based services;
- » Helping identify and track the availability of diagnostic services;
- » Protecting the safety of persons who wander; and
- » Supporting caregivers and healthcare professionals.

As of April 2018, 48 states and territories have published Alzheimer's disease plans and a few cities and counties have created regional plans. Nearly all of the published plans include public health recommendations and strategies for public awareness, early detection, education about brain health, and monitoring the burden of cognitive decline and caregiving. A majority of state plans highlight early detection and diagnosis as an essential component.

With the rapidly growing and changing nature of the Alzheimer's crisis, it is essential that state dementia plans are living documents that stakeholders implement, monitor, and periodically update. Public health is an essential partner in leading these efforts. ●



Montana Governor Steve Bullock, Alzheimer's Association Montana Chapter Policy Lead Nick Hart, and Montana Lieutenant Governor Mike Cooney (left to right) pose with the Montana Alzheimer's and Dementia State Plan in March 2017. Photo credit: Brittney Kuntz.





W = ASSURE A COMPETENT WORKFORCE

Outcome:


IMPROVED PRACTICE IN PROMOTING HEALTH AND REDUCING RISK

- W-1** Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve.
- W-2** Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.

Public health increasingly works side-by-side with an array of healthcare organizations to improve the health of communities. Sometimes this is through partnerships with federally qualified health centers (FQHCs), Medicaid providers, nonprofit hospitals, and health plans. Public health and healthcare professionals need materials they can share with consumers, especially credible information on brain health and ways to reduce risk of cognitive decline. Outreach to health professionals can call attention to the importance of supporting caregivers' health and their role in managing dementia and other chronic conditions and ensuring safety. Integrating cognitive

functioning and caregiving into existing health promotion and chronic disease efforts has the potential to increase the reliability of care and related outcomes.

The Geriatric Workforce Enhancement Program (GWEP), supported by the Health Resources and Services Administration (HRSA), a federal agency, is a valuable resource to educate healthcare professionals. Currently, 44 GWEP centers specialize in integrating geriatrics with primary care and are charged with developing a healthcare workforce that maximizes patient and family engagement and improves health outcomes for older adults.³⁵ The centers are mostly based in schools of medicine, nursing, allied health, and social work. ●

 *Caregivers in New Mexico learned how to better manage their own health through two community education programs. Learn more on page 49.*

COMPELLING DATA

- » More than 85% of people with Alzheimer's and other dementias have one or more additional chronic condition(s), and cognitive impairment often complicates the management and treatment of those conditions.¹
- » The current public health workforce has had little or no formal preparation on dementia as a public health issue.
- » Older adults with dementia have twice as many hospital stays each year as those without dementia and spend, on average, more than 22 days in a hospital or skilled nursing facility each year compared with an overall average for older adults of less than five days.¹
- » As of 2015, only two states require training in dementia for registered nurses, licensed practical nurses, and licensed vocational nurses.³⁶



Outcome:

IMPROVED EARLY DETECTION AND DIAGNOSIS

- W-3** Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.
- W-4** Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.



A statewide assessment in Utah helped increase promotion of early detection and diagnosis tools. Learn more on page 50.

Public health can impact early detection and diagnosis by developing professional competencies needed to effectively and compassionately interact with and assess people with cognitive impairment and their caregivers. For timely and accurate early detection to occur—and subsequent diagnosis and disclosure awareness—adults must feel comfortable discussing symptoms and concerns with their healthcare providers. This requires addressing barriers such as low public awareness of the early signs of Alzheimer's, emotional distress of Alzheimer's and other dementias on family members, and misperceptions about Alzheimer's and other dementias.^{37,38} In addition, public health should consider addressing obstacles faced by physicians such as: low recognition of the signs of cognitive impairment, confusion with conditions that may mimic dementia (including delirium, certain vitamin deficiencies, and depression), limited education or training on dementia care, concerns about stigma and the usefulness of an early diagnosis, lack of time, and difficulty talking about dementia or disclosing a diagnosis.^{39,40,41,42}

Strategies are needed to equip public health professionals with sound and credible information so that they are well informed when communicating with other healthcare providers and payers. Educational initiatives involving academic institutions, clinical practices, and caregiver organizations can enhance healthcare providers' knowledge and abilities, especially when these collaborations extend to

credentialing or accreditation. A combination of continuing education, practical tools and resources, and community-clinical linkages have the potential to shift standards of practice and cultural norms.

Important areas for education include:

- » Under-diagnosis of Alzheimer’s disease and other dementias as a problem;
- » Importance of and opportunities for early detection, diagnosis, documentation of diagnosis, and care of dementia (including the availability of the Medicare Annual Wellness Visit’s cognitive assessment benefit, availability of services and supports after a diagnosis, and the care planning billing code);
- » Benefits of actively monitoring high-risk populations’ cognition, similar to monitoring of other chronic conditions in high-risk cases;
- » Availability of resources including validated clinical assessment tools, guidance and toolkits such as the KAER toolkits developed by the Gerontological Society of America,⁴³ online training such as HRSA’s *Alzheimer’s Disease and Related Dementias Curriculum* and *Caregiving Curriculum*,⁴⁴ consultative support for making accurate diagnoses, and community-based social services;
- » Effective strategies to convey detection, diagnosis, and resource referral information in ways that are culturally-appropriate, candid, clear, and compassionate for different populations; and
- » Importance of using support systems for healthcare professionals because disclosing dementia diagnoses can take an emotional toll. ●

COMPELLING DATA

- » In a survey of 12 countries, 59% of respondents incorrectly believed that Alzheimer’s is a typical part of aging and 40% did not think it was fatal.⁴⁵
- » Adults are reluctant to discuss cognitive changes with a healthcare provider. Over half (55%) of adults age 45 and older who reported subjective cognitive decline in the previous 12 months had not discussed their symptoms with a healthcare provider.⁴⁷ Among those whose memory problems were creating functional difficulties, 42% had not shared these issues with a provider.⁴⁶
- » Physicians face barriers as well, evidenced by the low rate of documentation of cognitive decline in medical records. Less than half of those with Alzheimer’s and other dementias have their diagnoses documented in their medical records.^{47,48}
- » Economic modeling shows that early diagnosis can greatly reduce healthcare costs across the nation, particularly through reduced hospitalizations and better management of chronic conditions—potentially up to \$64,000 per person with dementia.¹

Outcome:

IMPROVED PROFESSIONAL CARE FOR PEOPLE WITH DEMENTIA

- W-5** Strengthen the competencies of professionals who deliver healthcare and other care services to people with dementia through interprofessional training and other strategies.
- W-6** Educate healthcare professionals about the importance of treating co-morbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia.
- W-7** Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.

Home, community, and long-term care professionals in Utah enhanced their knowledge and skills to better care for people living with dementia. Learn more on page 51.

Public health has a critical role in educating a broad array of providers who care for people with dementia: nurses, home health professionals, social workers, pharmacists, physicians, community health workers, and more. Each profession has specialized knowledge and competencies that, if shared, could help other professionals become more effective in their particular roles. Interprofessional training that involves professionals from different disciplines can facilitate greater appreciation for others' contributions and improve working relationships. Because Alzheimer's dementia complicates the management of chronic diseases, care planning—particularly when it is done by interdisciplinary teams—is key to coordinating and managing care. Care planning allows people with dementia diagnoses and their caregivers to receive a comprehensive assessment, learn about medical and non-medical treatments, and secure relevant services in the community that can support a higher quality of life. People receiving care planning specifically geared toward dementia have fewer hospitalizations, fewer emergency room visits, and better medication management.⁴⁹

The Current Procedural Terminology (CPT) billing code 99483 allows clinicians to be reimbursed for providing comprehensive care planning to cognitively impaired people. Effective since 2017, the code requires clinicians to provide detailed, person-centered care planning, caregiver assessments, and referrals to community resources. Public health efforts to ensure

systematic delivery of this service would likely improve care and quality of life for people with dementia and their caregivers.

With the rapid rise in the age of the U.S. population, more resources, training, and education will be vital for equipping primary care physicians and caregivers to handle the projected gaps. ●

COMPELLING DATA

- » Twenty states are considered to be neurology “deserts” due to a chronic shortage of neurologists and a rapid rise in people with Alzheimer’s and other dementias.⁵⁰
- » Care and treatment for people with Alzheimer’s is expensive, partly because of multiple chronic conditions. The average per-person Medicare spending on beneficiaries with dementia is more than three times higher than for beneficiaries without dementia. In 2018, total Medicare costs for people with dementia was an estimated \$140 billion.¹
- » Cardiovascular diseases are common chronic conditions among people with Alzheimer’s: 73% of people with Alzheimer’s and other dementias have hypertension, 38% have heart disease, 37% have diabetes, and 22% have had a stroke.¹ One small study found 29% of people with diagnoses of dementia had symptoms of depression.⁵¹
- » Current training does not adequately prepare healthcare workers to deal with the unique needs of those with Alzheimer’s. As of 2015, only 23 states required dementia training for staff of nursing homes, and the majority of states that did require training did so only for personnel in Alzheimer’s special care units. Further, only 19 states required dementia training for adult day staff, and only 13 states required it for licensed home health aides.⁵²

PARTNERING WITH FAITH-BASED GROUPS

The Balm In Gilead, Inc. builds and strengthens the capacity of African American faith communities to deliver programs and services that contribute to the elimination of health disparities. The organization develops educational and training programs specifically designed to establish sustainable, integrated systems of public health and faith principles, which helps to improve health outcomes of individuals living in urban, rural and remote communities. In 2015, the Centers for Disease Control and Prevention awarded a five-year cooperative agreement to The Balm In Gilead, enabling the nonprofit agency to develop The National Brain Health Center for African Americans. The Center's objectives are to:

- » **Raise awareness** of the issues affecting cognitive health among African Americans by building the capacity of African American congregations to become an integral partner in prevention, disease management, caregiving, and engagement in clinical studies;
- » **Train health professionals** regarding issues affecting cognitive health among African Americans via partnerships with the National Black Nurses Association (NBNA) and National Medical Association (NMA); and
- » **Engage faith institutions** in public health initiatives using its Faith-Based Community Mobilization Model.

Public awareness of and education on Alzheimer's and other dementias is a major component of The Balm In Gilead's cooperative agreement. The nonprofit

developed a brain health website that provides culturally-tailored information for African Americans and others. To bring information and education into communities, The Balm In Gilead initiated the Memory Sunday campaign. On the second Sunday of June, congregations nationwide educate their members about brain health, treatment, and research on Alzheimer's, and dementia caregiving for persons living with dementia. Faith communities that sign up for Memory Sunday can access a toolkit, obtain promotional materials, and receive training. In a more recent phase of work, The Balm in Gilead began assisting regional health ministries with finding ways to integrate cognitive health into their year-round health ministry work. Recognizing the important role of healthcare professionals, especially physicians and nurses, The Balm In Gilead created training regarding the increased physical and societal burdens associated with Alzheimer's and other dementias within the African American community. Providers and clinicians learn culturally-tailored approaches to improve overall patient care and effectively support caregivers impacted by Alzheimer's dementia. From 2016-2018, partnerships with NBNA and NMA and their chapters trained over 500 clinicians in 17 regions across the United States. A component of The Balm In Gilead's annual Healthy Churches 2020 National Conference is the training and dissemination of resources that increase awareness of cognitive health among African Americans. In addition to its national conference, the organization conducted five regional forums on healthy aging, which includes brain health, targeting persons 50 and older. ●

MODIFIABLE RISK FACTORS FOR COGNITIVE DECLINE AND DEMENTIA

Researchers do not yet fully understand what causes Alzheimer's disease, but it may be a combination of **genetic**, **environmental**, and **lifestyle** factors that affect the brain over a long period of time. While some of these factors cannot be altered (such as advancing age and family history), others may be modifiable to reduce risk of cognitive decline and dementia.

Several scientific panels have examined the increasing body of evidence regarding modifiable risk factors related to cognitive decline and dementia. They have examined this topic from varying perspectives and have utilized different review methodologies and standards, which account for variations in the conclusions reached by these groups. The most recent expert reports include the following.

- » Institute of Medicine, 2015: **Cognitive Aging: Progress in Understanding and Opportunities for Action**. The report discusses physical activity; cardiovascular risk factor (high blood pressure, diabetes, and smoking) reduction and management; and discussions with healthcare providers about health conditions and medications.
- » Alzheimer's Association (in *Alzheimer's & Dementia*, 11(6):718-726), 2015: **Summary of the Evidence on Modifiable Risk Factors for Cognitive Decline and Dementia: A Population-Based Perspective**. The report discusses regular physical activity; management of cardiovascular risk factors (diabetes, obesity, smoking, and hypertension); healthy diet; and lifelong learning/ cognitive training.
- » National Academies of Science, Engineering and Medicine, 2017: **Preventing Cognitive Decline and Dementia: A Way Forward**. The report discusses cognitive training; blood pressure management in people with hypertension; and increased physical activity.
- » The Lancet Commission on Dementia Prevention, Intervention and Care (in *The Lancet*, 390(10113):2673-2734), 2017: **Dementia Prevention, Intervention and Care**. The report discusses active treatment of hypertension in mid-life; childhood education; exercise; maintaining social engagement; reducing smoking; and management of hearing loss, depression, diabetes, and obesity. ●



M = MONITOR & EVALUATE

Outcome: **ENHANCED NATIONWIDE AND STATE DATA**

- M-1** Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.
- M-2** Support national data collection on dementia and caregiving.

Surveillance is a fundamental and essential public health tool for understanding the prevalence of disease, health risk factors, preventive health behaviors, and burden of diseases and conditions. Data gathered can inform strategies to reduce disease risk and apply effective interventions to lessen the burden of disease. The BRFSS is an established data collection tool used in every state, the District of Columbia, and the U.S. Territories.

The BRFSS Cognitive Decline Module asks about subjective cognitive decline, the potential difficulties it may cause with everyday activities, and whether people have discussed their memory challenges with a healthcare professional. The companion Caregiver Module includes questions about caregiving status and the caregiving situation, care recipient's health issues, and prospects for future caregiving needs.

These two BRFSS modules offer states an efficient mechanism for collecting data that affords comparisons with other states. Past use of the data indicate they can be instrumental in communicating the impact of cognitive problems and caregiving to state leaders, and facilitate understanding of their relationship with other chronic health conditions and health behaviors.

State public health agencies can also participate in additional national data collection efforts beyond BRFSS. One opportunity, for example, is to assess quality of services and use through Merit-based Incentive Payment System and Physician Quality Reporting System measures. Such data, when reported, is useful to set priorities, inform policies, communicate impact, and monitor trends. Participation in national data collection efforts helps states to learn from each other and compare burden and other impacts of Alzheimer's and other dementias and caregiver health. ●

Healthy Aging Data Portal

CDC's Healthy Aging Data Portal contains data on cognitive health and caregiving from the BRFSS modules as well as many other key indicators of health and well-being, screenings and vaccinations, and mental health among older adults at the national and state levels.

cdc.gov/aging/agingdata/index.html

COMPELLING DATA

In 2015–2016, 49 states, the District of Columbia, and Puerto Rico used the BRFSS Cognitive Decline Module, generating a nationwide sample of more than 227,000 respondents aged 45 and older. CDC analysis of these results indicates:

- » 11.2% of U.S. adults aged 45 and older report subjective cognitive decline (SCD);
- » Among people with SCD, 50.6% reported having functional limitations because of their SCD;
- » 15.2% of adults aged 45 and older with any chronic disease reported SCD;
- » More than one in eight (13.8%) of all adults who live alone reported SCD.⁴⁶

In 2015–2016, 38 states, the District of Columbia, and Puerto Rico implemented the BRFSS Caregiver Module, generating a sample of almost 233,000 respondents aged 18 and older. Of those respondents, nearly 50,000 reported providing regular care or assistance to a loved one with a health problem or disability, and nearly 5,000 did so primarily because of dementia or other cognitive impairment.⁵³

Ongoing collection of state-level data on subjective cognitive decline and caregiving is important in order to assist state health officials and policymakers with projections and planning for services and implementing programs related to Road Map Actions.

Outcome: IMPROVED DECISION MAKING USING STATE AND LOCAL DATA

- M-3** Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.
- M-4** Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.
- M-5** Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.



In New York, annual evaluations help shape and refine an extensive statewide dementia support initiative. Learn more on page 52.

Data specific to state and local areas can be invaluable in shaping priorities, policies, and programs tailored to the unique needs in those areas. Past and current data systems have produced a wealth of information—much of which has yet to be mined for public health purposes—to address Alzheimer’s and other dementias. A few examples are: death certificate data (particularly before the age of 80), Public Health Accreditation Board data, livability index data, claims data from all-payer claims databases, data from aging networks, health department accreditation findings, and hospital and community health needs assessments. Examining these data in new ways with pertinent public health questions in mind—using, for example, social network analyses, policy scans, and economic models—can be revealing and beneficial in informing actions that can be taken by state health leadership, legislators, health plans, and more. (A summary of potential data sources and methods can be found in the *Alzheimer’s Association Needs Assessment Toolkit*, alz.org/publichealth).

Effective public health practice relies on evaluation of training and programmatic activities to determine what difference they made—and for whom. Incorporating evaluation into newly developed and existing efforts across the care spectrum could be planned during early design phases in order to adequately assess quality, reach, and effectiveness. This applies at all levels of care: healthcare delivery, public health, first

responders, law enforcement, community programs, hospitals, caregivers, home- and community-based services, etc. Evaluation of current training and support programs is necessary to identify evidence-informed interventions for widespread distribution.

Lastly, the projected increase in people with dementia and their caregivers cannot be ignored. The majority will live in home and community settings; others will eventually need nursing homes or other residential care. They will need expanding numbers of social workers, adult day workers, healthcare professionals, community-based and long-term care service providers, occupational therapists, and transportation providers to help them to remain part of the fabric of their communities. Estimating the types and quantities of professionals to support this growing population is paramount if the nation is to be prepared. Understanding gaps in workforce readiness is the first step to developing effective solutions. ●

COMPELLING DATA

- » Current projections indicate that the number of people with Alzheimer's dementia will nearly triple in the next 35 years.¹
- » More than half of caregivers for people with dementia have low or no knowledge of formal support services in the community.⁵⁴
- » While many interventions, services, and supports exist for people with dementia and their caregivers, they are often disconnected and may not be widely available or easily accessible to the populations in need.
- » Many Americans have not planned or saved for long-term care expenses.⁵⁵

IV

THE HEALTHY BRAIN INITIATIVE: DEVELOPING THE THIRD ROAD MAP



In 2005, the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC) created the Healthy Brain Initiative—a collaborative effort to advance public health awareness of and action on Alzheimer's disease as a public health issue. Healthy Brain Initiative partners work together to better understand the public health burden of cognitive impairment through surveillance; build a strong evidence base for policies, communication, and programmatic interventions for promoting cognitive health and addressing cognitive impairment and caregiving; and translate that foundation into effective public health practice in states and communities.

The first major document to advance these goals was *The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health* (2007), which served as a catalyst for numerous accomplishments on the part of multiple stakeholders. Similarly, the second Road Map, *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*, is noted for stimulating the growing public health response to dementia. Since publication of the first Road Map, implementation of specific Road Map actions has increased year over year.

In updating and producing this third iteration, a Leadership Committee (see Appendix A) met over a six-month period to examine progress to-date and identify leading public health issues for the next five years. The Committee identified actions from the previous Road Map that had not been accomplished and issues that would require continued effort in the coming years. Five overarching issues emerged and formed the basis for small workgroups on risk identification and risk reduction, diagnosis, education and training, caregivers, and evidence on impact of the disease. Each workgroup (see Appendix B) engaged a wider range of stakeholders at national, state, and community levels—including content experts, practitioners, and decision makers—to determine an appropriate, attainable, and feasible set of proposed actions for state and local public health and their partners to implement between 2018 and 2023. Proposed actions were compiled, discussed, and amended by the Leadership Committee. What emerged was the action agenda found in Section III of this Road Map. Leadership Committee members, stakeholders, and subject matter experts all reviewed draft versions of this Road Map (see Appendix C for the full array of actions by topic area).

The Leadership Committee views this Road Map as a dynamic guide based on best practices and evidence documented at the time of publication. Committee members acknowledged that the science on cognitive health and Alzheimer’s and other dementias is evolving. New evidence and developments continue to emerge, often with implications for public health. Implementation of this Road Map, just like its development, should take into consideration the latest evidence and adopt newly-identified best practices. ●

The Healthy Brain Initiative

The Healthy Brain Initiative is designed to spread understanding of and support for cognitive aging as a central part of public health practice.

Rapid Development of Science: FINGER to U.S. POINTER

Findings from the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability study (the FINGER study), which were released in 2015, indicated that it is possible to delay cognitive decline by using a multi-component lifestyle intervention among older at-risk individuals.* Building on these findings, the Alzheimer's Association is funding U.S. POINTER, a two-year clinical trial to evaluate whether lifestyle interventions that simultaneously target many risk factors protect cognitive function in older adults who are at increased risk for cognitive decline. U.S. POINTER is part of a larger, international effort known as World Wide FINGERS and includes research in Europe, Australia, Singapore, and China to similarly test multi-component lifestyle interventions.

The U.S. POINTER is the first study to examine this combined multi-dimensional intervention in a large-scale U.S.-based population. Alzheimer's Association offices nationwide will participate in intervention delivery to set the stage for an accessible and sustainable community-based model for prevention. More detail can be found at: alz.org/us-pointer/. ●

* Ngandu T, Lehtisalo J, Solomon A, Levälahti E, Ahtiluoto S, Antikainen R, et al. A 2-year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): A randomised controlled trial. *Lancet* 2015;385 (9984):2255-63.





Public health practitioners can learn by example from state and local public health agencies who responded to the growing dementia crisis by implementing actions from the Healthy Brain Initiative Road Map. These short summaries highlight real-world examples of how public health is taking action in response to Alzheimer's and other dementias in their own communities. ●

Additional Guidance on Public Health Implementation

Many other examples and resources to help the public health community implement the Road Map are available at alz.org/publichealth.



Promoting Brain Health

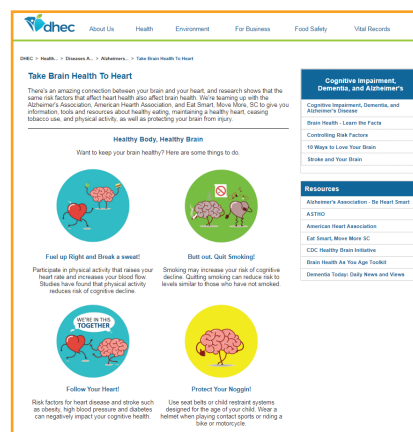
To raise awareness about brain health, the South Carolina Department of Health and Environmental Control (SC-DHEC) partnered with the Alzheimer's Association South Carolina Chapter, the American Heart Association, and Eat Smart Move More South Carolina on a multi-layered campaign: *Take Brain Health to Heart*. The multi-component initiative was purposefully designed to reach rural and racial/ethnic minority populations that have a higher prevalence of cardiovascular risk factors that also related to increased risk of cognitive decline and possibly dementia.

Campaign elements included a new website (see image), health education materials, social media messages, three radio PSAs, and an online pledge in which people commit to keeping their body, heart, and brain healthy. The messaging was designed to mobilize South Carolinians to protect their brain health by being more active, eating better, and taking other steps. Benedict College, a historically African American institution, and the University of South Carolina Prevention Research Center helped promote the campaign.

Over the course of a seven-week health-campaign period, the DHEC-led collaboration had nearly 1,500 PSAs aired on four radio stations, reaching over 2.7 million people from diverse demographic backgrounds. Print educational materials and social media reinforced

the messaging, reaching over 31,000 people and 6,500 social media users through these channels. South Carolinians were encouraged to visit the SC-DHEC brain health webpage and smokers to call the agency's tobacco quitline.

As part of the campaign, SC-DHEC offered a monthly drawing for a fitness tracker device. To enter the drawing—advertised on the SC-DHEC website—people pledged to engage in seven behaviors that promote brain health, such as exercising and using a seat belt. As another part of this campaign, SC-DHEC developed various educational materials: a floor display, brochure, factsheet, and social media resources. Messages focusing on risk factors for cognitive decline were synced with existing messages regarding exercise, smoking cessation, hypertension, diabetes, obesity, and traumatic brain injury. ●





Educating African Americans, Asian Americans and Pacific Islanders about Dementia

As a partner in Washington State's Dementia Action Collaborative, a voluntary statewide workgroup charged with implementing the state's Alzheimer's plan, the Washington Department of Health (DOH) began a two-part initiative to increase awareness of brain health among African Americans and encourage cognitive assessments among Asian Americans and Pacific Islanders (AAPIs). These efforts support implementation of the *Washington State Plan to Address Alzheimer's Disease and Other Dementias* regarding culturally-appropriate strategies to educate the public about reducing risk for cognitive decline and possibly dementia.

DOH prioritized African American women as a main audience for cognitive health education based on national prevalence data. DOH then reviewed evidence-based, brain health messages developed by the Alzheimer's Association for the Healthy Brain Initiative. After securing approval from Washington's state health officer, DOH partnered with the Seattle-based, nonprofit Center for MultiCultural Health (CMCH) to help tailor and disseminate brain health messages to African American audiences. CMCH identified African American churches as a promising venue to reach women and recommended creating hand fans printed with culturally-tailored messages (see image).

Additionally, the National Asian Pacific Center on Aging (NAPCA) and the University of Washington Healthy Brain Research Network (UW-HBRN) partnered to

conduct outreach and education for Seattle AAPIs. Through six focus groups, they solicited input from local Chinese and Japanese adults with at least one living relative age 65 or over. The focus groups assessed the acceptability of messages developed by the University of Pennsylvania HBRN Center to encourage non-Hispanic white or African American urban adults concerned about the cognitive health of an older relative to accompany that relative to an appointment with a healthcare provider. NAPCA and UW-HBRN released two briefs on their findings: *Connecting with AAPIs about Dementia: An Action Guide for Service Providers* and *Connecting with AAPIs about Dementia: An Action Guide for Policymakers*. Each offers dementia resources and information on treatment options. The importance of early detection of cognitive impairment is emphasized in the guide for service providers, as these professionals play a crucial role in facilitating older AAPIs' and their caregivers' access to cognitive assessment resources. The Dementia Action Collaborative provided guidance on the action briefs and also helped to disseminate them. UW-HBRN received a 2017 Seattle Innovation Fund grant for its work on the AAPI action briefs. ●





Using Social Media to Promote Engagement

The Puerto Rico Department of Health worked with the Prevention Research Center's South Carolina Healthy Brain Research Network at the University of South Carolina to implement the *Puerto Rico Alzheimer's Action Plan*, with a special focus on education and empowerment of individuals and families. One component was a collaborative educational initiative called *Un café por el Alzheimer*.⁵⁶ With special attention toward decreasing stigma, this initiative used social media and in-person gatherings to support informal but structured conversations with experts about Alzheimer's disease, risk factors, diagnosis, pharmacological and non-pharmacological treatments, management of behavioral changes, and healthy living. The Alzheimer's cafés enabled participants to have informal conversations in coffee shops across the island. The social media efforts built off of these in-person conversations to reinforce key messages as a way of engaging and educating the wider audience. Participants could raise questions at any time and were encouraged to share testimonials and comments. At the end of the gatherings, the participants were invited to continue the conversation online by following the Facebook page.

Pre/post surveys in four sessions with a total of 212 participants showed improved knowledge and high satisfaction ratings. All participants said they learned something new from the program, and 80% said most of the information presented was new to them. A total of 250 messages were posted on the *Un café por el Alzheimer* community Facebook page over a seven-month period. An average increase of nearly 65% in the number of people reached by the Facebook page offered evidence of the program's success in helping participants remain actively engaged while fostering social support and reducing stigmas and myths surrounding the disease.⁵⁷ ●



Encouraging Advance Care Planning for People with Dementia

Maryland's population of people with Alzheimer's dementia is projected to rise—from 110,000 people in 2018 to 130,000 in 2025, an 18% increase in eight years. As the number of people with dementia rises, so too does the need to assist families in planning for future care needs. The passage of Maryland House Bill 1385 in May 2016 allowed the state to increase advance care planning among families impacted by dementia. Among other mandates, the law directs the Maryland Department of Health (MDH) to encourage the use of electronic advance directives, develop an electronic platform to connect with healthcare providers at point-of-care using the state-designated health information exchange, and conduct outreach to increase public awareness of the Advance Directive Program. An early assessment found that advance care planning in Maryland is offered primarily through hospitals and hospice providers, with limited free care-planning services available through Maryland Legal Aid and Maryland Volunteer Lawyers Service Pro Bono Resource Centers.

To increase advance care planning, MDH collaborated with the Maryland Faith Health Network to lead a year-long series of community engagement activities on electronic advance directives. More than 500 Marylanders learned about advance care planning through health fairs, faith-based events, and end-of-life seminars. In addition, three local health improvement coalitions hosted seven advance-planning educational

sessions, with a combined total of 144 participants. More than twice as many participants were able to identify core legal and financial advance planning documents post-session (25%) as pre-session (10%). Also, a greater number of participants (post-session compared with pre-session) reported understanding the importance of involving people with cognitive impairment in advance planning.

The medical director of the MDH Center for Chronic Disease Prevention and Control served as a co-chair (along with a representative from the Maryland Department of Aging) of the governor-appointed Virginia I. Jones Alzheimer's Disease and Related Disorders Council during this time. The Council monitors implementation of the *Maryland State Plan on Alzheimer's Disease and Related Disorders*. As a tenet of the Maryland State Plan, MDH used this unique opportunity to engage partners to discuss potential cognitive health education and establish interventions in Maryland's public health programming. ●



Preparing First Responders for Interactions with People with Dementia

Emergency Medical Service (EMS) providers receive many calls to assist people with Alzheimer's and other dementias. However, they have little or no formal training to prepare them for the unique physical, behavioral, and communication challenges related to dementia.

To develop a dementia-competent workforce throughout Colorado, the Colorado Department of Public Health and the Environment (CDPHE) partnered with the Alzheimer's Association Colorado Chapter to deliver its *Approaching Alzheimer's: First Responder Training Program*. CDPHE marketed the availability of the free, in-person training through its internal networks and all 11 of Colorado's Regional Emergency and Trauma Advisory Councils.

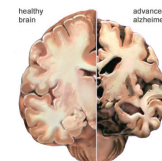
The training helps first responders serve people with Alzheimer's in situations involving wandering, disasters or other emergency situations, abuse or neglect, "shoplifting" because they forgot to pay, and driving. At the completion of training, participants receive a poster—*Tips for EMS Working with People with Alzheimer's*—to display and reinforce effective responses. ●

TIPS FOR EMS WORKING WITH PEOPLE WITH ALZHEIMER'S

THERE ARE 67,000 PEOPLE AGE 65 AND OLDER WITH ALZHEIMER'S DISEASE IN COLORADO. THAT NUMBER IS EXPECTED TO GROW TO 76,000 BY 2020.

ALZHEIMER'S DISEASE AND OTHER RELATED DEMENTIAS

are progressive impairments of cognitive function that affects a person's thinking, emotions and behavior. Signs include: memory impairment, aphasia (language disturbance), apraxia (impaired motor function), agnosia (failure to recognize otherwise-familiar objects) and disturbance in executive function (failure to plan, organize and think abstractly). These are not mental illnesses.



WHEN ENCOUNTERING A PERSON WITH ALZHEIMER'S



COMMUNICATE

Use the **TALK** tactics:

- Take it slow
- Ask simple questions
- Limit reality checks
- Keep eye contact

DO

- Approach slowly and from the front
- Introduce yourself and explain you are there to help
- Remain calm, smile and use a friendly voice
- Speak slowly and allow time for response (15-30 seconds)
- Change the subject to something pleasant if the person becomes agitated

DON'T

- Take comments personally
- Approach from behind without warning
- Argue or correct the person
- Touch without asking/ explaining
- Forget about co-morbidities

24/7 HELPLINE 800.272.3900
ALZ.ORG/CO

alzheimer's  association®



COLORADO
Department of Public
Health & Environment



Supporting Caregivers

Because New Mexico has a shortage of nurses and long-term care facilities (especially in rural areas),⁵⁸ state health officials realize the importance of helping people living with dementia stay in their homes as long as possible—a situation that is typically preferred but depends upon the availability of in-home caregivers.

To improve support for caregivers of people living with dementia, the New Mexico Department of Health partnered with the state's Aging and Long-Term Services Department to encourage caregivers to participate in two important courses.

Savvy Caregiver is a free, 14-hour educational program for caregivers of people with memory loss or dementia. Graduates learn how to handle the challenges of caring for a family member with Alzheimer's and other dementias and care for themselves.

Another set of courses for chronic disease self-management is an evidence-based intervention developed by Stanford University to help educate persons with chronic conditions and their caregivers. Topics include managing common chronic disease issues, participating in treatment decisions, problem-solving and adhering to treatment plans, making advance directives, and maintaining a healthy lifestyle.

The health department chose to co-market the programs because older adults living with dementia are more likely than their peers to have multiple chronic conditions, including hypertension, heart disease, or diabetes. Also, older caregivers for a spouse with dementia are twice as likely to have had a stroke and 50% more likely to have cardiovascular disease than married non-caregivers of the same age.⁵⁹ As an additional way to support people affected by dementia, the health department posted information on cognitive decline and dementia on the New Mexico Department of Health website. Over an 18-month period, the website had 1,384 page views or an average of about 75 per month. ●



Improving Early Detection during Medicare Annual Wellness Visits

Utah is one of the most rural and fastest growing states in America. Currently, about 11% of the state's three million residents is aged 65 or older, and the state has about 30,000 people with Alzheimer's dementia, which is expected to rise 40% to 42,000 by 2025. Diagnoses of dementia in later stages may lead to higher levels of disability while receiving care, delays in accessing timely primary care, lack of care coordination, and duplication of services.

To improve early detection of cognitive impairment, a focus of *Utah's State Plan for Alzheimer's and Related Dementias*, the Utah Department of Health (UDOH) contracted with HealthInsight, a quality improvement organization. HealthInsight interviewed providers about their experiences and processes conducting cognitive assessments during the Medicare Annual Wellness Visit (AWV). While some providers reported performing routine cognitive assessments during the AWV, others reported screening only under certain conditions, such as patient requests, patient has specific risk factors for cognitive decline, etc. Providers also expressed a need for better tools to detect early-stage memory loss. The resulting report, *Cognitive Assessments during Medicare Annual Wellness Visits*, was a collaborative product from HealthInsight; UDOH; the Center for Alzheimer's Care, Imaging and Research at the University of Utah; and Intermountain Medical Center.

Actions in the Healthy Brain Initiative Road Map include improving healthcare providers' ability to recognize the early warning signs of dementia and

knowledge of validated cognitive assessment tools. As a step in this process, UDOH sent the study report to all Utah primary care physicians, along with a list of resources for people with cognitive impairment and a recommendation from UDOH's executive director for routine cognitive assessment during the AWV using the Mini-Cog as the primary assessment tool, followed by the Montreal Cognitive Assessment tool (MoCA).

The project deepened UDOH's understanding of some challenges that physicians face in assessing cognition during the AWV, one of which is uncertainty about which validated tool to use. Receiving clear recommendations from UDOH's executive director may begin increasing physician use of the tools during AWVs or other occasions in which a physician has concerns about potential cognitive impairment. Use of validated early detection tools helps physicians assess cognitive functioning and detect potential concerns early, the first step in increasing early diagnoses.

With some legislative support, UDOH plans to continue collaborating with HealthInsight to develop:

- » Cognitive assessment training for primary care physicians and their office staff that will include use of recommended tools and workflow improvement techniques to instill a reliable, repeatable process in clinics.
- » Cognitive health and wellness toolkit to help health professionals navigate the cognitive assessment process, including assessment, diagnosis, referrals, and community resources. ●



Training Professionals through *Dementia Dialogues*

People with Alzheimer's and other dementias have care needs that are often challenging and demanding. For example, as dementia progresses, affected persons may have trouble recognizing when they are unhealthy or not safe; also, they often have problems communicating. Many professionals in home, community, and long-term care settings have not received adequate training on how to adjust care for the unique challenges of dementia. As a result, both professionals and unpaid caregivers (especially in rural areas with limited healthcare access) may not know how to use behavioral cues and other strategies to reduce injuries, avoid medication problems, and keep chronic conditions in check to minimize unnecessary hospitalizations.

Dementia Dialogues is an evidence-informed training to educate professionals working in the community, caregivers, and family members about dementia. Developed and tested by the Arnold School of Public Health, University of South Carolina, *Dementia Dialogues* can be cost-effectively delivered throughout a state, including rural areas. Over the five-session training, participants learn strategies for effective communication, ways to promote independence in activities of daily living, and mitigating challenging behaviors. Specifically, they gain skills in recognizing and using non-verbal cues, giving the care recipient a routine, responding if the person with dementia behaves aggressively, and helping caregivers and care

recipients devise care plans. This type of training for professionals and caregivers helps the state develop a more dementia-capable workforce.

Convinced of its value, the Utah Department of Health (UDOH) initiated *Dementia Dialogues* training in 2017. The University of South Carolina prepares a cadre of certified individuals who then are able to deliver free training in their communities. Those completing the training earn a dementia specialist certificate and 7.5 continuing education hours. UDOH secured sponsorships from Gamma Rho Chapter of Sigma Theta Tau International, Solstice Home Health & Hospice, Sunrise Senior Living, University of Utah, and funeral homes. Area agencies on aging and a local news radio station assisted with pro bono marketing of local courses.

By applying the knowledge and best practices embedded in *Dementia Dialogues*, both professionals and caregivers can better adapt chronic disease management, reduce agitation and difficult behavior associated with communication problems, and provide care to help optimize functioning. ●



Using Data to Expand Caregiver Services

Since the 1980s, the New York State Department of Health (NYSDOH) has supported people with Alzheimer's and other dementias and their caregivers. NYSDOH developed strong partnerships with many organizations, including the Alzheimer's Association, healthcare organizations, and researchers across New York State. These partnerships—bolstered by solid data documenting the impact of evidenced-based support models and state surveillance data on caregiving and cognitive impairment—enabled an unprecedented expansion of caregiver and clinical supports throughout the state.

To help keep people living with dementia in the community longer and reduce caregiver stress, NYSDOH proposed an initiative to expand dementia-related services statewide. With bipartisan legislative approval, the resulting NYSDOH Alzheimer's Disease Caregiver Support Initiative (ADSCI) is grounded in an effective model program developed by New York University (NYU) and others. Funded at \$25 million annually, ADSCI promotes early diagnosis and has protocol for providing education, care consultation, and a plan for medical and social services to persons living with Alzheimer's and the caregiver, thereby helping facilitate clinical-community linkages. Components include:

- » Ten teaching hospitals across the state are funded at \$500,000 each year for five years for early detection, education of professionals, and consultation for primary care providers when they need help with clinical decisions.
- » Ten regional contractors, covering every county in the state, are funded at \$1.5 million per year to deliver a wide range of supportive services that promote the mental and physical well-being of caregivers. Services include support groups, care consultation, family consultation, respite care, and education and wellness programs for caregivers.
- » A statewide contractor coordinates caregiver support, community education and partnerships with related organizations with \$5 million per year.

The first year of ADSCI enabled organizational capacity-building, including scaling up infrastructure, training, and hiring staff. Medical and service providers reported a growing awareness and demand for services as they expanded outreach activities. Almost all providers reported forming new partnerships, suggesting enhanced coordination between organizations and a strengthened network of providers. In the first year, community support services for people with dementia and their caregivers reached approximately 13,000 individuals and families; once the infrastructure reaches maturity, it will serve many more New Yorkers. The program evaluation for year 1 revealed barriers to expansion including home health aide workforce shortages and a lack of respite providers, particularly in rural areas. In addition, over one third of providers experienced challenges hiring and retaining community support staff with experience in dementia. ●

VI

CONCLUSION



The need for urgency is clear as the number of people affected by Alzheimer's and other dementias continues to rise. A quick and strategic collaboration between public health and public and private partners could prevent cognitive health and other issues of aging from consuming our healthcare system. Productivity, independence, and quality of life for millions of Americans depend on the nation's collective ability to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers.

Progress will require collaboration across sectors and by state and local agencies to improve systems and enhance service delivery in each and every community. This Road Map is a resource to assist with leveraging sustained partnerships to implement actions in addressing the Alzheimer's crisis. ●



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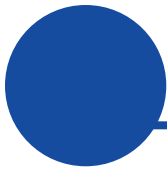
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APPENDIX C: ACTIONS BY TOPIC AREA

| EDUCATE & EMPOWER | | | | | |
|--|---|---|--|--|---|
| Actions | Risk identification and reduction | Diagnosis & quality of care | Caregiving | Education and training for professionals | Data and evidence for action |
| E-1 Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis. |  |  | | | |
| E-2 Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span. |  | | | |  |
| E-3 Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being. |  | |  | | |
| E-4 Promote prevention of abuse, neglect, and exploitation of people with dementia. |  |  | | | |
| E-5 Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia. | |  |  | | |
| E-6 Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia. | |  |  | | |
| E-7 Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence. |  | |  | |  |


















DEVELOP POLICIES & MOBILIZE PARTNERSHIPS

| Actions | Risk identification and reduction | Diagnosis & quality of care | Caregiving | Education and training for professionals | Data and evidence for action |
|--|---|---|--|---|---|
| P-1 Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia. |  |  |  | | |
| P-2 Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about brain health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces. | | | |  |  |
| P-3 Support better informed decisions by educating policymakers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem. | | | |  |  |
| P-4 Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes. | |  | | |  |
| P-5 Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers. |  | |  | | |
| P-6 Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia. | |  |  |  | |

ASSURE A COMPETENT WORKFORCE

| Actions | Risk identification and reduction | Diagnosis & quality of care | Caregiving | Education and training for professionals | Data and evidence for action |
|---|---|---|---|---|---|
| W-1 Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve. |  | | |  |  |
| W-2 Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being. | | |  |  | |
| W-3 Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action. | |  |  |  |  |
| W-4 Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management. | |  |  |  | |
| W-5 Strengthen the competencies of professionals who deliver healthcare and other care services to people with dementia through interprofessional training and other strategies. | |  | |  | |
| W-6 Educate healthcare professionals about the importance of treating co-morbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia. |  |  | |  | |
| W-7 Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services. | | |  |  | |

MONITOR & EVALUATE

| Actions | Risk identification and reduction | Diagnosis & quality of care | Caregiving | Education and training for professionals | Data and evidence for action |
|--|---|---|---|---|---|
| M-1 Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022. |  | |  | |  |
| M-2 Support national data collection on dementia and caregiving. | |  |  | |  |
| M-3 Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving. |  |  |  | |  |
| M-4 Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact. | | |  |  |  |
| M-5 Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers. | |  |  |  |  |

APPENDIX D: REFERENCES

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The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's disease®.