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From Policy to Practice: Supporting Brain Health and Caregiving at the State Level

Report Summary: This report explores promising policies, models, and strategies to promote brain health across the lifespan and support caregiving. By examining recently proposed and enacted legislation as well as innovative practice, ASTHO offers actionable recommendations that health agency staff and their partners can adapt and scale to strengthen their Healthy Brain Initiative (HBI) Road Map actions and public health impact.

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Introduction

Background

Alzheimer's disease and related dementias (ADRD) and caregiving are significant public health priorities. By 2060, nearly 14 million people in the United States will be living with <u>Alzheimer's disease</u>, the most common form of dementia. Each day, nearly 12 million Americans provide care to individuals living with dementia without compensation. There is a vital need to increase direct support for caregiver well-being and assistance with navigating complex health systems.

Existing evidence illuminates the population-level impact of dementia and caregiving, which positions public health to play a critical role. Due to their unique level of influence and authority, health agencies and state public health leaders can support brain health outcomes across the life course and decrease the burden of dementia.

Guided by the <u>National HBI State and Local Road Map Series</u>, public health professionals and their multisector partners have initiated efforts to reduce ADRD risk, facilitate early detection and diagnosis, and assist millions of caregivers who provide selfless support to family, friends, and community members each day.

ASTHO is committed to strengthening health agencies' capacity to promote health across the life course through sustainable policies, models, and strategies that support brain health and caregiving.

Purpose and Objectives

The impact of cognitive decline and dementia grows as the population ages, requiring <u>proactive policy responses</u>. Legislation is one type of policy intervention for jurisdictions that have recognized this need and are interested in specific, formalized strategies to support individuals with ADRD and their caregivers. These policies inform priorities and planning at the state level and establish critical infrastructure needed to implement and sustain effective public health initiatives.

In 2025, ASTHO explored recently proposed and enacted legislation as well as public health models and strategies to identify successful efforts across states. This report summarizes the key findings from this scan and outlines promising public health policies, models, and strategies to sustainably impact brain health and caregiving. The recommendations included in this report are specific to a state health official or agency's authority or influence.

Methods

Legislative Scan

ASTHO used commercially available legislative tracking software to perform a legislative scan of state-level policies that support brain health and caregiving. ASTHO's legislative scan focused on recent policy activity within the defined scanning period of January 2024-May 2025, encompassing the 2024-2025 legislative sessions. Specifically, ASTHO narrowed its search to bills enacted in 2024 and legislation under consideration through approximately May 1, 2025. It also explored legislative progression before publication when feasible. In addition, ASTHO considered promising or notable legislation identified by subject matter experts to supplement these findings when applicable.

The legislative scan concentrated on several key policy areas, as identified by ASTHO with support from ADRD experts from national organizations and state health agencies. ASTHO explored policies aligned with the HBI Road Map Action Agenda, with a concentration on activities considered to be within the authority or influence of state and territorial health officials. These topics included: 1) Policies to support a skilled workforce through education and training requirements for providers and other professionals who engage individuals with ADRD; 2) Policies that educate the public on issues related to brain health and healthy aging, including education that supports caregivers and individuals experiencing cognitive decline; 3) Policies that support collaboration and policy integration, including through dementia or aging-specific staffing, or policy coordination activities within health agencies, governments, and communities; and 4) Policies that support data collection and coordination to advance or support brain health or inform policy actions and activities.

This report excludes regulations, executive orders or directives, appropriations bills, and resolutions — though these actions are valuable avenues for health agencies looking to pursue specific policies to support brain health. This approach allowed for a targeted analysis of recent legislative activity within the defined scope of policy areas.

While ASTHO considered legislation at all phases, for bills considered in 2025, it focused on those that had either reached a certain threshold prior to publication (e.g., had passed at least one chamber), were similar to legislation considered or enacted in other jurisdictions even without significant advancement (e.g., several states considered a certain policy action through legislation), or were of particular interest to the field.

Additional policies that support brain health and caregiving or speak to broader trends that encompass years prior to 2024 may have been identified through ASTHO's environmental scan process.

Environmental Scan

To supplement the legislative scan, ASTHO explored promising state-level models and strategies to promote brain health, address dementia, and support caregivers. The non-legislative scan explored public health models implemented between 2020-2025 and included: 1) **Service delivery models**, public health programs and initiatives that directly and indirectly support risk reduction, early detection and diagnosis, and caregiving; 2) **State plans**, including Health Improvement Plans, ADRD Plans, Plans on Aging, and Multisector Plans on Aging; 3) **Partnerships and collaboration** across public, private, and non-profit sectors; 4) **Funding mechanisms**, including Medicaid eligibility and reimbursement for dementia care services and caregiving support, as well as other public health long-term care funding models; 5) **Data sources and practices** specific to dementia and caregiving.

ASTHO conducted an extensive online search of these models and strategies, gathered insights from subject matter experts, and utilized multiple sources to assess Medicaid funding mechanisms leveraged by states (e.g., web-based database of state Medicaid Managed Care contracts, Medicaid.gov state waiver, state plan amendment list).

ASTHO's analysis aimed to identify state-level practices that have a sustainable impact and prioritize brain health across the life course, dementia, and/or caregiving. Throughout this report, ASTHO intentionally braided the legislative and environmental scan findings and ensured alignment with related frameworks, such as the HBI Road Map Framework and Domains.

Key Findings and Insights

Supporting a Skilled Workforce

<u>ADRD-focused education</u> and training can ensure that health care workers have up-to-date information and understanding of the importance of early detection, diagnosis, and treatment options. Training may offer techniques for managing behavioral symptoms and improving quality of life. Similarly, education is crucial for first responders to effectively serve and support community members living with ADRD and their caregivers.

In 2024, at least six jurisdictions enacted legislation aimed at enhancing the knowledge and skills of the workforce who care for older adults and those who have dementia. Several states focused on individual health care providers, including **California** (SB 639), which will require nurse practitioners and physician assistants who care for older patients to complete at least 20% of their continuing education hours in gerontology or the special needs of patients living with dementia. Similarly, **Kentucky** (HB 459) added ADRD topics to its education requirements for licensure of physician assistants and nurses, while **Delaware** (SB 319) amended its continuing education requirements that address care of individuals with dementia to modify the scope, change the hours per reporting period, and clarify exempt providers.

While most jurisdictions focused on health care workers, **Florida** (<u>HB 801</u>) will require additional ADRD training opportunities for law enforcement officers that count toward the required instructional hours for continued employment, and **Virginia** (<u>HB 933</u>) now requires fire departments and emergency medical services agencies to develop training on ADRD for their personnel that covers communication, behavior management techniques, and local resources for individuals with ADRD and caregivers.

Several jurisdictions added ADRD-related training requirements for facility-based staff. **Arizona** (HB 2764) established required training standards for staff in memory care facilities, including at least eight hours of initial training and four hours of annual continuing education. **Minnesota** (SF 5335) clarified and expanded its dementia care training requirements for direct care workers in assisted living facilities, including additional orientation considerations for certain staff transfers. **Delaware** (SB 150) also addressed staffing plans and training in dementia care facilities by requiring detailed standards for staffing plans and tailored training based on staff roles within these specialized care settings, with broader requirements for training on communication and safety topics for individuals with ADRD.

As of May 2025, at least five states have considered legislation imposing additional obligations on facilities and other entities caring for individuals with ADRD. This includes **Massachusetts** (\$ 470), which is exploring additional oversight of certain home care providers that would require licensure and specific training for direct providers on ADRD care. Both **Florida** (HB 493) and **Kansas** (HB 2370) introduced legislation that would create additional standards or requirements for memory or dementia care providers, while **Illinois** (HB 3328) would require assisted living facilities to use a validated pre-admission assessment to identify and evaluate cognitive impairment. Finally, **Washington** enacted SB 5337, which establishes a mandatory certification program for memory care units and facilities in the state that would include, among other requirements, annual mandatory education for long-term care workers on ADRD-related topics.

Educating the Public

Improved awareness of ADRD can help combat stigma, foster understanding, and support affected individuals and their families by connecting them to health care providers or other relevant resources. In 2024, at least three states enacted laws that specifically require public health agencies to educate the public on ADRD topics. This includes Louisiana (HB 393), which made such education mandatory for providers and the public, as well as New York (SB 6504A), which specifically authorized an ADRD education and outreach program option for the health department. Finally, Connecticut (SB 1) required its health department to issue a public report on activities related to HBI. The report notes the steps the state is taking to educate the public on brain health, including a recently relaunched media campaign and plans for another if resources allow.

In 2025, at least 10 states considered legislation focused on educating the public about ADRD, including brain health and risk reduction measures, treatment options, and supportive programs or other resources for patients and families. Maryland enacted SB 748, which requires the health department to incorporate information regarding FDA-approved treatments for ADRD into its public health outreach programs, and in New York, companion bills A 4195/S 118 would require a publicly available database of successful programs supporting individuals with ADRD. With respect to broader public education campaigns, at least four states considered incorporating ADRD education into existing public health programs, including Maine (LD 1677), Alabama (HB 619), Rhode Island (HB 5619), and Mississippi (HB 116), while at least three states considered partnering with organizations or associations to meet specific objectives, including Florida (SB 398), Indiana (HB 1076), and Arizona (SB 1210). Finally, Massachusetts (H 468) is considering a comprehensive ADRD education and training bill that would require the health department to partner with other state agencies and community partners to develop a comprehensive public awareness campaign aimed at health care providers and the general public.

State-Led Public Awareness and Education Initiatives

In addition to recent legislative efforts steering increased awareness of ADRD, many states have launched successful initiatives to promote brain health across the life span and increase community members' awareness of existing resources.

The **Colorado Department of Public Health and Environment (CDPHE)** launched a comprehensive state-wide campaign in 2024 that has continued in 2025 to raise awareness about ADRD in Colorado. The campaign, <u>Talk About Dementia</u>, encourages open discussion about brain health, aiming to reduce stigma and promote early detection and prevention strategies. The campaign focuses on education and is designed to help Coloradans recognize the early signs of dementia, understand how to address personal risk factors, and take actionable steps to support their brain health.

"Supporting open discussion about these issues is the first step. It can lead to **better outcomes** and **more collaboration** to support and honor those who are aging in our community."

— Jill Hunsaker Ryan, Executive Director, CDPHE

The Alaska Legislature passed HB 308 in 2022, tasking the Alaska Department of Health with developing the Dementia Education and Prevention Program, which is associated with the existing work of the Alaska Dementia Action Collaborative. This program promotes brain health throughout the life course by increasing awareness of lifestyle modifications that reduce risk for ADRD, such as improved nutrition, physical activity, and mental stimulation. From this legislation, the agency expanded their existing Fresh Start Campaign in 2024 to provide dementia education, outline specific habits to improve brain health, and offer resources to support people living with ADRD and their caregivers. The campaign, which offered free education and programs that adults could join to improve their overall physical health, now includes an intentional focus on how these healthy behaviors and lifestyle changes also support brain health and reduce risk for ADRD. This campaign expansion is a notable example of blending communications relating to chronic disease prevention and brain health promotion to support risk reduction and reach a wide audience.

Sustainability Shoutout

By expanding their established public health campaign, which had contributed to more than 4,000 Alaskan adults enrolling in Fresh Start programs in the campaign's first year, the Alaska Department of Health thoughtfully leveraged existing infrastructure and community engagement. Building from foundations and resources that already exist can help state health agencies achieve their intended goals, maximize resources, and ensure long-term sustainability of their efforts.

Introducing dementia education for children and young adults equips them with the knowledge to keep their brains healthy across the lifespan to reduce their risk later in life and build greater empathy and understanding of brain health across generations. The Idaho Department of Health and Welfare offers brain health, Alzheimer's, and dementia education materials, including Noggin Stickers, to communicate strategies for protecting brain health to youth in a unique way. Furthermore, the Wisconsin Department of Health Services partnered with the Wisconsin Department of Public Instruction to craft and pilot an innovative School-Based Brain Health Curriculum for middle and high school students.

The **Georgia Department of Public Health** (GA DPH) launched the <u>Think About It</u> public awareness campaign in 2019, which educates individuals about brain health and demen a and aims to reduce the stigma associated with this topic. The initiative encourages individuals to have open conversations with their providers about brain health, offers helpful guidance about the cognitive assessment process, and emphasizes the importance of proactive health measures, such as annual check-ups and screenings.

Image: GA DPH Think About It Campaign



Image by GA DPH

The Georgia BOLD team is currently working to relaunch the campaign in 2025 with updated statistics and detailed risk reduction information. By embedding dementia awareness into broader public health efforts, campaigns educate and foster a culture of proactive care, early intervention, and community support.

Fostering Partnership and Collaboration

Multisector collaboration is essential to support risk reduction, early detection, and caregiving. Broader initiatives, such as <u>age-friendly ecosystems</u>, that address aging over the life course and overlap with brain health priorities may bolster collaboration across sectors. Formalizing partnerships, either through legislation or partnership agreements, supports the sustainability of connections and initiatives. Establishing an intentional staffing infrastructure allows health agencies to nurture innovative partnerships that support program implementation, extend the reach of essential services, and increase their public health impact on the communities they serve.

In 2024, both **Tennessee** (<u>HB 2890</u>) and **Pennsylvania** (<u>SB 840</u>) enacted laws aimed at restructuring agencies focused on aging. Tennessee's Department of Disability and Aging is a new <u>cabinet-level agency</u> formed by the merger of two executive branch entities with aging and disability and intellectual and developmental disabilities foci, respectively. Pennsylvania's law created the <u>first ADRD Office</u> in the commonwealth's Department of Aging, along with an advisory committee comprised of other agencies, community partners, providers, and other experts and interested parties invested in ADRD strategies and implementation considerations.

State units on aging play a distinct role in supporting caregivers of people with ADRD, often serving as the primary access point for direct services such as respite care, education, and resource navigation. These agencies are typically responsible for implementing federally supported programs, like the National Family Caregiver Support Program, and tailoring them to meet local needs. Public health agencies, while not direct service providers, can complement this work by addressing upstream factors that affect caregiver health and well-being (such as mental health, chronic disease prevention, and non-clinical factors of health) and by supporting data collection, policy development, and cross-sector collaboration through partnership with their aging agency counterparts.

Several states are also currently considering legislation to formalize interdisciplinary collaboration to support ADRD, such as councils, task forces, and advisory committees. In 2024, both Louisiana (SB 46) and West Virginia (HB 4756) created advisory councils to assess existing state ADRD policies, make recommendations for improvements, and assist in overall planning efforts. So far in 2025, at least six states have explored legislation requiring integration or collaboration to support older adults and individuals with ADRD. In Maine, LD 1677 would direct the health agency to create an HBI Council comprised of partner agencies, providers, and families with lived experience to make recommendations on state policy and planning for ADRD. Connecticut (HB 6771) established an ADRD task force to support the development of the state Alzheimer's plan and other policies to support people living with dementia. States that have explored legislation that centers the general needs of older adults include Vermont (H 414), which proposed a commission on aging to support and inform the state's aging plans; Minnesota (HF 2725), which would establish a healthy aging subcabinet focused on improving health outcomes for older adults and planning for the state's aging population; New Hampshire (SB 288), which would have created an advisory council focused on the systems of care to support healthy aging in the state; and Oregon (HB 3497), which would have established the Shared Future Oregon Task Force aimed at supporting the health of older adults. Championed by the Alzheimer's Association, establishing Dementia Services Coordinator (DSC) positions in state agencies is another way to encourage collaboration and expert oversight of ADRD-related programs.

While jurisdictions can pursue a coordinated approach with expert staff without a specific legislative directive to do so, at least 11 states have considered legislation to establish or expand a DSC program

so far in 2025. This includes Iowa, Maine, Massachusetts, Minnesota, Missouri, Nevada, New Jersey, New York, North Dakota, and Rhode Island. West Virginia enacted HB 2575, which directs the health department to establish a permanent, full-time dementia services director position to work with other partners and monitor/evaluate

"My role is about more than managing programs, it is about building a statewide movement to recognize brain health as a public health priority. By connecting state agencies local communities, and the voices of those directly by impacted dementia, we are creating a more coordinated, compassionate and informed response that supports individuals across the lifespan

 Jennifer Craig, Dementia Services Coordinator, **Kentucky Department for Aging and Independent Living**

services and strategies to support individuals with dementia and their caregivers.

Additionally, partnering with community members, particularly those living with ADRD and their caregivers, is essential across all public health strategies. Their lived experience provides critical insights that ensure policies, programs, and services are relevant, responsive, and grounded in real world needs. Innovative non-traditional partnerships are showing promise, such as those with local art communities (e.g., libraries, museums, theaters, and music and improv groups). In Georgia, the Department of Public Health has partnered with Dad's Garage, a theater group using improv to foster social connection and laughter among people with dementia and their care partners. Similarly, in Texas, a Dallas-based group called Stomping Ground Comedy offers improv for caregivers to build resilience and reduce stress through collaboration with state agencies and other multisector partners. Engaging non-traditional partners, including those who focus on music therapy or art-based programming, can offer connection and creativity for community members, people living with ADRD, and their caregivers.

Strengthening Data Collection and Utilization

Collecting and communicating data on dementia can help policymakers understand the scope and impact of ADRD, identify trends, allocate resources, assess caregiver needs, and develop targeted initiatives. While only a few states operate ADRD registries, many jurisdictions gather data on dementia, caregiving, or cognitive decline through other methods, and are increasingly leveraging these varied data sources to inform policy, increase awareness, and support individuals living with ADRD and their caregivers. Notably, several states are strengthening cross-sector data collaboration, working with advocacy groups, academic institutions, and health care systems to fill data gaps and co-develop solutions. Together, these efforts have elevated the visibility of brain health and caregiving in public health planning and helped states identify opportunities for health improvement, establish priorities, and develop more impactful interventions.

Insights from KY **DSC**

ASTHOReport

In recent years, some states have moved to formalize ADRD data collection through legislation. In 2024, **Virginia** (<u>HB 1455</u>) enacted legislation directing the <u>Memory Project</u> at Virginia Commonwealth University to collect and analyze ADRD data and support education and connections for families and providers. Funded by the Virginia Department of Health (VDH) and CDC, this initiative serves as an epidemiological database for dementia and other neurodegenerative disorders.

The <u>Virginia Memory Project</u> illustrates the power of legislative policy and innovative partnership. Through this initiative, VDH determined the need for additional respite programming and identified partners to expand their options for providing resources and care statewide.

So far in 2025, at least eight states have considered legislation addressing dementia-related data collection or accessibility, including **Hawaii** (<u>HB 700</u>), which will create a dementia data pilot program using certain cognitive assessment data to support Hawaii's <u>Alzheimer's plan</u>. Arkansas (<u>HB 1592</u>) considered legislation that would enhance ADRD data collection and created a public dashboard showing prevalence and geographic distribution information, along with certain health care-related metrics and outcomes. **Maryland** enacted <u>SB 748/HB1004</u>, which requires the creation of a public website with Alzheimer's prevalence information and related hospitalization data.

In **South Carolina**, one of the few states with an existing dementia registry, S 637 would require that the state's Alzheimer's plan use data from the registry and earmark appropria ons to ensure that support. The South Carolina Department of Health and Human Services provides core support and data access, enabling a robust academic-public health collaboration. **Massachusetts** is considering two similar bills (H 769 and S 468) that emphasize data collection and would require the health department to utilize the Behavioral Risk Factor Surveillance System (BRFSS) survey to collect and track ADRD- or caregiving-related data over time.

Georgia maintains a dementia surveillance registry through its Department of Public Health, which synthesizes data from multiple sources, including subjective cognitive decline and caregiving metrics from BRFSS. The Subjective Cognitive Decline Data Summary of 2023 offers insights into the cognitive health trends at the population-level, informing outreach and provider education efforts. The registry also received diagnostic data transfers from Georgia Memory Net providers via a piloted portal program. Additionally, the **New York Department of Health** is centering brain health through a Statewide registry of ADRD services by county, supporting improved understanding of trends, public health resources, and service gaps by geographic location.

Tennessee's Multi-Sector Plan for Aging Dashboard (Version 2), developed through a partnership between the Tennessee Department of Health and Tennessee State University, compiles aging and dementia-related indicators across agencies and sectors. This integrated platform supports data-informed state planning and demonstrates the value of academic–public health collaboration in driving coordinated aging and brain health data strategies.

Coordinated State Planning

Coordinated state-wide plans are imperative for strategic alignment of priorities to reduce risk for ADRD, increase early detection and diagnosis, and support caregivers. Regardless of the type of plan, it is important **that public health agencies** have a seat at the table for state-wide planning efforts. Public health is uniquely positioned to bring together invested parties, offer ideas that span different levels of prevention, and promote comprehensive, community-based plans that address specific topics (e.g., brain health and caregiving) at a population

Idea for Action!

Consider convening a group of partners across agencies and developing your own action plan of how you will collaborate and support each other's plan objectives. See the appendix for additional resources on aligning state plans.

level. Existing plans, like the ones described in the following section, can also be used to coordinate efforts by conducting a crosswalk of priorities and strategies across plans to identify areas for collaboration.

State Health Improvement Plans (SHIPs) guide long-term strategies for addressing identified statewide health priorities and reflect the health needs and priorities of communities across the jurisdiction. While SHIPs may not explicitly reference brain health, dementia, and/or caregiving, they often include related focus areas (e.g., chronic disease prevention and management, healthy aging, mental health and emotional well-being, access to care, public health infrastructure, etc.).

Strategies for SHIP development and implementation that advance priorities:

- Integrate ADRD and caregiving data into the State Health Assessment and other collaborative data efforts.
- Frame brain health and caregiving as cross-cuttng priorities that intersect with chronic disease, aging, mental health, etc.
- Analyze how current SHIP strategies and goals support dementia risk reduction and support caregivers.
- Build collaborations to maximize identified areas of intersection and address gaps.

State ADRD Plans drive the implementation of HBI Road Map strategies to support brain health and caregiving. Since 2007, all 50 states and Washington, D.C., have published State ADRD Plans. These plans establish accountability by helping policymakers create the infrastructure necessary to address the growing crisis. Additionally, what gets measured and reported gets done! Developing organizational measuring and reporting structures bolster these state plans. Comprehensive reporting helps demonstrate a return on invested time and resources and supports relationship building and increased buy-in among multisector partners and key decision-makers.

State Plans on Aging (SPoAs), which are federally required through Section 307(a) of the Older Americans Act, specifically address facets of older adult well-being, including brain health, ADRD, and caregiving. These plans are administered through State Units on Aging and, regardless of how the state unit/division/department may be organized, there is value to ensuring a public health lens for these plans. As key informants, public health agencies can support consistency of priorities, facilitate integration and coordination of services, increase efforts to build upon existing infrastructure and initiatives, and maximize resources to promote healthy aging state-wide.

Multisector Plans on Aging (MPAs) typically provide a 10-year blueprint for addressing specific prioritie within the context of broader healthy aging initiatives, including brain health and caregiving. Public health involvement may vary in the planning, development, and implementation of MPAs; however, being a contributor strengthens the collaboration between state health departments and their aging agency counterparts and promotes system-level changes. For example, the New York State Department of Health has teamed up with the New York State Office for the Aging to co-develop and implement their Master Plan on Aging. Both agencies play a distinct role in crafting the plan and delivering the essential services that are outlined to support communities statewide.

Funding and Reimbursement Mechanisms

Medicaid is the number one payer for long-term care services and supports (LTSS), including institutional care and Home and Community-Based Services (HCBS), and for some states, Medicaid is within the purview of the state health official and provides ample opportunity to support dementia care as its coverage of key services is available through several pathways and in a variety of settings. For states considering Medicaid reimbursement pathways, there is an opportunity to model successful state-funded programs or incorporate bene ts as seen in other states.

HCBS Options in Medicaid

While nursing facility care is a required benefit in Medicaid, states have the option to provide HCBS, including personal care services, through either state plans or waiver authorities. The breadth of home care services varies, and a state's coverage of services may differ based on population. As of April 2025, HCBS is offered through the personal care state option (34 states) and the Community First Choice state option (10 states). HCBS 1915(c) waivers (47 states) are another option to provide HCBS services as an alternative to institutional level care to Medicaid members. Additionally, Section 1115 Medicaid demonstration waivers (14 states) offer an avenue to test new approaches in Medicaid that differ from what is required by federal statute and may provide states additional flexibility in their programs' operations.

Medicaid Flexibilities for Caregiver Support

Among all state Medicaid HCBS programs, 39 states specifically provide support for family caregivers. All states operating HCBS programs provide some form of payment for caregivers, typically an hourly wage; however, only 10 states operate a structured family caregiving program where Medicaid pays a provider agency a daily stipend which covers care coordination, home visits, and a fixed payment to the family caregiver. Missouri is currently the only state that has a structured waiver specifically for caregivers of people with ADRD, including training and an overview of ADRD. A total of 26 states have chosen to cover training, counseling, or education for family caregivers for older adults or individuals with disabilities via waiver authority. In addition to Missouri, Massachusetts, Maryland, and New Jersey specify providing dementia education, counseling, or training for family caregivers through HCBS waiver authority.

States may also support caregivers through Medicaid Managed Care contract requirements. As of July 2024, 42 states, including the **Washington**, **D.C.**, operate their Medicaid program through risk-based managed care plans. These states have flexibility in certain contract requirements outlined for Managed Care Organizations (MCOs). New Jersey and Tennessee have specifically outlined caregiver assessment and assistance in contracts with their Medicaid MCOs.

Medicaid Flexibilities for Expanded Eligibility and Benefits for HCBS

States can utilize 1115 Waivers to offer Medicaid coverage of state plan services and other targeted HCBS to individuals not otherwise eligible for Medicaid. A specific strategy is to provide access to HCBS for those who will likely require an institutional level of care in the future, determined through specific eligibility screening. This pathway has the potential to improve the individual's quality of life while also decreasing future Medicaid spending on long-term services and support, as demonstrated by Washington State's model.

Since 2017, Washington's 1115 waiver, the <u>Washington Medicaid Transformation Project</u>, has expanded eligibility to support older adults and delay or prevent the need for LTSS, offering three tiers of caregiver support based on individual circumstances. <u>Evaluation data</u> from these programs demonstrated that investing in family caregivers has been successful in containing health care costs, preventing hospitalizations, and delaying Medicaid LTSS. Two eligibility pathways are included in the waiver:

- The Tailored Supports for Older Adults (TSOA) benefit provides two packages of services to older adults (55+) who are not currently resource eligible for Medicaid but are at risk for future Medicaid LTSS. One supports unpaid caregivers of eligible care receivers with respite and a suite of budget-based service options, including dementia training, adult day services, home-delivered meals, and personal emergency response systems. The other package provides personal care, instead of respite, to those who do not identify as an unpaid caregiver along with the same choice of services at the same level of budget-based benefit. This program was originally modeled after Washington's Family Caregiver Support Program, a non-Medicaid state-funded program.
- The **Medicaid Alternative Care (MAC)** benefit is for adults 55 and older who qualify for traditional Medicaid LTSS but instead choose for their caregiver to receive MAC supports (same caregiver package as described under the aforementioned TSOA). Individuals enrolled in Washington's Community First Choice Program, or COPES waiver, may not also receive support for their unpaid family member.

Additional Funding Models for Consideration

In addition to Medicaid reimbursement pathways, innovative demonstrations for funding dementia care and caregiving support include:

- <u>Guiding an Improved Dementia Experience (GUIDE) Model</u>: A CMS Innovation Model that was launched in July 2024 and is expected to run for eight years. The GUIDE Model is a voluntary nationwide model testing an alternative payment methodology for participants that delivers comprehensive, coordinated dementia care. There are currently 350 participants.
- Program for All-Inclusive Care for the Elderly (PACE): A Medicare option available to Medicaid recipients via a state plan option. The PACE program provides comprehensive coordinated care to certain frail, community dwelling older adults, who are often dual eligibles. Financing for program services is capped, which allows providers to deliver all services participants need as opposed to only Medicaid or Medicare reimbursable services.
- <u>LTSS Social Insurance</u>: A promising approach to providing universal and affordable LTSS within states, this pathway considers a state-sponsored option for long-term care insurance. Currently Washington state is the nation's first to successfully establish an LTSS Social Insurance program, the <u>WA Cares Fund</u>.

Expand Medicaid Coverage of Cognitive Assessment and Care Planning

Following the adoption of coverage by Medicare in 2017, many state Medicaid programs have also begun covering CPT code 99483, which allows clinicians to be reimbursed for assessing cognition and providing care planning services. In recent years, Alaska, Nevada, Oregon, South Dakota, and West Virginia have each adopted Medicaid coverage for this service, joining numerous other states that had previously done so.

Support Reimbursement Processes Through Provider Training

To facilitate the process of reimbursement for dementia care and caregiving, state health agencies have the opportunity to provide targeted training on billing for providers. To ease administrative burden, states, such as <u>Texas</u>, have developed specific training modules and resources for providers focused on diagnostic and screening codes for ADRD.

State Success Showcase

Vermont Department of Health

The **Vermont Department of Health** has implemented a number of promising practices to protect brain health and amplify the public health response to dementia in Vermont. Their agency leverages critical partnerships and leads key initiatives to increase public awareness and support body and brain health across the lifespan. In close collaboration with other federally funded chronic disease programs, Vermont Department of Health ensures state planning coordination, and explores/establishes pathways for a dementia-capable system of diagnosis, management, care, and pre-Medicaid eligibility.



As a measure to sustain dementia and risk reduction awareness building, <u>S.302 (Act 164)</u> directs Vermont Department of Health to provide education on specific topics to increase public awareness about ADRD. Through the BOLD grant and this legislation, Vermont Department of Health has established a set of successful integrated brain health and chronic disease campaigns, <u>Healthy Body, Healthy Brain</u>. This webpage has been routinely updated and offers essential information on brain and heart health as well as free self-management workshops.

Vermont Department of Health and its partners have established state-wide plans that serve distinct purposes yet offer complementary strategies for addressing dementia and promoting risk reduction at all prevention levels. The plans support healthy aging and address public health priorities. These state plans include the Vermont State Plan on Aging, the state's multisector plan Age Strong VT, Vermont Action Plan on Aging Well, and Vermont State Health Improvement Plan. Collectively, the alignment and coordination across these plans propels the state's advancement toward a shared goal, to enable all Vermonters to age with dignity, respect, and independence in the healthiest manner possible.

Vermont Department of Health, the Department of Disability, Aging and Independent Living, and numerous partners prioritize a lifespan approach of disease prevention, address social drivers of health, and ensure quality dementia care. In addition to monthly meetings to discuss expanding dementia-capable infrastructure which includes the University of Vermont and Bennington Memory Programs, primary care teams, Adult Day Centers, community health teams, hospitals and clinics, this workgroup is part of a larger Alzheimer's Disease and Healthy Aging Coalition. The coalition consists of three workgroups, including the Governor's Commission on ADRD which examines and puts forward health system and legislative policies.

The Vermont Choices for Care (CFC) Program has established pre-Medicaid eligibility pathways through the Vermont Global Commitment to Health 1115 Waiver. The CFC program establishes three levels of need for LTSS: moderate, high, and highest. Vermont provides some Medicaid LTSS benefits, such as case management, homemaker services, and adult day services to pre-Medicaid eligible adults with "moderate needs" to prevent decline into a higher need category. Initial evaluation of the CFC program found a high level of consumer satisfaction, and results showed that it increased access to HCBS and enabled individuals to be served in the care setting of their choice. Vermont leadership continues to work to increase funding for the moderate needs group to address interest.

Pathways to Progress

The following table outlines actionable recommendations for state health agencies and their partners to strengthen policies and implement effective initiatives that promote brain health and caregiving in their jurisdictions. Drawing on insights from existing state-level policies, models, and strategies, and aligned with the HBI Road Map, these recommendations offer practical pathways for implementation across policy and programmatic domains.

Recommendations				
Objective	Strategies	Key Partners		
Increase public awareness.	 Promote provider-patient dialogue on brain health. Educate the public about dementia risk reduction and early detection and the importance of planning for caregiving needs. Integrate brain health messaging into existing chronic disease and wellness initiatives. 	 Aging agencies. Health care providers. First responders (e.g., Emergency Medical Responders, law enforcement, firefighters). Municipal or regional planning commissions. State policymakers. Communications departments and media channels. Community members living with dementia and their caregivers. 		

Objective	Strategies	Key Partners
Coordinate state planning.	 Activate public health involvement in state planning for aging and ADRD. Crosswalk state plans to identify shared priorities and collaboration opportunities. 	 State policymakers. State agencies. Community-based organizations. Community members living with dementia and their caregivers.
Expand and formalize partnerships.	 Develop intentional staffing infrastructure to support aging work. Implement multisector collaboration structures such as task forces, advisory committees, and workgroups. Establish partnership agreements such as MOUs. Engage communities and formalize input mechanisms (e.g., participatory planning models, advisory councils with compensation for community members). 	 Aging agency counterparts. State Medicaid counterparts. State policymakers. Community-based organizations. Non-traditional partners, (e.g., first responders, law enforcement, transportation, housing, municipal planning commissions, library systems, community art collaboratives, museums, etc.). Community members living with dementia and their caregivers.
Strengthen collection and utilization of brain health, dementia, and caregiving data.	 Analyze data to inform public health action from sources such as: BRFSS Cognitive Decline and Caregiving Modules. State Medicaid data. Demographic datasets from the Census Bureau and university research institutes. Input from community members affected by dementia, such as by hosting caregiver focus groups and fielding community needs assessments. 	 Insurance providers/Medicaid agencies. Local, state, federal agencies. Private sector partners (e.g., universities and academic medical centers, hospital systems/clinics, health insurance companies and MCOs, home health and long-term care companies). Community members living with dementia and their caregivers.

Conclusion

Policy and sustainable practices are key to taking a comprehensive public health approach to brain health and caregiving. Legislative and organizational initiatives are supported by leveraging cross-sector partnerships and embedding brain health and caregiving strategies into existing public health infrastructure and initiatives (e.g., state health plans, Medicaid waivers, and workforce development).

A public health approach grounds policy and practice in community-driven prevention and prioritizes risk reduction, early detection, data-informed action, and community engagement, enabling upstream interventions that support health across the lifespan.

Call to Action:

State and territorial health agencies are well positioned to advance brain health.

Public health leaders are equipped to influence policy, implement HBI strategies, and design scalable programs to improve brain health and strengthen caregiving supports by convening partners, leveraging data, and embedding prevention into care systems, ensuring ADRD is uplifted as a public health priority.

Sustainable progress requires coordinated action.

A single sector would not be able to address the complexities of ADRD navigation alone; however, formalized partnerships, complementary state plans, and strong data systems allow public health to work effectively with partners across aging services, Medicaid, and community-based organizations.

Public health policy is key to translating science into sustainable, practical systems.

From promoting workforce development and public education, to establishing fortified data systems and multisector partnerships, state policies can reinforce HBI Road Map actions and lay the groundwork for long-term progress on brain health and caregiving.

Appendix: Support Tools and Resources

Explore the following tools and resources to advance the public health impact and sustainability of your HBI efforts through collaboration and planning.

Tools and Resources

- ASTHO Resource Hub: Integrating Sustainability into HBI Implementation
- Needs Assessment Toolkit for Dementia, Cognitive Health and Caregiving
- <u>Fillable Tools</u> from the toolkit (e.g., partner matrix, shared goals worksheet, assessment timeline, report checklist)
- Performance Measures Matrix for Alzheimer's and Dementia

ASTHO Technical Packages and Journal Articles

- Public Health Agency Approaches to Improving Access to Care
- Supporting Healthy Aging and Older Adult Health: The Role of State and Territorial Health Agencies
- Improving Older Adult Health by Operationalizing State Plans on Aging and Health Improvement
- Bridging Silos: Aligning State Health Improvement, Aging, and Dementia Plans