



HEALTHYBRAIN INITIATIVE

State and Local Road Map
for Public Health, 2023–2027



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About the Cover: *The cover represents individuals across the life course and the dementia continuum, and highlights the importance of caregivers. The bottom left photo features members of the 2022–2023 Alzheimer’s Association Early-Stage Advisory Group and their care partners. Members of this group also participated in the review of the HBI Road Map.*

FOREWORD

Welcome to the fourth edition of the Healthy Brain Initiative (HBI) Road Map. We are glad you are joining the thousands of public health practitioners working to improve brain health nationwide.

You will see a greater emphasis on partnerships and health equity in this new edition, reflecting feedback and guidance from over 100 experts working in health departments, nonprofits, academic institutions, health systems and the private sector. The changes in this Road Map also recognize the stronger evidence base around risk reduction and continued progress in the fields of brain health, dementia and caregiving. The social determinants of health, which have measurable impacts across many chronic diseases, also affect brain health. Public health agencies can be conveners and leaders as this scientific work advances and is translated into action for communities.

Please share your successes, discuss your challenges and help grow the community of public health professionals working to take a life course, public health approach to brain health. Whether you are getting started with one action or have a comprehensive plan, your efforts are contributing to the public health impact and improving the lives of individuals across your communities. Together, through our collective action, we can increase knowledge, awareness, and access to services that promote brain health and improve the quality of life for people affected by dementia.

HBI Road Map Leadership Committee Co-Chairs,



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ACTION AGENDA AT A GLANCE

P STRENGTHEN PARTNERSHIPS AND POLICIES

Increase community partnerships

P-1 Convene and leverage diverse and inclusive multi-sector coalitions to strengthen supportive, equitable policies within communities, workplaces and health care settings across the life course of brain health.

P-2 Utilize community-clinical linkages to improve equitable access to community-based chronic disease prevention, dementia support and healthy aging programs.

P-3 Partner across the community to promote equitable access to services, supports and quality care for people living with dementia and their caregivers.

P-4 Partner with public and private health plans to implement evidence-informed policies and programs that impact social determinants of health related to brain health and cognitive impairment.

Increase integration with other chronic disease efforts

P-5 Build on existing state and local public health chronic disease, healthy aging, and disability programs and policies to address social determinants of health and improve health equity related to brain health.

Increase policy action and implementation

P-6 Equip policymakers with information on risk factors, the stigma associated with cognitive impairment and the impact of social determinants of health; and offer evidence-informed policy options across the life course.

P-7 Join ongoing coalitions and partnerships to prevent or remediate abuse, neglect and exploitation of people living with dementia.

M MEASURE, EVALUATE AND UTILIZE DATA

Increase data availability, quality and utilization

M-1 Support implementation of the Behavioral Risk Factor Surveillance System (BRFSS) optional modules for Cognitive Decline and Caregiving and use the data to develop and inform programs and policies.

M-2 Supplement existing state, local and BRFSS data with data from health systems, health plans, pharmacies, and other health care providers and community organizations to better understand disparities and opportunities for improving equity.

M-3 Evaluate implementation of the HBI Road Map actions to identify successes and needed improvements.

Increase data-informed decision making and action

M-4 Translate data analyses and evaluation findings into state and community strategic and health improvement plans that support brain health across the life course and quality of life for people living with dementia and their caregivers.

M-5 Share findings with community organizations, agencies, policymakers and provider associations to help focus and inform community awareness efforts, resource needs, programs and policies, particularly for populations most impacted.

BUILD A DIVERSE AND SKILLED WORKFORCE

Reduce stigma and bias about cognitive decline

W-1 Provide evidence-informed training and informational resources for primary health care providers to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course.

Increase knowledge and skills of current and future workforce

W-2 Train current and future public health professionals about risk factors for cognitive decline and dementia and ways to integrate this information with other chronic disease prevention strategies.

W-3 Promote inclusion of the life course approach to brain health in licensing, certification and continuing education requirements for health care and allied professionals.

W-4 Strengthen training of community health and direct service workers about brain health across the life course to improve equitable care and quality of life for those living with cognitive decline and to support caregivers.

W-5 Partner with public safety and emergency response agencies to improve their ability to recognize and meet the needs of people living with cognitive decline and dementia.

ENGAGE AND EDUCATE THE PUBLIC

Increase public knowledge about brain health, risk factors for dementia and benefits of early detection and diagnosis

E-1 Engage diverse audiences to develop culturally responsive messaging about brain health, cognitive decline, healthy aging and caregiving.

E-2 Disseminate culturally responsive messaging to encourage conversations about brain health, cognitive decline, healthy aging and caregiving.

E-3 Engage with communities, especially those at highest risk, about risk factors for dementia and how people living with dementia can best thrive in their communities.

E-4 Embed cognitive decline risk factors into evidence-informed health promotion and chronic disease prevention awareness and education campaigns.

E-5 Partner with educational systems (K-12 and post-secondary) to include brain health and dementia in their curricula.

Increase public knowledge and use of services for people living with dementia and their caregivers

E-6 Enhance communication with people living with dementia, their families and caregivers about how to access services, care and social supports.

E-7 Ensure caregivers have information, tools and resources about their vital role and ways to maintain their own health and well-being.

INTRODUCTION

Since the initial creation of the Healthy Brain Initiative (HBI) in 2005, HBI partners have worked together to implement public health strategies that promote brain health, address dementia and support people with dementia and their caregivers. The Healthy Brain Initiative Road Map Series guides this effort by creating a framework for public health action. It reflects the longstanding collaboration between the Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC) to advance understanding and inclusion of cognitive decline as a central part of public health practice. This newest Road Map in the series — *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023–2027* — is a guidebook for state and local public health practitioners to address brain health in their communities.

Much has been learned about how public health systems can impact brain health. Public health systems are commonly defined as “all public, private, and voluntary entities that contribute to the delivery of essential public health services within a jurisdiction.”¹ The efforts of these systems have led to an increasing number of states and jurisdictions creating, updating and implementing plans that address brain health, cognitive impairment, dementia and caregiving. Their work has been accelerated by passage of the Building Our Largest Dementia Infrastructure for

Alzheimer’s Act (BOLD Act) (Public Law 155-406) in 2018.² The BOLD Act supports public health efforts for strengthening systems, environments and policies to promote risk reduction, improve early detection and diagnosis, prevent and manage comorbidities, avoid preventable hospitalizations and support dementia caregiving. This Road Map builds on the progress to date and advances equity by fully integrating brain health and caregiving into state and local public health practice and addressing social determinants of health that impact brain health across the life course.



The overarching vision of the HBI is that everyone deserves a life with the healthiest brain possible.

To help achieve this vision, the HBI Road Map's specific outcomes are to:

- » *Increase community partnerships*
- » *Increase integration with other chronic disease efforts*
- » *Increase policy action and implementation*
- » *Increase data availability, quality and utilization*
- » *Increase data-informed decision making and action*
- » *Reduce stigma and bias about cognitive decline*
- » *Increase knowledge and skills of current and future workforce*
- » *Increase public knowledge about brain health, risk factors for dementia and benefits of early detection and diagnosis*
- » *Increase public knowledge and use of services for people living with dementia and their caregivers*



The chapters of the Road Map address these outcomes in four domains with specific actions for each outcome. Data and examples are included throughout to help state and local health departments achieve these outcomes both individually and collectively. More information on the development of this Road Map and the members of the Leadership Committee and Workgroups can be found in the Appendices. ●



PUBLIC HEALTH AND DEMENTIA

THE PUBLIC HEALTH ROLE

“Public health promotes and protects the health of people and the communities where they live, learn, work and play.”³ To carry out this role, public health focuses on prevention strategies and employs a variety of tools at three points along the disease continuum. The three points of prevention, as defined by the Centers for Disease Control and Prevention (CDC), are:

Primary Prevention — or risk reduction — strives to intervene **before health effects occur**, through measures such as promoting healthy and safe behaviors (e.g., eating well, exercising regularly, not smoking), mandating safe and healthy practices (e.g., use of seatbelts and bike helmets), and limiting exposure to factors associated with a disease or health condition (e.g., asbestos, lead and mercury). Just as public health works to keep people physically healthy across the lifespan, public health must help people stay cognitively healthy.

Secondary Prevention — or early detection and diagnosis — aims to identify diseases **in the earliest stages**, before the onset of more severe symptoms (e.g., increasing awareness of symptoms, promoting early diagnosis and educating health care providers about the benefits of early diagnosis and intervention strategies). Public health plays a unique role in

This edition of the Road Map accelerates ongoing public health efforts to improve the lives of people with dementia and those who care for them.

- David P. Hoffman, Leadership Committee

building relationships between communities and health systems to ensure equitable access to detection and diagnostic services for all people.

Tertiary Prevention — or management of comorbidities — involves managing disease **post diagnosis** to minimize negative health and quality of life effects. Comorbidities occur when a person has more than one disease or condition at the same time. The public health framework takes a culturally tailored approach and encourages thinking about how a person’s preferences, other diagnoses, and circumstances impact their overall health (e.g., recognition and coordination of medications, notation of caregiver status in medical records). Tertiary prevention is also important when thinking about caregivers, who are influential in managing care and reducing complications, sometimes at the expense of their own health.⁴

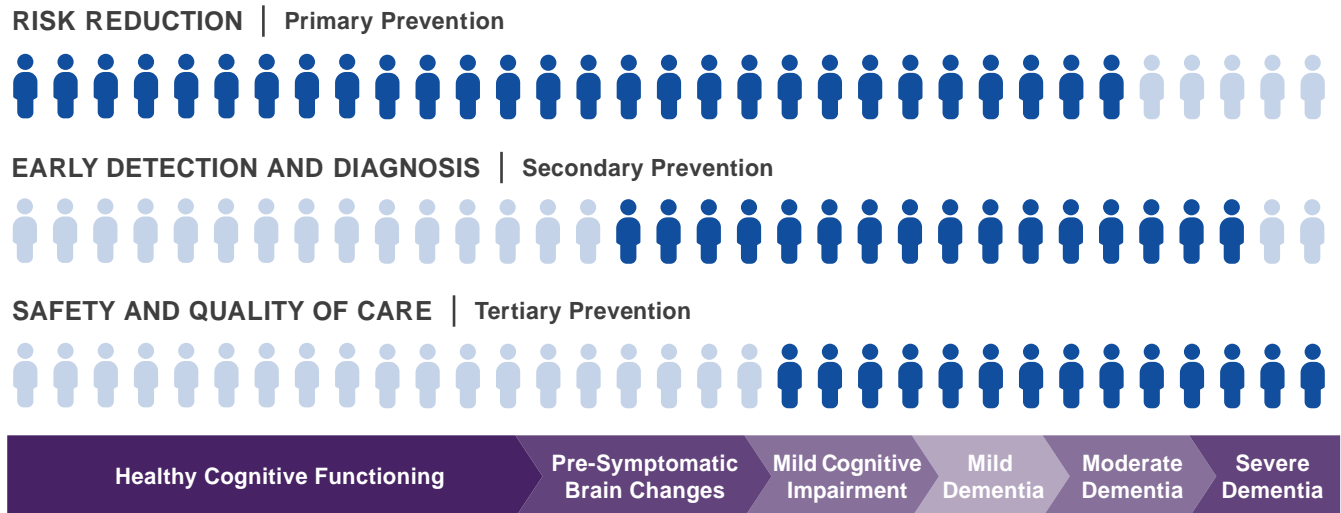
TAKING A LIFE COURSE APPROACH

Dementia, a general term for loss of memory and other thinking abilities serious enough to interfere with daily life, is most commonly caused by Alzheimer's disease, a degenerative brain disease. Other diseases that cause dementia include vascular disease, Lewy body disease, frontotemporal degeneration, Parkinson's disease, hippocampal sclerosis and mixed pathologies. There are many other diseases, disorders and conditions that can cause dementia symptoms. The variety of symptoms along with the age of onset, order, intensity and other characteristics of symptoms

experienced depend on the underlying causes, the lived experience of each individual and access to appropriate clinical and non-clinical supports.

Much like other chronic diseases, a diagnosis of Alzheimer's disease or other disease that causes dementia can be framed as a continuum along the life course. Figure 1 builds on the dementia continuum to overlay the layers of prevention. In early life and throughout the life course, **primary prevention can make a difference in sustaining cognitive function across a population.** Public health primary prevention strategies use the latest science on

Figure 1. Opportunities for Public Health Intervention Across the Dementia Life Course



There are opportunities for public health intervention across the dementia life course. The public health community can intervene across the points of prevention — primary, secondary and tertiary — to impact the brain health of the population. The figure shows the potential impact of the different prevention points throughout the continuum of dementia. Public health action is critical to reduce the risk of mild cognitive impairment, improve access to early detection and diagnosis and improve the safety and quality of care for people living with dementia.

how to maintain and promote a healthy brain and translate this research into educational messages, programs and policies. Several chronic conditions — and modifiable risk factors that can lead to these conditions — may increase the risk of cognitive decline and dementia. These include traumatic brain injury, midlife hypertension, midlife obesity, diabetes, physical inactivity, smoking, poor sleep quality and sleep disorders, poor diet quality, depression and hearing loss.⁵ Preventing, remedying or managing conditions that increase risk improves quality of life for individuals who develop cognitive impairment. Addressing these risk factors is also relevant for caregivers to maintain their own health as they care for others.

Some adults may experience changes in the brain that lead to cognitive decline. Mild cognitive impairment (MCI) is an early stage of memory loss or other cognitive ability loss (such as language or visual/spatial perception) that can be diagnosed by a health care professional. MCI is part of the continuum of cognitive impairment and can have many causes.⁶ Individuals with MCI maintain the ability to perform most activities of daily living independently. At this stage, **secondary prevention in the form of early detection and diagnosis is paramount.** An early diagnosis can improve the quality of care a person receives and the quality of life they enjoy, can slow the disease process, and may reduce the financial and emotional impact of the disease.⁶ Early detection of cognitive issues also allows clinicians to identify potentially reversible or treatable causes, including vitamin deficiencies and medication side effects.

MORE ABOUT MILD COGNITIVE IMPAIRMENT (MCI)

Subtle cognitive changes in memory and thinking are often a feature of “normal aging.” For some individuals, however, these changes are serious enough to be considered MCI. Individuals with MCI may have a higher risk of developing dementia.⁶ While not everyone with MCI will develop dementia, an estimated 15% of individuals with MCI develop dementia after two years, and about one-third of people with MCI develop dementia due to Alzheimer’s disease within five years.⁶

For those whose cognitive impairment further progresses, dementia symptoms become noticeable and the disruption to cognition and everyday life can range from mild to severe. At this point, **tertiary prevention strategies can connect the person living with dementia to treatment and support services to help preserve their independence and quality of life for as long as possible.** In addition, caregivers can help reduce complications such as wandering, medication mistakes and potential for dangerous situations. A strong public health response can help maintain the health, well-being, independence and quality of life for people living with dementia and their caregivers, and reduce associated costs. The most effective interventions actively involve

NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE

On January 4, 2011, the National Alzheimer's Project Act (NAPA) (Public Law 111-375) was signed into law. The Act required the Secretary of the United States (U.S.) Department of Health and Human Services (HHS) to create and maintain an integrated National Plan to overcome Alzheimer's disease. Five initial goals have been foundational to this plan. They are:

1. Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025
2. Enhance Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress

A new goal, added in 2021, prioritizes healthy aging:

6. Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias

The public health strategy presented in the HBI Road Map contributes to the achievement of these goals. Goals 4, 5 and 6 are most relevant to this Road Map because they align clearly with the Road Map domains and the Essential Public Health Services. Goal 4 is evident throughout the Engage and Educate the Public domain, while Goals 5 and 6 align to the Measure, Evaluate and Utilize Data domain. The intent of Goal 6 is to build the infrastructure for translating risk reduction interventions into health care and public health practices. In addition, Goal 6 addresses inequities in dementia, particularly those in Black and Hispanic communities, which lead to higher prevalence of dementia in those communities. The reduction of risk factors is woven through the Road Map.

caregivers and are tailored and flexible to meet the specific and evolving needs of individuals living with dementia and their caregivers.⁶

With new developments in dementia diagnosis and treatment on the horizon, public health can play a pivotal role in creating healthy communities that reduce

the risk of many chronic diseases and ensure equitable access to early detection, diagnosis, community-based supports and treatment across all populations. ●

COMPELLING DATA

Compelling data show that cognitive decline and dementia warrant serious, concerted public health attention. Many data points are featured in this section and in blue boxes throughout the Road Map.

The prevalence of MCI and dementia is large — and growing. An aggressive public health effort to reduce the prevalence of risk factors, such as high blood pressure, could result in an estimated 1.2 million fewer people with Alzheimer's in 2050.⁷

- » An estimated 10% of Americans aged 45 and older report subjective cognitive decline (SCD).⁸ SCD, self-reported worsening difficulties in thinking and memory that have not been measured objectively on assessment tests, is one of the earliest warning signs of future dementia risk.⁹
- » The number of people living with MCI increases with age. Roughly 16.6% of people aged 65 and older have MCI.¹⁰ One in 4 individuals aged 80 to 84 experience symptoms of MCI.¹⁰
- » An estimated 6.7 million Americans are living with Alzheimer's in 2023. By 2060, this number is expected to more than double.⁶
- » Alzheimer's disease was the sixth leading cause of death in the U.S. in 2019, and the seventh leading cause of death in 2020 and 2021, with the emergence of COVID-19. Alzheimer's kills more people than breast cancer and prostate cancer combined.⁶
- » Alzheimer's is also a leading cause of disability and poor health in older adults. Before a person with Alzheimer's dies, they live through years of morbidity as the disease progresses.⁶
- » Younger-onset Alzheimer's disease, when dementia develops before age 65, affects an estimated 115 of every 100,000 people, or about 200,000 Americans.¹¹
- » About 60% of people living with frontotemporal dementia (FTD) are ages 45 to 60. In a systematic review, FTD accounted for about 3% of dementia cases in studies that included people aged 65 years and older and about 10% of dementia cases in studies restricted to those younger than 65 years.¹²
- » Dementia with Lewy bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function. Early symptoms include sleep disturbances, well-formed visual hallucinations and visuospatial impairment. About 5% of older individuals with dementia show evidence of DLB alone, but most people with DLB also have the brain changes of Alzheimer's disease.¹³
- » Vascular dementia occurs from blood vessel blockages or hemorrhages, such as a stroke. Between 5% and 10% of individuals with dementia have vascular dementia alone, with even more having mixed pathologies that could include Alzheimer's disease.¹⁴

Caregiving is common and its value is underrecognized. Embedding support for dementia caregiving in policies, systems and environments is essential to protect caregivers' health and reduce the toll of their unpaid assistance — an estimated 18 billion hours in 2022, valued at \$339.5 billion.⁶

- » More than 11 million family and friends provide an estimated 18 billion hours of unpaid care annually to people living with Alzheimer's and other dementias. Approximately two-thirds of dementia caregivers are women.⁶
- » Nearly half (48%) of people who provide help to older adults do so for someone with Alzheimer's or another dementia.⁶
- » Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent but also for at least one child.⁶
- » Seventy-four percent (74%) of dementia caregivers were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver.⁶

The impact is costly — and on the rise. Alzheimer's continues to top the list of the most expensive diseases in America. Federal and state governments shoulder two-thirds of this cost through Medicare and Medicaid.⁶

- » Nearly 1 in 4 people with dementia has a preventable hospitalization.¹⁶

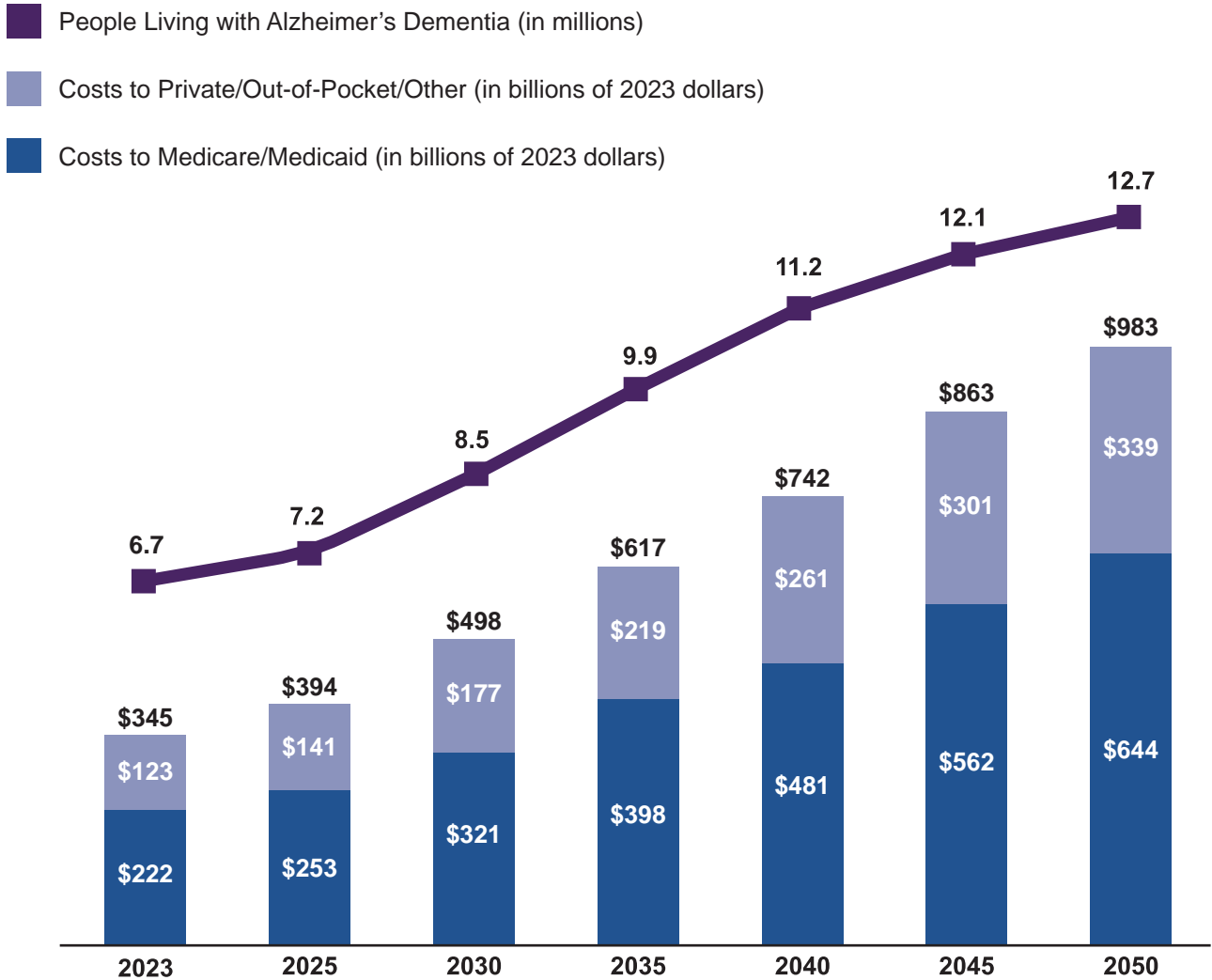
- » In 2023, the total health and long-term care costs of caring for people living with Alzheimer's and other dementias is an estimated \$345 billion. Added to this cost is the value of informal caregiving provided by family and other unpaid caregivers of people with dementia: \$339.5 billion in 2022.⁶
- » Most people living with Alzheimer's and other dementias (95%) have at least one other chronic condition, such as heart disease, diabetes, or stroke.¹⁵ Alzheimer's complicates the management of these chronic conditions, resulting in poorer health outcomes and quality of life and increased health care costs.
- » By 2050, the projected cost of Alzheimer's will be nearly \$1 trillion.⁶



The public health data on brain health demands action at the national and state level, and in our local communities. Addressing risk, early detection and caregiver health cannot wait.

- Marti Macchi, Leadership Committee

Figure 2. Projected Alzheimer's Prevalence and Costs⁶



HEALTH EQUITY AND SOCIAL DETERMINANTS OF HEALTH

Health equity is defined as the attainment of the highest level of health for all people.^{17,18} Public health departments are increasingly focusing on equity and partnering across sectors to address systemic injustices. Historically, many sectors including public health and health care systems have not sufficiently addressed health equity and have, consciously or unconsciously, perpetuated systemic inequities.¹⁹ With this context, thinking about a public health approach to dementia and cognitive health that advances health equity requires placing value on all individuals and communities.¹⁸ This requires attention to health care delivery, while also addressing the social determinants of health that contribute to health inequities.

Health inequities are “systematic, unfair, and avoidable differences in health outcomes and their determinants between segments of the population, such as by socioeconomic status, demographics, or geography.”²⁰ They have historically received attention in acknowledging health differences, but do not assign systematic reasons to those differences. “Health disparities are differences in health outcomes and their determinants between segments of the population as defined by social, demographic, environmental or geographic category.”²¹

Although significant strides have been made in the U.S., health inequities persist, resulting in continued disproportionate impact. Health inequities exist today in brain health and dementia related to risk reduction, early detection, diagnosis, care, support and

treatment. In particular, women, Black, Hispanic and American Indian/Alaska Native individuals, people with intellectual disabilities and other disabilities, as well as people with lower socioeconomic status and lower educational attainment are disproportionately impacted.

Groups disproportionately affected by health inequities may live in or experience conditions and environments that do not promote health. For example, they may lack access to basic health care, healthy food, affordable housing, quality education, physical activity opportunities, transportation, affordable health insurance, adequate household income, safe neighborhoods and freedom from racism, ageism, ableism and other forms of discrimination.²² These conditions, called *social determinants of health* (Figure 3),²³ are the non-medical factors that can drive health outcomes.¹⁷ They make up the environment in which

Figure 3. Social Determinants of Health²³



people are born, live, learn, work, play, worship and age.²⁴ Social determinants of health can affect a wide range of health outcomes, functionality and quality of life — and can shape individual health behaviors.²³

Social determinants of health contribute to inequities. In addition to increasing the risk of health conditions, some of which may be risk factors for dementia, exposure to some social determinants of health is associated with an increased risk of dementia and may affect the health and well-being of people living with dementia and their caregivers.

Health inequities persist with Alzheimer's disease and other dementias — including in the prevalence, diagnosis and treatment of the disease along with access to community-based support services — as well as in caregiving.

As a starting point, consider the following Compelling Data about health inequities experienced by individuals based on the following characteristics.

Race and Ethnicity[†]

- » **Discrimination is a barrier to Alzheimer's and dementia care.** More than one-third of Black adults (36%), and nearly one-fifth of Hispanic adults (18%) and Asian adults (19%), believe discrimination would be a barrier to receiving Alzheimer's care.²⁵ Forty-nine percent (49%) of Native American adults say that they have access to culturally competent providers.²⁶ Discrimination affects access to care and support services, trust

INTERSECTIONALITY AND DEMENTIA

When thinking about health inequities and the impact of dementia, it is critical to note the role of intersectionality — multiple overlapping factors such as race, class, income, education, age, disability status, sexual orientation, immigration status, ethnicity, indigeneity and geography.⁶ For example, someone who identifies as a Black woman may experience different health inequities than someone who identifies as a Black man or a White woman. All dimensions of people and their communities must be considered.

in providers and the health care system, and participation in clinical trials and research.²⁵

- » **Disproportionally later diagnosis results in more costly care.** When Black or Hispanic adults are diagnosed with Alzheimer's disease, it is often in the later stages of dementia when cognitive and physical impairment are more severe and require more medical care. Later diagnoses often result in higher costs of care — including hospitalizations, doctor visits, home health services or long-term care.²⁷ People who have a later diagnosis may also miss some of the benefits of an early diagnosis, including receiving support in making legal, financial and advanced care plans; building a care team; participating in support services; accessing medications; and enrolling in clinical trials.

[†]This report keeps the racial and ethnic terms used in source documents. When not referring to data from specific source documents, the adjectives "Black," "Hispanic" and "White" are used.

- » **Experiences of racism are associated with lower memory scores and increased risk factors.** Exposure to interpersonal and structural racism for Black adults is associated with lower subjective memory scores.²⁸ Experiences of racial micro- and macro-aggressions are associated with depression, anxiety and poorer sleep quality, all of which have been associated with cognitive decline.^{29,30}

Sex and Gender

- » **A majority of people with Alzheimer’s disease are women.** Nearly two-thirds of people in the U.S. living with Alzheimer’s are women. At age 65, a woman’s estimated lifetime risk for developing Alzheimer’s is more than 1 in 5;³¹ for breast cancer, it is 1 in 10.³² The higher prevalence of Alzheimer’s among women is largely due to women living longer than men.
- » **Most caregivers are also women, which can lead to disproportionate financial and health impacts.** Of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women.⁶ Of those providing care to someone with dementia for more than five years, 63% were women.⁶
 - » Nearly 19% of women caring for a person with Alzheimer’s had to quit work either to become a caregiver or because their caregiving duties became too difficult.³³ Given the financial cost of providing care and the associated increased stressors, leaving work increases the inequities experienced by women caregivers.⁶



Equity is embedded in every aspect of this Road Map, providing public health practitioners opportunities to reach diverse communities and reduce health disparities.

- Ocean Le, Leadership Committee

- » Caregivers who are women may experience slightly higher levels of stress, impaired mood, depression and impaired health than caregivers who are men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, assume more caregiving tasks, and care for someone with more cognitive, functional and/or behavioral problems.⁶
- » Women who are Latina and African American who are caregivers contribute 47% and 34%, respectively, of their annual income to caregiving.³⁴

Sexual Orientation and Gender Identity

- » **Stigma is a barrier to adequate care and support.** LGBTQ+ (lesbian, gay, bisexual, transgender, queer, and others) older adults are disproportionately affected by stigma as they age, exacerbating existing challenges in accessing aging and support services and upholding barriers to receiving care for Alzheimer’s or other dementias.³⁵

- » Compared with older adults who do not identify as transgender and nonbinary, transgender and nonbinary older adults with subjective cognitive decline were more likely to report experiencing discrimination in medical settings.³⁶ People who experienced this discrimination were 4.5 times more likely to have worsening memory than those who did not and were 7.5 times more likely to have poor or fair memory.³⁷
- » Some LGBTQ+ individuals may face discrimination in access to community-based or residential care and support services. This may result in denial of access or forced “re-closeting” to access services, which may worsen co-occurring stress, anxiety, depression and social isolation from friends and chosen family.^{35,38}
- » **Caregivers of LGBTQ+ people may be older and face more barriers.** Caregivers of LGBTQ+ people are often chosen family members, friends and community members, since LGBTQ+ older adults are less likely to have children to assist them and are more likely to be single.³⁹ As a result, caregivers of LGBTQ+ older adults may be the same age as the person for whom they are caring. Additionally, if they are not designated as the health care proxy, caregivers of LGBTQ+ who are not legal or biological family members have limited legal power to be involved in decision making, which may happen as cognitive decline worsens.⁴⁰
- » **Intersectionality is important to consider.** In one study, 1 in 4 LGBTQ+ adults aged 50 and older reported subjective cognitive decline, which may be associated with developing dementia. Having depressive symptoms, functional impairment and identifying as a racial/ethnic minority were also associated with subjective cognitive decline among this group of LGBTQ+ people.⁴⁰



Intellectual and Developmental Disability

- » **People with Down syndrome are more likely to develop Alzheimer's in middle age.** Adults with Down syndrome, an intellectual disability, develop Alzheimer's at a greater rate and at an earlier age than other adults.^{6,41,42} Adults with Down syndrome age prematurely and generally experience onset of dementia symptoms at an average age of 53.⁴³
- » **Stigma is a barrier to timely diagnosis and treatment.** Delay in the diagnosis of Alzheimer's disease among people with intellectual disabilities often results in delayed treatment, resulting in a reduced therapeutic window for effective intervention.⁴¹
- » **Misdiagnosis and underdiagnosis are barriers to appropriate treatment, care and support.** Often, adults with intellectual disability who develop cognitive impairment in their 40s and 50s are mis- or under-diagnosed. Most clinicians are unfamiliar with differentiating changes in function and behavior to determine if they are due to a lifelong cognitive disability or dementia. Further, most common screening and assessment instruments are not designed well for determining the start of cognitive decline in adults with an intellectual disability. There are also delays in diagnosis because cognitive changes are not recognized as a sign of dementia and instead assumed to be related to aging or the intellectual disability. These delays may reduce the ability to access medications and other supports and interventions.⁴⁴ ●



See the Case Studies chapter to learn more about how California, Georgia, Mississippi, Texas, Washington and Local Health Departments integrated health equity into their work.

THE ACTION AGENDA

USING THE ROAD MAP

Public health can be viewed through the lens of the 10 Essential Public Health Services (EPHS),¹ which describe the activities that public health professionals in all communities should undertake. Another useful lens is Public Health 3.0,⁴⁵ in which public health “leaders serve as Chief Health Strategists, partnering across multiple sectors and leveraging data and resources to address social, environmental, and economic conditions that affect health and health equity.”

The framework of the Healthy Brain Initiative (HBI) Road Map consists of four domains (see Figure 4). The domains (inner portion of the circle) and areas of practice (outer ring of the circle) build on the EPHS and Public Health 3.0. In this fourth edition of the HBI Road Map, the domains have been renamed to showcase the evolution of thinking in these topic areas and to align more closely with the 2020 update to the EPHS language. They have also been reordered to help guide health departments on where to start to achieve the most action and impact. The color coding for the domains remains the same to facilitate connection between the previous years of work and the years ahead.

As demonstrated by the EPHS, health equity must remain a central component to achieving success

in these domains — thus its prominent place at the framework’s core. Surrounding the domains, shown on the outer circle of the framework, are the areas of practice across the life course that affect the domains: risk reduction of cognitive decline; dementia caregiving; early detection, diagnosis and management of cognitive impairment; and community-clinical linkages.

The primary audience for this HBI Road Map is public health departments at state and local levels. A flexible agenda of 24 actions are offered for public health departments and their partners to consider for advancing brain health among those they serve and represent. The actions recognize that some health departments may be beginning activities in this area; others will be further along and have ongoing efforts on which to build. In addition, the actions consider the range of resources available to health departments. Some actions may require little to no funding or staff time; some may create opportunities to tap into alternative or non-traditional sources of funding or in-kind support. Others may be more complex or ambitious actions for departments with greater resources. While the actions are written for health departments, they cannot be accomplished alone. The Road Map aims to guide multi-sector collaboration and can also be a tool for community partners and national and local nonprofit leaders to identify ways they can contribute to shared goals and outcomes.



STRENGTHEN PARTNERSHIPS AND POLICIES:

Public health strengthens, supports and mobilizes community partnerships to improve brain health. It also creates, champions and implements supportive policies and plans.



MEASURE, EVALUATE AND UTILIZE DATA:

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. Findings are translated into data-informed programs and policies to improve brain health across the life course.



BUILD A DIVERSE AND SKILLED WORKFORCE:

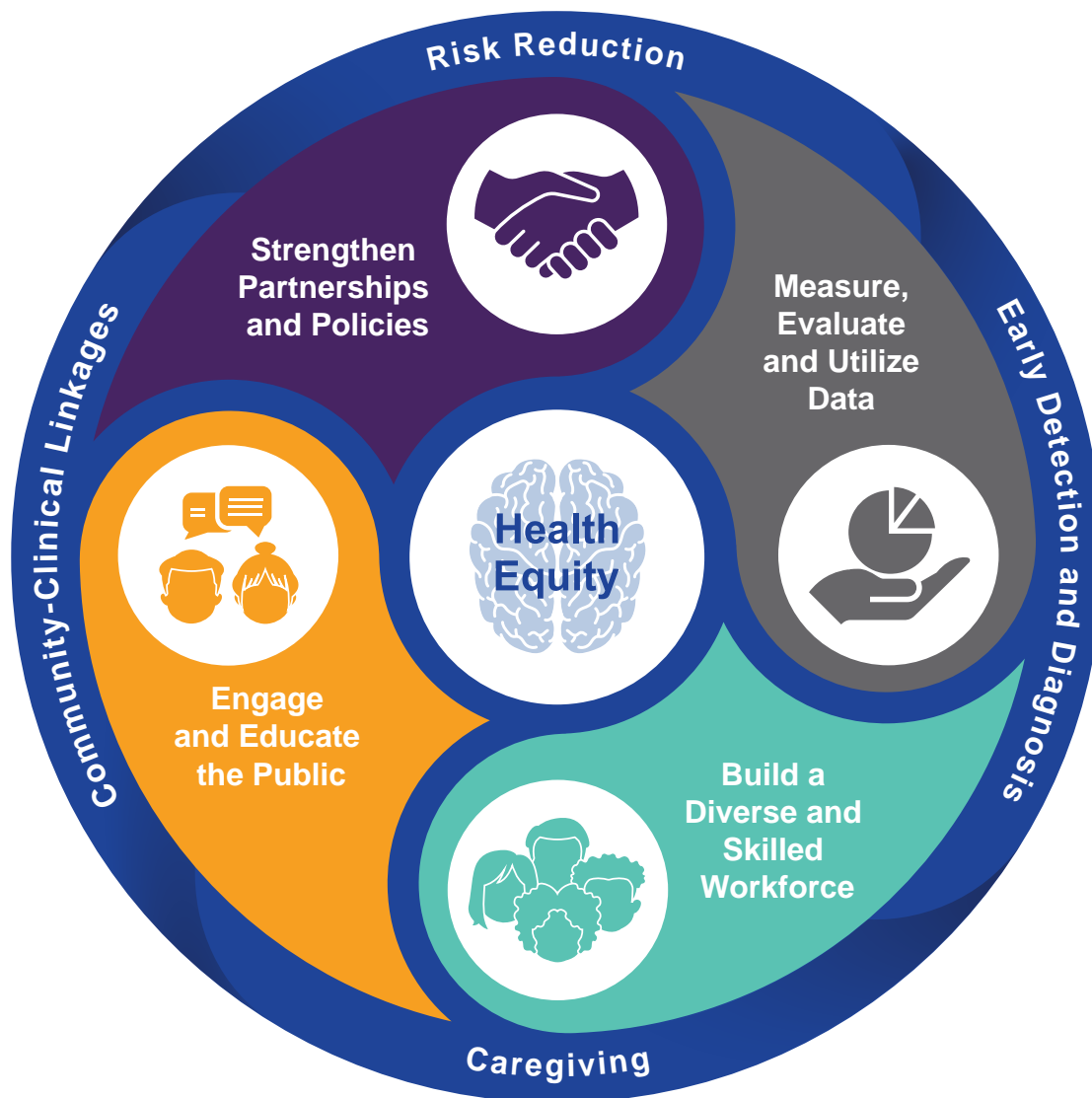
Public health trains and prepares the public health and health care workforce to educate their constituents and provide the best care to people at risk for or living with dementia while supporting caregivers.



ENGAGE AND EDUCATE THE PUBLIC:

Public health engages with diverse communities to understand how messages are best delivered and what information to convey to specific populations. Public health communicates effectively to educate people about factors that influence brain health and ways to maintain or improve their cognitive health and quality of life.

Figure 4. Conceptual Framework for the Healthy Brain Initiative Road Map



The framework of the HBI Road Map consists of four domains built from the Essential Public Health Services. The framework is centered on the principles of health equity and surrounded by the areas of practice across the life course. The wheel depicts the interconnectedness of these elements showing the essential nature of each in a successful strategy to improve brain health.

KEY QUESTIONS TO SELECT ACTIONS AND FOCUS PLANNING

1. What coalitions or partnerships exist in your state or community?
2. Can any current partnerships be leveraged to plan coordinated action?
3. How can available data and other information be used to understand the needs of the community and then influence policy and practice changes to meet these needs?
4. Which Road Map actions best fit state or local priorities, opportunities and capabilities?
5. Have the voices of the groups disproportionately affected by dementia been included in planning?
6. How can identified actions best be integrated into existing initiatives? Are any new initiatives needed to improve health equity?
7. Can planned actions be accomplished with existing resources? If not, what are possible funding sources and how can they be secured?
8. How will implementation and impact be evaluated? How and with whom will progress be shared? ●

HELPFUL TOOLS

To support the work of state and local health departments, the Alzheimer's Association and CDC offer an array of tools and resources that will be updated and expanded over time.

- » **Implementation Guide:** a practical manual on how to plan and implement specific Road Map actions
- » **Evaluation Tool:** a resource to help monitor program impact, and to learn how to contribute to a national evaluation by tracking similar measures
- » **Topic specific resources:** short briefs on overarching issues related to brain health — Caregiving, Community-Clinical Linkages, Early Detection and Diagnosis, Health Equity and Risk Reduction

All current and future tools will be maintained and available at alz.org/HBIRoadMap.



The HBI Road Map provides public health professionals with directions to the key 'destinations' for improving brain health. You can't travel everywhere. The Road Map helps you select the most important 'destinations' for your population and get the trip underway.

- James C. Appleby, Leadership Committee



STRENGTHEN PARTNERSHIPS AND POLICIES



OUTCOME: INCREASE COMMUNITY PARTNERSHIPS

- P-1 Convene and leverage diverse and inclusive **multi-sector coalitions** to strengthen supportive, equitable policies within communities, workplaces and health care settings across the life course of brain health.
- P-2 Utilize **community-clinical linkages** to improve equitable access to community-based chronic disease prevention, dementia support and healthy aging programs.
- P-3 Partner across the community to promote **equitable access to services, supports and quality care** for people living with dementia and their caregivers.
- P-4 Partner with **public and private health plans** to implement evidence-informed policies and programs that impact social determinants of health related to brain health and cognitive impairment.

At this critical juncture in the evolution of science and understanding of brain health, serving as a convener is an important and unique role for public health. This role cascades into nearly every aspect of the HBI Road Map. Numerous agencies, both public and private, have been working with the aging population and people living with dementia for many years. Public health can support and further this work by leveraging established relationships, bringing in traditional and non-traditional partners from many sectors across the life course, identifying connections and gaps and facilitating coordinated action. Non-traditional partnerships include those outside of the health field such as faith communities, small businesses, unions,

schools, media, civic and social justice organizations, and fraternities and sororities.

This role is not new to public health and has been successfully employed for decades by other chronic disease and health promotion programs, most notably cancer, heart disease, diabetes and healthy aging. By exercising strong leadership, public health can bring these diverse partners together and accelerate the community's response to dementia.

Partnerships also offer opportunities to address social determinants of health (SDOH) and health equity from different angles. For example, partnerships and coalitions can promote equitable access to healthy and

safe neighborhoods and environments. Partnerships can also promote access to community resources that encourage socialization, especially for those living with disabilities, living alone or in areas with limited transportation options.

Partnerships with state and community agencies can improve access to programs and provide critical links to valuable services. By recognizing community-clinical linkages and serving as a conduit for relationship building and connection, public health can have a pivotal impact. New coalitions need to be created or the health department could join existing coalitions, broaden their membership and expand the scope to address brain health. Expanding partnerships increases the reach of the health department's programs and overall utilization of a community's resources.

The focus of these coalitions will vary, depending on priorities and needs. Some may address risk reduction by working with community-based partners to disseminate messages about healthy aging and ways to reduce the risk of cognitive decline throughout the community. Others may focus on promoting technology and tools that are available for the detection and management of cognitive impairment and dementia in community and health care settings. As more treatments and early detection methods become available, these partnerships and coalitions will be critical to prevent inequities in detection, diagnosis and treatment from growing. Coalitions may also focus on identifying caregivers' needs, reviewing benefits and practices to support them, and educating the public about connecting with clinical and non-clinical supports for caregivers.

CONSIDER THESE POTENTIAL PARTNERS:

- » Area Agencies on Aging
- » Community-based programs
- » Condition-specific specialists
- » Elected officials
- » Employers and the business community
- » Faith-based organizations
- » Health and social care providers
- » Medical and primary care associations
- » Nonprofits and community leaders representing people from historically marginalized populations
- » Nutrition programs
- » Other governmental agencies
- » Other local, tribal, city and state health departments in your region
- » People with lived experience with cognitive decline
- » People with caregiving experience
- » Public safety and emergency response officials
- » Respite services

COMPELLING DATA

- » Approximately 65% of people with dementia live in the community, with 1 in 4 living alone.⁴⁶
- » Eighty-three percent (83%) of people with subjective cognitive decline have at least one additional chronic condition.⁴⁷
- » In March 2021, only 23% of U.S. civilian workers had access to paid family leave.⁴⁸
- » Lower wage workers were less likely than higher wage workers to have access to paid family leave. In March 2021, 6% of private industry workers with an average wage in the lowest 10% had access to paid family leave, compared with 43% of workers with an average wage in the highest 10%.⁴⁹

Another way that public health can collaborate with partners is to convey the importance of public and private health coverage plans that address brain health, cognitive impairment and the special needs of people living with dementia and their caregivers. As an example, public health could review and integrate policy and practice priorities from the National Strategy to Support Family Caregivers⁵⁰ to amplify best practices for both in-person and virtual supports and services in their state health insurance plans. This could include resources tailored for diverse populations to facilitate a coordinated system of care focused on addressing SDOH and systemic inequities. By joining these coalitions, health plans can positively impact their member populations. Employers in the coalitions may also request or require that their contracted health plan cover evidence-informed resources.

Many of the actions that fall in the other domains of the HBI Road Map — data sharing, workforce training and public education — will be most successful if implemented jointly by these multi-sector coalitions.



The HBI Road Map is a valuable resource for health departments to leverage their expertise, meaningfully support cross-sectoral partners and serve their communities to support brain health, including by adopting a life course approach to health.

- Peter L. Holtgrave, Leadership Committee



See the Case Studies chapter to learn more about how California, Georgia, Iowa, Mississippi, Texas, Washington and Wisconsin are working in the P domain.



OUTCOME: INCREASE INTEGRATION WITH OTHER CHRONIC DISEASE EFFORTS

P-5 Build on existing **state and local public health chronic disease, healthy aging, and disability programs and policies** to address social determinants of health and improve health equity related to brain health.

Much can be done internally across state or local government agencies to address SDOH and health equity in a culturally appropriate and coordinated fashion. As a start, programs can adopt a shared understanding of principles of health equity. This includes the consistent use of agreed upon terminology to inform communications and actions advancing brain health and addressing dementia. Collaboration can focus on existing initiatives around broader health equity, SDOH, and shared modifiable risk factors such as: traumatic brain injury, midlife hypertension, midlife obesity, diabetes, physical inactivity, smoking, poor sleep quality and sleep disorders, poor diet quality, depression and hearing loss. Making a true impact on SDOH requires the collective power and synergy of multiple disease-specific programs working together to address them.

Public health can also lead by example by improving internal health department policies and business practices and encouraging community partners to follow suit. Information can be shared with staff and community members on the inequities that impact brain health, particularly among historically marginalized populations, including SDOH, structural bias (such as institutional, interpersonal and internalized bias) and their root causes as drivers of these inequities.



See Build a Skilled and Diverse Workforce for actions on training public health and health care professionals, community health and direct service workers, and the public safety and emergency response workforce.



OUTCOME: INCREASE POLICY ACTION AND IMPLEMENTATION

- P-6 Equip **policymakers** with information on risk factors, the stigma associated with cognitive impairment and the impact of social determinants of health; and offer evidence-informed policy options across the life course.
- P-7 Join ongoing coalitions and partnerships to **prevent or remediate abuse, neglect and exploitation** of people living with dementia.

Since 2007, when the first Road Map was published, more state legislation has been introduced and enacted related to public health approaches to cognitive health and dementia: from 50 bills introduced in 2007 to more than 300 in 2022.⁵¹

To make informed decisions, state and local policymakers need information on the basics of brain health, cognitive decline, and the impact of dementia on people living with cognitive impairment, caregivers and communities. They also need current data on the impact of SDOH in their communities and how addressing these SDOH can improve brain health and quality of life for people with cognitive impairment and those who support them. Providing policymakers with information and primary prevention strategies to reduce dementia risk (such as improving early childhood education, air quality, physical activity accessibility and nutrition security) can set the stage for policies that support brain health for all.

Coalitions can also produce information that empowers policymakers to adopt policies and practices that promote brain health and reduce cognitive decline by

addressing SDOH and structural biases. Policies can also advance health equity for people with cognitive impairment and their caregivers. One approach is emphasizing the accomplishments of Health in All Policies, a collaborative approach that integrates and articulates health considerations in policies across sectors to improve the health of all communities and people.⁵² Historically, dementia has not been part of many chronic disease programs and may not be considered in discussions of Health in All Policies.⁵² Educating policymakers about risk reduction and the impact of SDOH on brain health and cognitive decline can add even more importance to these efforts.

As new conversations on risk reduction and early detection emerge, it is important to not lose sight of the need for policy attention in the prevention and remediation of abuse, neglect and exploitation of people living with dementia. While abuse can happen to anyone, both at home and in care settings, people living with dementia are especially vulnerable because the disease may prevent them from recognizing the abuse or reporting it. They also may be taken advantage of by family, friends, professionals and

strangers due to their cognitive impairment. This can include online scams and financial or identity theft.

Caregivers, both family and professionals, can be the abusers of older people. In many cases, stress and frustration may provoke unintentional physical or psychological harm. Research has documented the effects of caregiver stress on people living with dementia and their use of health care services.⁶ For example, when family caregivers report higher levels of distress, there is an associated increased risk of institutionalization of the person living with dementia, exacerbated behavioral and psychological challenges in the person living with dementia, and increased likelihood of abuse of the person living with dementia.

Abuse, neglect and exploitation were previously listed in the third edition of the HBI Road Map under the Educate and Empower domain. They were moved to the Strengthen Partnerships and Policies domain to reframe the public health role as one focused on improving policies through partnerships with adult protective services, law enforcement, aging network service providers and other community-based organizations. Recent partnerships that include financial institutions show promise in preventing people living with dementia from becoming victims of fraud or other forms of financial exploitation. Availability of support services for caregivers is also a critical policy function for public health to help reduce the stress that may lead to abuse. Policies can improve the awareness and availability of these services as well as where to turn for help and to report abuse.⁵³ ●





MEASURE, EVALUATE AND UTILIZE DATA



OUTCOME: INCREASE DATA AVAILABILITY, QUALITY AND UTILIZATION

- M-1 Support implementation of the **Behavioral Risk Factor Surveillance System** (BRFSS) optional modules for Cognitive Decline and Caregiving and use the data to develop and inform programs and policies.
- M-2 Supplement existing state, local and BRFSS data with data from **health systems, health plans, pharmacies, and other health care providers and community organizations** to better understand disparities and opportunities for improving equity.
- M-3 Evaluate **implementation of the HBI Road Map actions** to identify successes and needed improvements.

The uptake of the Behavioral Risk Factor Surveillance System (BRFSS) optional Cognitive Decline and Caregiver modules has produced actionable data across the U.S. In the five-year time period of the previous Road Map, 48 states, the District of Columbia (D.C.) and Puerto Rico implemented the Cognitive Decline Module, and 49 states, D.C., and Puerto Rico implemented the optional Caregiver Module at least once. Both modules are among the most widely adopted optional modules of the BRFSS.

The Cognitive Decline Module allows monitoring of the Healthy People 2030 objective DIA-03: increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider. Continuing to implement these modules is essential, both to monitor national and state trends and to better



Shaping public health systems to support people's brain health is the key to our communities thriving with better cognitive health for all.

- Sarah Lock, Leadership Committee

understand individual state landscapes. If a state is not able to implement the modules every year, adhering to the suggested schedule — the Cognitive Decline Module in 2023 or 2024, and the Caregiver Module in 2025 or 2026 — allows for a larger national cohort in those specific years. Many states have secured routine legislative appropriations for implementing these modules. At the local level, health departments have supplemented BRFSS data by oversampling in

COMPELLING DATA

CDC analysis of 2019–2020 BRFSS Cognitive Decline Module data⁴⁷ shows:

- » One in 10 people aged 45 and older report experiencing subjective cognitive decline (SCD).
- » Forty-one percent (41%) of people with SCD had to give up day-to-day activities.
- » One in 3 people with SCD say it interfered with social activities, work or volunteering.
- » Less than half of people with SCD have discussed their thinking and memory difficulties with a health care provider.
- » Thirty-five percent (35%) of people with SCD need help with household tasks.

CDC analysis of 2015–2017 BRFSS Caregiver Module data shows:

- » One in 5 adults are caregivers, caring for a friend or family member due to any health condition or disability.⁵⁴
- » Of those providing care to someone living with dementia, over half have provided care for at least two years, and nearly 1 in 3 provided care for at least 20 hours per week.⁵⁵
- » Among dementia caregivers, 80% manage household tasks such as cleaning and cooking, and over 60% assist with personal care such as bathing and dressing.⁵⁵

specific areas of interest or adding questions on family caregivers in the core sections. Some large metro health departments (such as Boston and New York City) operate their own survey and utilize language from both the Caregiver and Cognitive Decline Modules.

Advancing public health's understanding of brain health requires expanding beyond the optional BRFSS modules to incorporate a variety of other diverse data sources. Public health departments can form new or utilize existing partnerships by sharing data

with health and health care organizations, health plans, pharmacies, other health care providers and community organizations, the technology sector, public and private payers, and other experts. These partnerships can help unify collection and analysis of similar data points, such as identifying caregivers in medical claims records or variations among dementia diagnoses between geographic regions.

Program evaluation is useful to better understand progress and impact and to identify needed improvements in design and implementation.

As the work of the HBI and the Building our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act evolve, the public health field is moving from planning to action to impact. This Road Map is the first to have an accompanying evaluation tool. On a national level, the Alzheimer’s Association is committed to tracking the nationwide impact of the Road Map. To do this, state and local level evaluation is needed.

Like BRFSS, data collection and evaluation work best when public health departments are all tracking similar measures at a similar cadence. Throughout the Road Map, each domain lists desired outcomes for groups of related actions, allowing for state and local public health efforts to work toward collective impact. The evaluation tool offers example measures for data collection associated with each action.

THE VALUE OF DISAGGREGATION AND OVERSAMPLING

One of the Essential Public Health Services (EPHS) is to assess and monitor population health status. This is often thought of as the **aggregation** of population data to view what is occurring overall in the country, state or community as a whole. Another important aspect of assessment is **disaggregation**:⁵⁹ separating the data into parts by such factors as race or ethnicity, gender, socioeconomic status, disability, education level and age. Disaggregation is a useful tool to help track different potential root causes of disparities and inform equitable action.

Looking closely at differences within a specific population helps to better understand the needs of that community and what programs, messaging and interventions might work best. Doing this type of

analysis accurately, however, requires enough data from different population groups to derive valid conclusions. **Oversampling**⁶⁰ is another data collection method that can ensure enough data are collected to disaggregate. It involves deliberately sampling a greater number of certain participants than would be obtained by random sampling to ensure the resulting analysis remains valid. Oversampling has been used by cities, states and tribal communities to be able to understand more about specific populations. For example, the category “Asian” encompasses a large group of people from regions of the world with vast cultural differences. Oversampling can help discern important differences within these groups in the Asian community.



See the Case Studies chapter to learn more about how California, Georgia, Rhode Island, Texas, Vermont, Washington and Tri-County Health Department in Colorado are working in the M domain.



OUTCOME: INCREASE DATA-INFORMED DECISION MAKING AND ACTION

- M-4 **Translate data analyses and evaluation** findings into state and community strategic and health improvement plans that support brain health across the life course and quality of life for people living with dementia and their caregivers.
- M-5 **Share findings** with community organizations, agencies, policymakers and provider associations to help focus and inform community awareness efforts, resource needs, policies and programs, particularly for populations most impacted.

Once data are collected and analyzed, they should be used to inform and engage relevant audiences like decision makers, partners and the public. To do this, data analyses and evaluation findings must be translated into messaging and communications that are culturally relevant, meaningful and easy to understand. Each year, CDC updates the Alzheimer's and Healthy Aging Data Portal with the latest Cognitive Decline and Caregiver BRFSS data. The Alzheimer's Association and CDC also create state-specific fact sheets and infographics based on those data that can be used to educate partners and decision makers. These tools can be a starting resource for health departments to further develop information and materials that meet the needs of their residents and partners.

A final but often overlooked action is sharing data back with the community, local organizations, providers and other state and local agencies after being collected and analyzed. Just as important as ensuring these groups are invited to coalitions and decision making meetings is sharing the information they have helped gather. Sharing data helps build trust with the community and creates a sense of ownership and validation. This is particularly important when a multi-sector partnership has a shared goal to improve health equity in dementia. Continuing to share data helps keep momentum and buy-in of the group and allows the partnership to pivot when needed to improve outcomes. ●

HEALTHY PEOPLE 2030 OBJECTIVES

Healthy People 2030 (HP2030)⁵⁶ is the framework that sets the nation's disease prevention and health promotion objectives for the next decade. Three of these objectives focus public health attention on cognitive impairment:⁵⁷

DIA-01: Increase the proportion of older adults with dementia, or their caregivers, who know they have it.

DIA-02: Reduce the proportion of preventable hospitalizations in older adults with dementia.

DIA-03: Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.





BUILD A DIVERSE AND SKILLED WORKFORCE



OUTCOME: REDUCE STIGMA AND BIAS ABOUT COGNITIVE DECLINE

- W-1 Provide evidence-informed training and informational resources for **primary health care providers** to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course.

Primary care providers (PCPs) play an integral role in promoting brain health, reducing risk of cognitive decline, ensuring early detection and diagnosis, and providing referrals to community supports. Their long-term relationships with patients provide them the opportunity to develop rapport and trust, discuss brain health and risk reduction strategies throughout the life course, and conduct cognitive assessments at appropriate times to establish useful baselines. Doing so requires an understanding of how to accurately assess cognitive impairment and manage dementia as a chronic condition. PCPs and health systems can help destigmatize dementia diagnoses and embrace an early life emphasis that supports more comfortable brain health conversations. Ultimately, this lays the groundwork for potential treatments that are most effective in the early stages of cognitive decline.

PCPs also play an important role in encouraging caregiver health. Caregiving is associated with an increased incidence of hypertension, coronary heart disease, and a number of physiological changes that could increase the risk of developing chronic



Early detection leads to better care, and primary care is the entryway to make that happen.

- Barak Gaster, Leadership Committee

conditions, including high levels of stress hormones, impaired immune function, and slow wound healing.^{6,64,65} PCPs' awareness and understanding of their patients' caregiving responsibilities can help them manage the caregivers' stress and physical health effects of caregiving, link them to needed resources and improve their overall quality of life.

Primary care practices are often the only clinical resource available to people living in underserved communities. Advancements in technology, such as Project ECHO[®],⁶⁶ create a bridge between primary care clinics and specialist teams at academic medical centers through weekly virtual meetings. Project ECHO[®], developed at the University of New Mexico

Health Sciences Center, is a collaborative model of medical education and care management that helps clinicians provide expert-level care to patients wherever they live.⁶⁷ Using video-conferencing technology to train, advise and support primary care providers, the ECHO model increases access to specialty care in rural and underserved areas for a variety of conditions. The Alzheimer's and Dementia Care ECHO program,⁶⁸ hosted by the Alzheimer's

Association, has supported nearly 150 primary care practices with dementia care experts to enhance dementia care in underserved areas. Public health professionals can continue to strengthen linkages between community-based programs and primary care providers and increase educational opportunities and peer engagement in these settings.

COMPELLING DATA

- » Eighty-five percent (85%) of people first diagnosed with dementia were diagnosed by a non-specialist physician, usually a primary care provider (PCP).⁶¹
- » Seventy-five percent (75%) of PCPs say they are on the front lines of providing care to patients with mild cognitive impairment (MCI), with two-thirds (62%) of them reporting they receive questions at least weekly from their patients about symptoms consistent with MCI.⁶²
- » Less than half of people with subjective cognitive decline have discussed their thinking or memory issues with a health care provider.^{6,47}
- » Only about half of Medicare beneficiaries with a diagnosis of Alzheimer's disease or dementia report being told of the diagnosis.⁶
- » Nearly half of PCPs sometimes choose not to assess patient cognition because treatment options are limited.⁶³
- » Most PCPs (55%) report that there are not enough dementia specialists in their area to meet demand for referral, diagnosis and treatment.⁶



See the Case Studies chapter to learn more about how California, Minnesota, Rhode Island, Vermont, Wisconsin and Sarasota and Nassau Counties in Florida are working in the W domain.



OUTCOME: INCREASE KNOWLEDGE AND SKILLS OF CURRENT AND FUTURE WORKFORCE

- W-2 Train current and future **public health professionals** about risk factors for cognitive decline and dementia and ways to integrate this information with other chronic disease prevention strategies.
- W-3 Promote inclusion of the life course approach to brain health in **licensing, certification and continuing education requirements** for health care and allied professionals.
- W-4 Strengthen training of **community health and direct service workers** about brain health across the life course to improve equitable care and quality of life for those living with cognitive decline and to support caregivers.
- W-5 Partner with **public safety and emergency response agencies** to improve their ability to recognize and meet the needs of people living with cognitive decline and dementia.

Training is needed on the life course approach to brain health, the intersection of SDOH and structural bias, and the role of stigma in perpetuating brain health inequities. Educating those within the health department can contribute to improved collaboration and shared resources by including brain health and dementia risk reduction messaging alongside other chronic condition, health equity and SDOH messaging and programs.

In collaboration with jurisdictional regulatory authorities, public health departments can work to include brain health, dementia and caregiving competencies in public health and health care licensing, credentialing and certification programs. Such programs could reach a variety of health professionals including physicians, nurses and social workers.

To strengthen training of community health and direct service workers, public health departments can partner with governmental and non-governmental organizations to clearly define and differentiate roles and responsibilities for each sector — including direct care and the broader dementia care workforce. This could include inviting community health workers to join a coalition to encourage community-based identification of dementia warning signs during home visits and appropriate referral. The coalition could also encourage members of historically marginalized groups to enter the dementia-related professional workforce while highlighting the importance of improved wages and working conditions, training and career progression opportunities.

Public health departments can play a role in expanding access to existing programs for caregivers



and establishing new and innovative programs for home and community-based services and long-term services and supports. This includes access to care coordination services from community health workers, transportation services and mental health specialists. This workforce should provide empathy, understanding, support and advice for families in a culturally responsive way on a comprehensive range of medical and non-medical issues using currently available evidence-informed programs. It should also ensure that clinical and non-clinical care providers are able to identify family caregivers (also referred to as “care partners” or “carers”) across systems and sectors to offer, deliver, refer or improve access to and use of evidence-informed interventions and other needed support services. This will not only enhance caregivers’ health, well-being and independence but also recognize that not all people who serve as family caregivers self-identify with the terms “caregiving” or “caregiver.”

Lastly, it is critically important that personnel in public safety and emergency response agencies — including law enforcement, emergency medical services, fire, disaster relief, adult protective services and others — are able to recognize the signs of cognitive impairment and dementia, communicate with people living with dementia, locate and involve caregivers and link families to appropriate resources. The more these front line professionals know and understand about dementia, the better able they will be to respond with sensitivity and compassion, maintain positive relationships with the community and protect the health and dignity of people with dementia. ●



ENGAGE AND EDUCATE THE PUBLIC



OUTCOME: INCREASE PUBLIC KNOWLEDGE ABOUT BRAIN HEALTH, RISK FACTORS FOR DEMENTIA AND BENEFITS OF EARLY DETECTION AND DIAGNOSIS

- E-1 **Engage diverse audiences** to develop **culturally responsive messaging** about brain health, cognitive decline, healthy aging and caregiving.
- E-2 Disseminate culturally relevant messaging to **encourage conversations** about brain health, cognitive decline, healthy aging and caregiving.
- E-3 **Engage with communities**, especially **those at highest risk**, about risk factors for dementia and how people living with dementia can best thrive in their communities.
- E-4 Embed cognitive decline risk factors into evidence-informed **health promotion and chronic disease prevention awareness and education campaigns**.
- E-5 Partner with **educational systems (K-12 and post-secondary)** to include brain health and dementia in their curricula.

Public health has long been engaged in educating the public to increase awareness and understanding of many diseases and conditions. One example is breast cancer. Although breast cancer has affected women throughout history, it was considered “an unspeakable condition” until the later part of the 20th century and was viewed as incurable.⁷³ Today, after years of messaging and investment on the part of many organizations and coalitions, conversations about breast cancer are common and stigma is less of

a barrier to early detection and diagnosis. In addition, increased research funding led to new treatment options, which elevated the value of early detection.

The approach and lessons learned for breast cancer can serve as a model for dementia. Public health has an important role to educate the public about brain health and cognitive decline, support open conversations around dementia including the benefits of an earlier diagnosis and detection, and encourage

people to have discussions about cognitive concerns with their primary care provider and with their friends, family and support systems. This messaging can also help support the emotional health of people living with dementia and their caregivers. When conversations about cognitive decline are more common, people living with dementia and caregivers can feel supported in their community. Medical research to find treatments for Alzheimer's disease and other diseases that cause dementia is accelerating rapidly due to continued investment in research from the federal government and private organizations. As new treatments become available, it is public health's role to ensure that the public is well-informed about the benefits of early detection and that stigma does not interfere with honest, timely conversations with providers to take full advantage of these treatments.

This Road Map is guided by its vision that everyone deserves a life with the healthiest brain possible. To effectively implement the Road Map requires messaging that reduces stigma, increases uptake of risk reduction strategies and facilitates early detection and diagnosis of cognitive impairment. While this is a starting point, it is important to understand the motivations, reservations and trusted sources of information within specific populations and communities.

A successful messaging campaign can be woven through the other domains of the Road Map. Messages should be developed with input from people with lived experience. Additionally, culturally tailored messaging is critical, with emphasis on meeting needs of populations with limited access to health care and



Health equity considerations and implications were at the forefront of the Leadership Committee's minds and ideas. This is illustrated throughout the actions of the HBI Road Map.

- David X. Marquez, Leadership Committee

support (e.g., low-income populations, health facility deserts and historically marginalized populations). This may involve equipping faith community leaders, physicians or other trusted community leaders with reliable information or recruiting a community member to talk about having a cognitive screen. Translating messages into other languages and for people with limited English proficiency is also critical.

Lastly, to increase public knowledge and reduce stigma around cognitive decline, cultural change must begin at younger ages. If children begin learning the dangers of tobacco and risk reduction strategies for cardiovascular health in primary school, they can also learn about how to protect and promote brain health. Structured classroom discussions with peers can help reduce stigma around brain health and demonstrate regular, routine conversations about dementia, particularly since so many children are living with or have family members with dementia. A helpful resource is the Reframing Aging Initiative,⁷⁴ a long-term social change endeavor designed to improve the public's understanding of what aging means and the many ways that older people contribute to society. This greater understanding helps counter ageism and guide

COMPELLING DATA

- » More than 2 in 5 Americans (43%) report they have never heard of mild cognitive impairment (MCI). When prompted with a description of MCI, more than half of all Americans (55%) say MCI sounds like “normal aging.”⁶²
- » Nearly one-half of Americans (47%) say they worry about developing MCI in the future,¹¹ but only 4 in 10 Americans say they would talk to their doctor right away when experiencing symptoms of MCI.⁶²
- » Assuming a causal link between 12 modifiable risk factors — including hypertension, smoking and diabetes — and dementia, as many as 40% of all cases of dementia worldwide are attributable to those risk factors.⁶⁹
- » A randomized controlled trial found that aggressive control of blood pressure significantly reduced the risk of developing MCI.⁷⁰ Yet, the prevalence of hypertension remains high — affecting half of U.S. adults aged 45 years or older⁷¹ — and on average, only about half of adults with hypertension have their high blood pressure controlled.⁷²
- » Seventy-four percent (74%) of caregivers of people with dementia reported in a 2014 survey that they were “somewhat concerned” to “very concerned” about maintaining their own health since becoming a caregiver.⁶

the nation’s approach to ensuring supportive policies and programs as people move through the life course. It could also inspire students to consider a career in public health, the aging field or focus on dementia care. Identifying and leveraging evidence-informed health curricula and youth workforce development programs can expose and nurture members of historically marginalized communities at a young age to enter science, public health and health care related professions.



See the Case Studies chapter to learn more about how California, Georgia, Washington and Baltimore, Maryland are working in the E domain.



OUTCOME: INCREASE PUBLIC KNOWLEDGE AND USE OF SERVICES FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CAREGIVERS

- E-6 Enhance communication with **people living with dementia, their families and caregivers** about how to access services, care and social supports.
- E-7 Ensure **caregivers** have information, tools and resources about their vital role and ways to maintain their own **health and well-being**.

Education and engagement around risk reduction and early detection is critical to reducing the health equity gap in diagnosis. The stigma around cognitive decline and dementia often results in isolation for people living with dementia and their caregivers. They may not seek or be made aware of a dementia diagnosis. Public health can help by facilitating conversations within communities among people living with dementia, their caregivers, their friends and neighbors. Information can also be shared about how to access services, care and social supports across the life course. The intimacy, shared experiences and memories that are often part of the relationship between a caregiver and person living with dementia may be jeopardized due to the memory loss, functional impairment, and psychiatric or behavioral disturbances that can be caused by the progression of dementia.⁶ Although many caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, they also frequently report higher levels of stress.⁶ For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications.⁷⁵

Interventions to support dementia caregivers have been developed and evaluated. The goal of these interventions is to improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Some also aim to delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological and/or technological) to continue caring for their relatives, friends or neighbors at home. Specific approaches include providing education to caregivers, helping caregivers manage dementia-related symptoms, improving social support for caregivers and providing caregivers with respite from caregiving duties.

Public health can expand implementation and availability of these interventions using available awareness and messaging channels to focus on the overlapping needs and challenges related to cognitive decline, healthy aging and dementia caregiving. Efforts can educate the public using localized, culturally and linguistically tailored messages about care-related tasks, managing stress, social isolation and mental health; and connect people to resources, consumer-ready facts about symptoms, diagnosis, services and other resources. ●

WHAT IF?

The HBI Road Map actions are intended to strengthen public health capacity to address current challenges — but they also help prepare public health to meet the challenges of tomorrow.

What if, before the fifth edition of the Healthy Brain Initiative Road Map Series is published:

- » New diagnostic techniques and tools are available for people experiencing memory and thinking difficulties?
- » Effective treatments are widely available and accessible for early stages of dementia?
- » Research leads to better understanding of effective risk reduction strategies and their impact?
- » Conversations about brain health are easier and less hampered by stigma and bias?
- » Inequities in risk, detection and diagnosis are lessened and access is increased?
- » Technologies are developed to support the direct care workforce to bring risk reduction, detection and diagnosis, care and support to remote and hard-to-reach populations?
- » People living with dementia and their caregivers are supported by their communities and health care systems?
- » Alzheimer's disease has its first survivor?

It was with these *What Ifs* in mind that the 24 actions and corresponding text were written. What if the public health field is fully prepared when these *What Ifs* become reality? This Road Map is the next step to continue equipping public health for the work ahead.

With strong partnerships and policies in place, a robust workforce, a solid foundation of data for decision making and a more engaged, educated public — public health will be ready for the path forward. ●

Preparing for 'What Ifs' lays the foundation to transform possibilities — created by advances in funding, workforce capacity, partnerships, policy, technology, science and more — into tangible, equitable and person-centered progress. Proactive public health strategies empower us to be ready.

- Ian Kremer, Leadership Committee

CASE STUDIES

Eleven case studies highlight a sampling of recent efforts by state and local health departments to implement Road Map actions. The case studies are listed in alphabetical order and the corresponding domains are referenced at the bottom of the page.



Increasing Impact through State and Local Health Department Partnerships

The California Healthy Brain Initiative was successfully piloted by six local health departments (LHDs) from 2020 to 2022. Utilizing state funding to integrate brain health into core public health work, LHDs were nimble in identifying solutions tailored to the diverse and unique communities they served. Through lessons learned during this pilot, several best practices emerged as key components for building successful local partnerships, spreading awareness of dementia and improving accessibility to resources across various populations. These successes speak to the importance of prevention and risk reduction in public health efforts to address Alzheimer's disease and other dementias and demonstrate how actions within different domains of the Road Map can create synergies for positive outcomes.

Over the course of the grant term, the LHDs achieved several outcomes across the four HBI domains.

Measure, Evaluate and Utilize Data: Collectively, the LHDs produced 28 different types of informational materials for the public and advancement of their healthy brain projects. The most common types of materials produced were community needs assessment/action plans and caregiver/patient educational outreach materials, including media campaigns.

Engage and Educate the Public: During the funding period, 101 media campaign assets were launched in four different languages — English, Spanish, Chinese and Vietnamese. Sacramento and Santa Clara Counties launched media campaigns in all four of these languages to meet the needs of their diverse communities. Additional methods to educate the general public about brain health and dementia included providing educational/training activities on 53 topics and providing information and resources to 11,337 participants.

Build a Diverse and Skilled Workforce: The LHDs conducted 91 educational/training sessions for 5,423 professional individuals including social workers, first responders, physicians and nurses.

Strengthen Partnerships and Policies: In total, the LHDs collaborated with 103 partners, 63% of which were new partnerships formed during the grant period.

The California Healthy Brain Initiative was funded through state appropriations and allowed for the expansion of the Healthy Brain Initiative work through local health departments.



Building Community Partnerships to Expand Reach and Foster Sustainability

In 2018, the Georgia Department of Public Health (GA DPH) launched Think About It, a statewide media campaign to increase awareness about early detection and diagnosis of Alzheimer's disease and ways to reduce risk. Comprised of radio spots, billboards, media posts during sporting events and on buses and trains, and printed flyers distributed through pharmacies and related partners, the campaign has garnered over 6 million impressions to date. Since its launch, the GA DPH BOLD team has extended outreach, community engagement, and dissemination of the Think About It campaign through partnerships with Rural Extension Offices, Emory University, University of Georgia, Alter, Second Wind Dreams, the State Unit on Aging, local public health and Georgia's Area Agencies on Aging.

To further expand reach into African American communities in the state, GA DPH partnered with Alter, a nurse-led collaborative focused on expanding education on dementia in African American faith communities and reducing stigma and isolation. This partnership has significantly expanded engagement

with dementia caregivers within the African American faith community, while promoting healthier caregivers and communities.

GA DPH and Alter seek to improve access to resources and awareness of Alzheimer's disease and other dementias in African American communities by providing education and conducting research. Alter accomplishes this by working with places of worship to reduce the stigma of dementia, support caregivers and increase resource utilization and research participation. The partnership between GA DPH and Alter assists churches in identifying African American individuals in rural and historically under-resourced communities who can benefit from becoming dementia friendly. GA DPH contributes by providing Think About It campaign materials, preventable hospitalization educational materials, and technical assistance in expanding the reach of Alter's work. This partnership has allowed Alter to address other health concerns of church members and has enabled GA DPH to reach a population at high risk for dementia with messaging about chronic disease, nutrition, and injury prevention.



Convening Dementia Care Summit to Spur Action and Collaboration

Shortly after the Iowa Department of Health and Human Service's Alzheimer's Disease and Related Dementias (ADRD) Program Coalition created Iowa's new strategic plan, they sought to convene decision makers at the state and national level to discuss issues surrounding dementia care and resources. To address this need, the "Develop Policy and Mobilize Partnerships" Work Group (made up of Coalition members) held a Dementia Care Summit in December 2022, which drew 90 registrants from across Iowa and from a wide variety of backgrounds and connections to Alzheimer's and dementia. To advertise the Summit, the ADRD Program Coordinator appeared on statewide Iowa Public Radio to talk about the meeting's purpose and to answer listener questions about Alzheimer's and dementia.

The Summit began with comments from Iowa's lieutenant governor, whose family has a connection to Alzheimer's, along with speakers and panelists that included the Iowa Department of Health and

Human Services director, Iowa Department on Aging director, Iowa Medicaid director, Broadlawns Hospital's chief medical officer, Alzheimer's Association Iowa Chapter's director, the leaders of two BOLD Public Health Centers of Excellence, the coordinator of Dementia Friendly Iowa, the national Alzheimer's Association's senior health systems director and the leader of Wisconsin's Dementia Care Specialist program. Small group discussions by attendees at the end of the day yielded strategies for improving Iowa's dementia landscape.

As a result of the Summit, new partnerships formed. The Work Group is exploring the implementation of several ideas and is considering a future Summit directed at caregivers and the general public. Attendee input has also influenced ADRD Program activities and yielded new Coalition members.



Engaging Community Health Workers Around the Importance of Brain Health at Every Age

The Minnesota Department of Health's (MDH) Oral Health Program partnered with the Volunteers of America (VOA) Caregiver Support and Dementia Services team to develop and conduct training for VOA community health workers (CHWs).

Topics included:

- » How to educate family caregivers about common oral conditions;
- » Importance of maintaining good oral health; and
- » Skill development to prevent dental disease in older adults with dementia, including hands-on activities and skills testing.

MDH also created a flip chart for CHWs to use when educating caregivers in the community. The Oral Health Team delivered the training to 10 practicing CHWs and 25 CHW students. These trained CHWs then recruited approximately 75 unpaid caregivers attending the VOA's "Breakfast with Caregivers" and trained them in oral health care for older adults, including adults with Alzheimer's disease and other dementias.

Building on this successful CHW engagement and with support from the Centers for Disease Control and Prevention's BOLD program award, MDH partnered with the Minnesota Community Health Worker Alliance to create ongoing training for CHWs that covers dementia risk reduction, early detection, caregiver well-being and support for those living with dementia. The training is comprehensive and specifically addresses CHWs' vital role in supporting brain health and dementia. CHWs were involved in the creation and review of the training modules, which included a case study about a family experiencing dementia.

In addition, MDH expanded its partnership with the VOA Caregiver Support and Dementia Services Team to build stronger community-clinical linkages between community health centers and VOA's dementia-related CHW services in areas such as memory screening, caregiver support and brain health education. These linkages include establishing bi-directional referral protocols between the VOA Mobile Memory Clinic and community health center partners, cross-training CHWs to conduct the Mini-Cog® and increasing referrals for older adults to VOA's caregiver support, well-being and brain health programs, including "Know Your Risks: Brain Health" and caregiver support groups.



Coalition Building for Collective Impact

In 2022, Mississippi released an update to *“The State of Mississippi, Strategic Plan for Alzheimer’s Disease and Related Dementias, 2020–2025.”* This effort expanded the reach and capacity of public health to improve brain health, prevent or delay cognitive decline, and pursue a more comprehensive and coordinated approach to implementing the HBI Road Map.

The State Coalition working on the plan consisted of existing state agencies, health care providers, community organizations and private sector groups. The Mississippi (MS) BOLD Program was able to enhance its efforts and bring together diverse public health resources and approaches to improve brain health and prevent or delay cognitive decline. The State Coalition, led by the Memory Impairment and Neurogenerative Dementia (MIND) Center at the University of Mississippi Medical Center, is comprised of representatives from various state agencies, such as the Departments of Health, Aging, and Mental Health, as well as other relevant agencies like the Department of Medicaid, and community organizations, all working together to identify and align existing state programs and policies related to cognitive health and aging with the goals of the HBI Road Map. This helped to eliminate duplication of efforts and maximize the use of resources. In 2023, the State Coalition increased its diversity with the addition of tribal community and intellectual and developmental disability community representatives.

The State Strategic Plan consists of five goal groups dedicated to addressing challenges faced by families and individuals living with Alzheimer’s disease and other dementias across the life course: Brain Health, Caregiver Support, Coordinated Care, Community Awareness, and Research and Data. For each goal group, a volunteer Health Equity Ambassador was identified and trained on cultural competency, health disparity and health equity issues, and the social determinants of health for Alzheimer’s disease and related dementias. This training improved the ambassadors’ ability to understand and address the unique needs of their communities, enabling them to identify and implement at least two activities annually that address the Social Determinants of Health for Alzheimer’s disease and related dementias.

The Health Equity Ambassadors will assist in the implementation of a community outreach initiative to target African American and Hispanic communities who have been disproportionately affected by Alzheimer’s disease. Through this initiative, ambassadors will be able to educate and engage these communities on the importance of early detection and access to care, which will lead to an increase in early detection among African American and Hispanic individuals. A formal volunteer description was developed by the MS BOLD program to increase replication across and within other chronic disease programs.



Implementing Measurement and Improving Primary Care Through Innovative Partnerships

The Rhode Island Department of Health (RIDOH) Alzheimer's Disease and Related Disorders (ADRD) Program launched a Quality Improvement Collaborative in August 2022. Its goal is to identify and implement dementia focused quality improvement measures within primary care practices throughout the state. Co-facilitated by RIDOH and a physician consultant, the Collaborative engages key partners including the Rhode Island Geriatric Workforce Enhancement Program, which receives Health Resources and Services Administration (HRSA) funding to support initiatives such as Project ECHO, and the Care Transformation Collaborative of Rhode Island, which has an established track record of promoting primary care transformation in Rhode Island. Health plans, physicians and community-based organizations have also been key partners in this work.

The Collaborative has identified several dementia focused measures and designed a pilot model for implementation that includes an ECHO Learning Series and a Quality Improvement process. The Collaborative has utilized its breadth and depth of community and health system partners to recruit nearly 80 health care professionals for participation in the ECHO learning opportunity. At least two primary care practices will be recruited for measure implementation. A Practice Facilitator will lead the practices within the quality improvement cycle. The Collaborative plans to meet with primary care sites to identify barriers to implementation, successes and lessons learned.



Using State BRFSS Data to Drive Grants and Programs

The Texas Department of State Health Services (TX DSHS) has implemented the optional Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Decline and Caregiver Modules for the 2019 and 2021 surveys and used the data for grant applications and programmatic activities. Underlining the value of these data, the Texas state budget has previously included financial support to implement the Cognitive Decline and Caregiver Modules. Routine collection of data like these builds a larger dataset in which both disaggregation and oversampling are possible.

Graph A shows data for the state of Texas, where 12.8% of adults report subjective cognitive decline (SCD), aggregated from the 2019 and 2021 BRFSS surveys.

Graph B disaggregates this overall figure by race and ethnicity, revealing the highest SCD prevalence among Black adults in the state (13.7%), followed by Hispanic (13.6%), White (12.1%), and other/multiracial (11.3%).

Similarly, Graph C shows another way to disaggregate the data, focusing on the prevalence of SCD among people with a chronic condition (arthritis, asthma, coronary heart disease, non-skin cancer, chronic obstructive pulmonary disease, diabetes, and stroke). Texans without a chronic disease have lower rates

of SCD (6.1%) and the rate of SCD goes up with the number of chronic conditions, with Texans reporting three or more chronic conditions having rates of SCD at 29.7%.

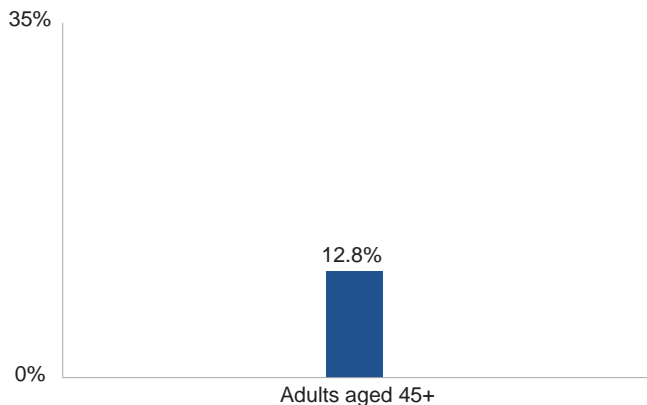
Finally, Graph D shows a multi-level disaggregation looking only at Black residents of Texas and the difference in reported SCD based on specific chronic conditions. The highest rate of SCD was among adults who reported having a stroke (29.5%), followed by chronic obstructive pulmonary disease (COPD, 28.2%), non-skin cancer (27.9%), asthma (27.0%), coronary heart disease (CHD, 25.1%), arthritis (20.5%), and diabetes (20.0%).

Looking closely at differences within specific populations helps to better understand the needs of the community and which programs, messaging and interventions might work best to reach the most people. Doing this type of analysis accurately, however, requires enough data from different population groups to derive valid conclusions. For Texas, knowing which populations and which communities experience these disparities allows TX DSHS to determine target populations for awareness campaigns, caregiver surveys and activities for grant applications.

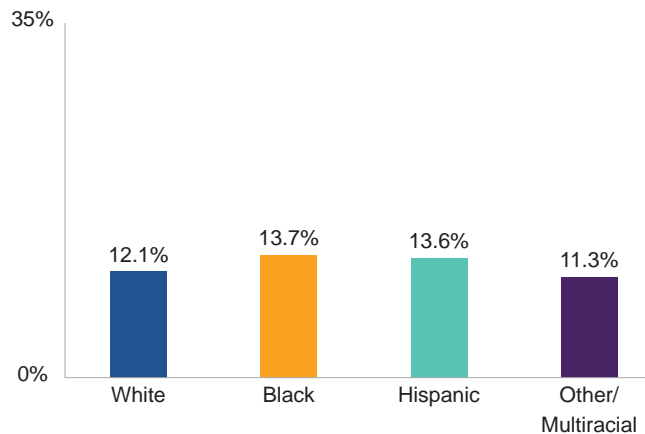


Texas BRFSS Data Disaggregated

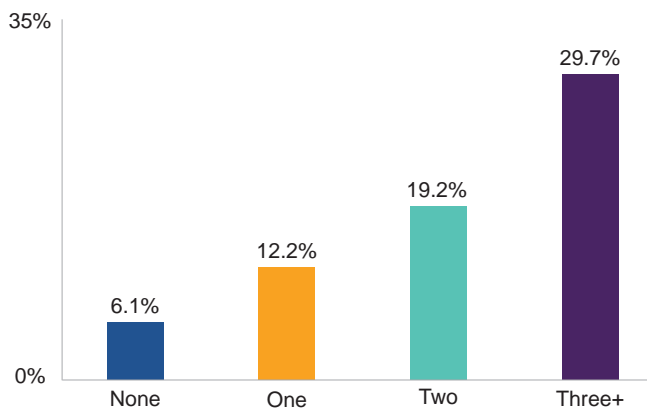
A. SCD in Texas, 2019 & 2021 BRFSS



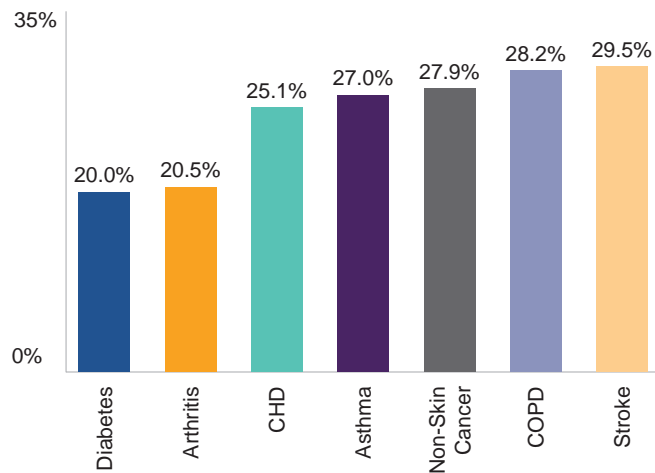
B. SCD in Texas by Race/Ethnicity, 2019 & 2021 BRFSS



C. SCD in Texas by Number of Chronic Conditions, 2019 & 2021 BRFSS



D. SCD Among Black Residents in Texas by Select Chronic Condition, 2019 & 2021 BRFSS



Public Health Workforce Training for Brain Health and Chronic Diseases

For Alzheimer's and Brain Awareness Month, the Vermont Alzheimer's Disease and Healthy Aging Program used a multi-pronged approach to build awareness and engagement with the public, the human services workforce, community-based organizations, and the chronic disease division at the health department. Dementia risk reduction, addressing caregiver needs, and increasing early detection are priorities in the state. Alzheimer's and Healthy Aging Program staff meet quarterly with chronic disease colleagues to discuss evidence and plan for communications and campaigns that highlight the brain health benefits from hypertension and diabetes prevention and control, and smoking cessation.

The program coordinated with the Alzheimer's Association Vermont Chapter to curate an educational series for public health practitioners, Clinical-Community Health Teams and human services professionals. The goal of the series was to equip this workforce with the knowledge and skills to deliver dementia informed services to support Vermonters experiencing cognitive decline. The series had the added benefit of educating and supporting individuals who are facing Alzheimer's disease and other dementias in their own lives.

The Alzheimer's Disease and Healthy Aging Program also organized and promoted a panel presentation,

titled "Brain Health and Chronic Disease: Reducing Dementia Risk." Collaborating with the Heart Disease, Diabetes, Oral Health and You First (breast and cervical cancer screening) programs in the health department, the presentation addressed modifiable risks that can curtail or prevent chronic disease and cognitive decline. The webinar was live streamed and 90 individuals representing public health, Area Agencies on Aging and community-based agencies attended. This included individuals from 16 organizations outside of the health department.

The positive impact of this integrated messaging can be seen in the increased number of Vermonters exploring *My Healthy Vermont* and ultimately signing up for healthier living and chronic disease prevention workshops available online. Visits to the *My Healthy Vermont* website almost doubled during the two months of the online campaign linking hypertension and brain health, going from an average of 119 visits per day in the two weeks prior and post campaign to 232 visits per day during the two-month campaign. The goal is to increase the proportion of Vermonters accessing *My Healthy Vermont* resources at any stage of life but with particular focus on increasing participation among those in mid-life and current dementia caregivers. Working collaboratively to address common risk factors and increasing the public health workforce's knowledge and awareness has increased Vermont's capacity and expanded the public health response to Alzheimer's disease and dementia.



WASHINGTON STATE

Where Are We Now? Washington State, Five Years Later

The work of Washington State's Dementia Action Collaborative (DAC) was featured in the previous HBI Road Map. Since then, DAC has continued and advanced several efforts to increase brain health among people who are African American, Asian, Pacific Islander and Hispanic/Latino. The partnership between Aging & Disability Services of King County and Center for MultiCultural Health (CMCH), initiated in 2018, continued promoting culturally tailored hand fans with brain health messages in its Memory Sunday project with African American churches. The number of participating churches increased from a handful to 22 in 2021, reaching around 2,000 individuals during that year.

With strengthened relationships and materials developed, the WA Department of Health (DOH) used mini-grants to support partnerships with CMCH and African American churches to offer an interactive brain awareness event and to share public awareness campaign materials carrying a culturally tailored message around the value of early diagnosis. Events included information for staff on dementia; health fairs (virtual and in person); social media marketing; messages from the pulpit; free health screenings with short cognitive exams, blood pressure, glucose, and cholesterol screenings; and encouragement to connect with primary medical providers.

The DAC's Diversity and Disparities project team also developed and audience-tested an *Alzheimer's African American Action Brief: A Call to Action for Community-Based Organizations* to raise awareness around disparities and share suggested strategies, resources and actions. Over two years, DOH contracted with media companies to conduct insight interviews and focus groups, then used the findings to develop materials and campaign strategies for the African American and Hispanic/Latino communities posted on their website. Washington DOH is currently measuring website views and visitors. In spring of 2023, a contracted media company created and fielded television ads in geographic regions where Hispanic/Latino populations are the highest throughout the state. The television ads focus on the value and importance of early detection, diagnosis and planning related to dementia.

Washington State plans to build upon lessons learned and new partnerships to increase reach and engagement with community members and partners aimed toward increased awareness and action steps for risk reduction, early detection, and brain health education among populations at elevated risk of dementia.



Expanding Reach and Access to Care with Public Health and Aging Services Partnerships

The Wisconsin Dementia Care Specialist Program serves individuals, families, communities and tribes as part of county-based aging and disability resource centers. The statewide program helps agencies become dementia capable, acts as a catalyst for dementia friendly communities, and supports individuals living with dementia to remain in their homes longer.

The Dementia Care Specialist has three pillars of the program: 1) train staff at the Aging and Disabilities Resource Center (ADRC) and other county and municipal offices to assist local systems to become dementia capable; 2) help communities become dementia friendly where people with dementia can remain active and safe, and caregivers can feel supported by their community; and 3) provide education and support to people with memory concerns or dementia, and their families, to allow them to live at home safely. The program began as a pilot in 2013 with five Dementia Care Specialists, and expanded to 16 Specialists in 2014, covering 26

counties. With continued annual growth, Dementia Care Specialists are now housed in Wisconsin's Aging and Disability Resource Centers and cover all 72 Wisconsin counties (some ADRCs are consortiums of multiple counties) and 11 federally recognized tribal nations.

As one example of impact, when Wisconsin was awarded a BOLD Program grant in 2020, it further catalyzed this program by emphasizing the local partnerships with Adult Protective Services. As a part of regular program services working with families, Dementia Care Specialists specifically included information about crisis prevention to increase the number of families that developed a pre-crisis plan should something unexpected happen to a caregiver or a person living with dementia. As part of the continued partnership, the Division of Public Health in the Department of Health Services plans to evaluate the Dementia Care Specialist Program in the coming years.



LOCAL HEALTH DEPARTMENTS

The Power of Public Health Strategists in Florida, Colorado & Maryland

The Road Map Strategist Initiative, inspired by the Public Health 3.0 Model, is aimed at growing the use of Road Map actions at the local level. Road Map Strategists are public health officials selected annually to serve as system change agents. Equipped with the support of training, technical assistance and peer cohorts, they work to develop organizational capacity to address brain health. Strategists represent a wide range of health departments that vary in organization size, geography and populations served; consequently, they pursue an array of different approaches tailored to meet the needs of their communities.

Build a Diverse and Skilled Workforce: The Florida Department of Health in Sarasota and Nassau Counties focused on workforce development, each using a variety of strategies to advance knowledge about early detection and diagnosis of dementia among both the provider community and public health officials. Working with local partners, including other government agencies, a memory disorder clinic, health care system and physicians' group, they held a Grand Rounds and promoted continued education through online offerings for clinicians and direct care workers. They also integrated training on brain health into onboarding of all health department staff to establish baseline knowledge among their public health workforce as well as a source of retained institutional knowledge. To ensure brain health remains a priority,

they are working toward integrating Road Map actions into strategic plans for the department.

Measure, Evaluate and Utilize Data: Tri-County Health Department in Colorado collaborated with community partners to prioritize data sources and meaningful indicators related to aging and cognitive health. Working with their epidemiology team, they built a virtual dashboard on their website to house and encourage use of these data. This resource served as a tool for internal planning and evaluation, and provides valuable data to community-based organizations working to support adults experiencing cognitive decline.

Engage and Educate the Public: Baltimore City Health Department in Maryland created a multi-point plan to increase awareness about Alzheimer's disease and other dementias in their agency and broader community. Adopting a peer-to-peer Ambassador model to educate priority populations about COVID-19 vaccination campaigns, they are in the process of recruiting teams of older adults experienced in health and human services and community outreach. Through strategic university and community partnerships, they plan to provide educational resources in community locations, with particular attention to addressing health inequities and risk factors associated with dementia among the Black community in Baltimore.



GLOSSARY

Key terms in the Road Map are defined below. Each definition reflects the term's specific use and intent within the Road Map and may differ in other contexts.

Alzheimer's disease is an irreversible, progressive brain disorder caused by damage to neurons in the brain. It is the most common cause of dementia. Early symptoms include difficulty with memory and thinking. As the disease progresses, symptoms include impaired communication and judgment, confusion, behavior changes and challenges with basic bodily functions. Symptoms usually develop slowly and worsen over time, becoming severe enough to interfere with daily tasks. Alzheimer's disease is fatal.

Alzheimer's disease and other dementias include Alzheimer's disease as well as vascular contributions to cognitive impairment and dementia (VCID), Lewy body dementia (LBD), frontotemporal dementia (FTD), Parkinson's disease, hippocampal sclerosis, mixed etiology dementias (MED) and many other less common diseases, disorders and conditions that can result in dementia. This term is sometimes referenced as ADRD (Alzheimer's disease and related dementias) in scientific publications.

Brain health is 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, understand and maintain a clear, active mind.

Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. The recipients of care can live either in the community or institutional settings, range from children to older adults and have chronic illnesses or disabling conditions. Because of their partnership with people living with dementia in making joint decisions to enhance their care and quality of life, caregivers can also be referred to as "care partners" or "carers."

Caregiving for people with dementia is unpaid help provided by spouses, partners, adult children, other relatives and friends to people living with dementia. Caregivers for people with dementia often assist with activities of daily living such as personal care, household management, medication and health care management and coordination of financial matters.

Chosen family is a group of individuals who deliberately choose one another to play significant roles in each other's lives. It is a term often used in the LGBTQ+ (lesbian, gay, bisexual, transgender, queer and others) community.

Cognitive decline is changes in memory, thinking and/or reasoning that are worsening over time.

Cognition is the mental function 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 no clinical symptoms to mild cognitive impairment to Alzheimer's and severe dementia.

Cognitive functioning is a combination of mental processes that includes the ability to learn new things, intuition, judgment, language and remembering.

Cognitive health is present when cognitive functioning is working well and making the most of the brain's ability to remember, learn, play, concentrate and maintain a clear, active mind.

Cognitive impairment is trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.

Comorbidities refer to when a person has more than one disease or condition at the same time. Conditions described as comorbidities are often chronic or long-term conditions. Other names to describe comorbid conditions are coexisting or co-occurring conditions and sometimes multimorbidity or multiple chronic conditions.

Community-clinical linkages are connections between community and clinical sectors that aim to improve health within a community. They are an effective, evidence-based approach to preventing and managing chronic diseases such as Alzheimer's and other dementias.

Dementia is a general term for a particular group of symptoms, including difficulties with memory, language, and skills that are severe enough to interfere with daily life. Alzheimer's disease is the most common cause of dementia. Other causes include vascular contributions to cognitive impairment and dementia (VCID), Lewy body dementia (LBD), frontotemporal dementia (FTD), Parkinson's disease, hippocampal sclerosis, mixed etiology dementias (MED) and many other less common diseases, disorders and conditions that can result in dementia.

Disease prevention levels are opportunities for public health intervention that include primary (e.g., dementia risk reduction), secondary (e.g., early detection and diagnosis; linkages to treatment, care, and services), and tertiary (e.g., prevention and management of comorbidities leading to preventable hospitalizations and poor health outcomes; caregiving for people with dementia) prevention.

Down syndrome is a condition in which a person is born with extra genetic material from chromosome 21, one of the 23 human chromosomes. The extra copies of genes cause developmental problems and health issues, nearly always affecting learning, language and memory.

Early detection and diagnosis — or secondary prevention — aims to identify diseases in the earliest stages, before the onset of more severe symptoms. Public health plays a unique role in building relationships between communities and health systems to assure equitable access for all people to diagnostic services.

Essential Public Health Services describe the 10 public health activities that all communities should undertake. The framework was first developed in 1994 by the Core Public Health Functions Steering Committee, which included representatives from U.S. Public Health Service agencies and other major public health organizations. The latest update to the framework occurred in 2020.

Evidence-informed approaches are health or public health practices, procedures, programs, or policies that have been shown to be effective, however have not gone through the rigor to be deemed evidence-based. The effects are clearly linked to the activities themselves, not to outside, unrelated events.

Frontotemporal degeneration refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes (the regions behind the forehead) or its temporal lobes (the regions behind the ears) that lead to frontotemporal dementia.

Health promotion is the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behavior towards a wide range of social and environmental interventions.

Healthy aging is the process by which older adults retain their health and independence, while avoiding disease and injury. For older adults with chronic diseases, this includes helping them effectively manage their diseases and avoid complications.

Healthy behaviors are practices that can prevent or reduce the likelihood of a chronic disease such as not

smoking, maintaining a body weight appropriate for height and frame, being physically active, not drinking alcohol or drinking in moderation and getting sufficient sleep.

Health disparities are preventable differences in the burden of disease, injury, violence or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.

Health equity is the assurance of optimal health for all people.

Health inequities are preventable, unjust differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work and age.

Intellectual and developmental disabilities (IDD) are disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual and/or emotional development. Many of these conditions affect multiple body parts or systems. Intellectual disability starts any time before a child turns 18 and is characterized by problems with both: (1) intellectual functioning or intelligence, which include the ability to learn, reason, problem solve and other skills; and (2) adaptive behavior, which includes everyday social and life skills. The term "developmental disabilities" is a broader category of often lifelong disability that can be intellectual, physical, or both.

Intersectionality is a concept that describes the ways in which systems of inequality based on gender, race,

ethnicity, sexual orientation, gender identity, disability, class and other forms of discrimination “intersect” to create unique dynamics and effects.

Lewy body disease is associated with abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. This is called dementia with Lewy bodies or DLB.

Mental health includes emotional, psychological and social well-being. It affects how we think, feel and act. It also helps determine how we handle stress, relate to others and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood.

Mild cognitive impairment (MCI) is a medical condition typified by an early stage of memory loss or other type of cognitive ability loss (such as language or visual/spatial perception) in individuals who maintain the ability to independently perform most activities of daily living. MCI is a part of the continuum of cognitive decline; it can be caused by brain diseases but also can be due to hormonal or nutritional imbalances.

Modifiable risk factors are the lifestyle and behaviors that can reduce or increase a person’s chances of developing a disease.

Primary care providers are health practitioners who can diagnose, treat and prevent many conditions and illnesses affecting physical and mental health. In addition to providing preventive health care services, they can manage long-term care for chronic diseases such as diabetes and hypertension.

Primary prevention is intervening before health effects or conditions occur. This means dementia risk reduction activities such as altering risky behaviors like poor eating habits or tobacco use or preventing and managing certain chronic conditions such as high blood pressure.

Provider includes any individual who promotes, protects and improves the health of individuals and communities. This includes health care providers, first responders, paid caregivers and others who provide care or services to people living with dementia and/or their caregivers.

Public health approach focuses on improving the health of entire populations across the lifespan, including dementia risk reduction, early detection and diagnosis, prevention and management of comorbidities leading to preventable hospitalizations, community-clinical linkages, referral to services and caregiving for people living with dementia. It also includes building coordinated systems that bind together jurisdiction efforts for dementia and caregiving.

Public health systems are all public, private and voluntary entities that contribute to the delivery of Essential Public Health Services within a jurisdiction.

Risk reduction — or primary prevention — strives to intervene before health effects occur through measures such as altering health risk behaviors (e.g., poor eating habits, tobacco use) and banning substances known to be associated with a disease or health condition (e.g., asbestos, lead and mercury). Modifiable risk factors are the lifestyle choices and behaviors that can reduce or increase a person’s chances of developing a disease.

Secondary prevention is detecting diseases in the earliest stages before the onset of more severe symptoms. This means early detection and diagnosis of cognitive impairment and dementia and linkages to treatment, care and services.

Social determinants of health (SDOH) are the conditions in places where people are born, live, learn, work and play. These conditions can have a profound effect on a person's health, including their risk for Alzheimer's disease and other dementias.

Stigma is a negative social attitude and social disapproval that can lead unfairly to discrimination against an identifiable group of people, a place or a nation. It is associated with a lack of knowledge, a need to blame someone, fears about disease and death, and gossip that spreads rumors and myths.

Subjective cognitive decline (SCD) is the self-reported experience of worsening or more frequent difficulties in thinking and memory in the past year. It is an early sign of possible cognitive impairment and can be an indicator of future risk of Alzheimer's disease and other dementias.

Systemic inequities are systems, laws, written or unwritten policies, and entrenched practices and beliefs that produce, condone, and perpetuate widespread unfair treatment and oppression of people of color, with adverse health consequences.

Tertiary prevention includes managing disease after diagnosis to minimize disease progression and negative health and quality of life effects. It also encompasses prevention and management of comorbidities.

Vascular dementia is caused by inadequate blood flow to the brain, sometimes due to a stroke, and results in changes in thinking skills.



APPENDIX A: DEVELOPING THE ROAD MAP

Partnerships and collaborations across sectors are vital for success, including in the development of this Road Map. The process for preparing this edition of the Road Map aimed to gather feedback from the public health community as well as key members of other sectors and leaders in related fields. Five methods were used to engage, elicit input and foster collaboration.

Leadership Committee: In spring 2022, the Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC) invited 20 national leaders in public health, aging, academia, health systems and Alzheimer’s to guide the development of the fourth HBI Road Map by joining the Leadership Committee (see Appendix B). The Leadership Committee reviewed data from state and local health departments about their implementation of the previous Road Map and developed five workgroups that would guide the revision of the Road Map actions. Members of the Leadership Committee served as both members and chairs of the workgroups and reviewed various versions of the text of this document.

State and Local Health Department Listening Sessions: The Association of State and Territorial Health Officials (ASTHO) and the Alzheimer’s Association elicited input from state and local

health departments on their use, implementation of and experience with the HBI Road Map Series through facilitated listening sessions. A total of 22 health department staff participated in the listening sessions: 75% of participants represented state and 25% represented local health agencies. Participants reinforced the value of the HBI Road Map as a guiding public health document, particularly in the areas of education, collaboration, strategy, quality improvement and advocacy. Several themes emerged, including resources and health department staff capacity limitations, barriers to inter- and intra-departmental collaboration, and the need for stronger emphasis on health equity throughout the Road Map.

Expert Workgroups: Five topic-specific expert workgroups were formed to develop recommended actions for this document: Risk Reduction of Cognitive Decline; Timely Detection, Diagnosis and Management of Cognitive Impairment; Dementia Caregiving; Health Equity; and Community Linkages. Leadership Committee members chaired each workgroup and additional subject matter experts — including disability, health equity, public health and research experts — joined the workgroups and served throughout the two-month workgroup process. The workgroups developed overarching and topic-specific recommended actions. In total, 68 experts contributed to the workgroup

process (see Appendix C), brainstorming over 180 recommended actions.

Open Input: In July and August 2022, an open public input period was held for state and local public health departments, and other interested organizations and individuals, to provide input on the HBI Road Map's proposed content. In total, 47 submissions were received. Analysis of the input was presented to the Leadership Committee alongside the expert workgroup recommendations for their consideration. Half of the responses were from state and local health departments.

Review: This document went through six rounds of review. It was first reviewed by teams at the Alzheimer's Association and CDC. Then the document went through an external health equity review (see Appendix B). After this, the Leadership Committee reviewed the document. Following incorporation of the Leadership Committee's comments, the document underwent further external review by members of the HBI Collaborative, Alzheimer's Association Early-Stage Advisory Group, the Road Map Workgroups and other national leaders. Then, the text and full layout with photos and graphics was reviewed again by the external firms. Finally, the document was reviewed in the CDC approval and clearance process.



Photo of Leadership Committee and Federal Liaisons at the fall 2022 meeting to review draft HBI Road Map actions.

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The Health and Aging Policy Fellows Program

APPENDIX D: ACTION AGENDA ACROSS THE DEMENTIA LIFE COURSE















The Road Map actions vary in the extent they relate to three points of prevention (primary, secondary and tertiary) and for caregivers. This table shows the intended impact of each action across the life course.

P – Strengthen Partnerships and Policies				
Actions	Primary	Secondary	Tertiary	Caregiving
P-1 Convene and leverage diverse and inclusive multi-sector coalitions to establish supportive, equitable policies within communities, workplaces and health care settings across the life course of brain health.				
P-2 Utilize community-clinical linkages to improve equitable access to community-based chronic disease prevention, dementia support and healthy aging programs.				
P-3 Partner across the community to promote equitable access to services, supports and quality care for people living with dementia and their caregivers.				
P-4 Partner with public and private health plans to implement evidence-informed policies and programs that impact social determinants of health related to brain health and cognitive impairment.				
P-5 Build on existing state and local public health chronic disease, healthy aging, and disability programs and policies to address social determinants of health and improve health equity related to brain health.				
P-6 Equip policymakers with information on risk reduction, the stigma associated with cognitive impairment and the impact of social determinants of health; and offer evidence-informed policy options across the life course.				
P-7 Join ongoing coalitions and partnerships to prevent or remediate abuse, neglect and exploitation of people living with dementia.				






















M – Measure, Evaluate and Utilize Data

Actions	Primary	Secondary	Tertiary	Caregiving
M-1 Support implementation of the Behavioral Risk Factor Surveillance System (BRFSS) optional modules for Cognitive Decline and Caregiving, and use the data to develop and inform programs and policies.				
M-2 Supplement existing state, local and BRFSS data with data from health systems, health plans, pharmacies, and other health care providers and community organizations to better understand disparities and opportunities for improving equity.				
M-3 Evaluate implementation of the HBI Road Map actions to identify successes and needed improvements.				
M-4 Translate data analyses and evaluation findings into state and community strategic and health improvement plans that support brain health across the life course and quality of life for people living with dementia and their caregivers.				
M-5 Share findings with community organizations, agencies, policymakers and provider associations to help focus and inform community awareness efforts, resource needs, programs and policies, particularly for populations most impacted.				

W – Build a Diverse and Skilled Workforce

Actions	Primary	Secondary	Tertiary	Caregiving
W-1 Provide evidence-informed training and informational resources for primary health care providers to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course.				
W-2 Train current and future public health professionals about risk factors for cognitive decline and dementia and ways to integrate this information with other chronic disease prevention strategies.				
W-3 Promote inclusion of the life course approach to brain health in licensing, certification and continuing education requirements for health care and allied professionals.				
W-4 Strengthen training of community health and direct service workers about brain health across the life course to improve equitable care and quality of life for those living with cognitive decline and to support caregivers.				
W-5 Partner with public safety and emergency response agencies to improve their ability to recognize and meet the needs of people living with cognitive decline and dementia.				

E – Engage and Educate the Public

Actions	Primary	Secondary	Tertiary	Caregiving
E-1 Engage diverse audiences to develop culturally responsive messaging about brain health, cognitive decline, healthy aging and caregiving.				
E-2 Disseminate culturally responsive messaging to encourage conversations about brain health, cognitive decline, healthy aging and caregiving.				
E-3 Engage with communities , especially those at highest risk , about risk factors for dementia and how people living with dementia can best thrive in their communities.				
E-4 Embed cognitive decline risk factors into evidence-informed health promotion and chronic disease prevention awareness and education campaigns .				
E-5 Partner with educational systems (K-12 and post-secondary) to include brain health and dementia in their curricula.				
E-6 Enhance communication with people living with dementia, their families and caregivers about how to access services, care and social supports.				
E-7 Ensure caregivers have information, tools and resources about their vital role and ways to maintain their own health and well-being .				

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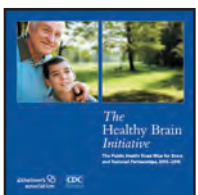
OVERVIEW OF THE HEALTHY BRAIN INITIATIVE ROAD MAP SERIES

In 2005, Congress appropriated funds for the Centers for Disease Control and Prevention (CDC) to focus on brain health and dementia for the first time. This action led to the Healthy Brain Initiative (HBI) and the longstanding collaboration between the Alzheimer's Association and CDC to advance understanding of and support for cognitive decline as a central part of public health practice. Since that time, HBI partners have worked together to implement public health strategies that promote brain health, address dementia and better support caregivers. The Healthy Brain Initiative Road Map Series guides this effort.



The first HBI Road Map — *National Public Health Road Map to Maintaining Cognitive Health* — was released by the Alzheimer's Association and CDC in 2007. It was the first framework for viewing

cognitive health and dementia as a public health issue. It outlined 44 actions to address dementia at the national level and laid the foundation for the public health community more broadly to engage on the issue.



The second HBI Road Map was *The Public Health Road Map for State and National Partnerships, 2013–2018*.

This guidebook expanded the role that state and local public health departments and partners could play

by offering 35 actions to promote cognitive functioning, address cognitive impairment and dementia and help meet the needs of caregivers.



The third HBI Road Map — *State and Local Public Health Partnerships to Address Dementia, The 2018–2023 Road Map* — continued to chart a course for state and local public health departments and their partners.

This Road Map prepared communities to act quickly and strategically by stimulating changes in policies, systems and environments. Alignment of HBI Road Map's 25 actions with Essential Public Health Services ensured that initiatives to address Alzheimer's could be incorporated easily and efficiently into existing public health efforts.



The Healthy Brain Initiative Road Map for Indian Country, published in 2019, is the first public health guide focused on dementia in American Indian and Alaska Native communities. This Road Map offers eight broad public health strategies designed to support discussion about dementia and caregiving within tribal communities and to encourage a public health approach as part of a larger holistic response.



The Healthy Brain Initiative and the development and dissemination of the HBI Road Map is supported by the Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$3,045,933 with 100 percent funding by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.



The Alzheimer's Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support and research. Our mission is to lead the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia®. Visit alz.org or call 800.272.3900



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