

The national public health response to Alzheimer's disease and related dementias: Origins, evolution, and recommendations to improve early detection

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Abstract

Longstanding gaps in the detection of Alzheimer's disease and related dementias (ADRD) and biopsychosocial care call for public health action to improve population health. We aim to broaden the understanding of the iterative role state plans have played over the last 20 years in prioritizing improvements in the detection of ADRD, primary care capacity, and equity for disproportionately affected populations. Informed by national ADRD priorities, state plans convene stakeholders to identify local needs, gaps, and barriers and set the stage for development of a national public health infrastructure that can align clinical practice reform with population health goals. We propose policy and practice actions that would accelerate the collaboration between public health, community organizations, and health systems to improve ADRD detection—the point of entry into care pathways that could ultimately improve outcomes on a national scale.

KEYWORDS

Alzheimer's disease, identification, other dementias, population health, primary care

HIGHLIGHTS

- We systematically reviewed the evolution of state/territory plans for Alzheimer's disease and related dementias (ADRD).
- Plan goals improved over time but lacked implementation capacity.
- Landmark federal legislation (2018) enabled funding for action and accountability.
- The Centers for Disease Control and Prevention (CDC) funds three Public Health Centers of Excellence and many local initiatives.
- Four new policy steps would promote sustainable ADRD population health improvement.

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1 | INTRODUCTION AND BACKGROUND

Dementia affects 1 in 10 older Americans. Although dementia is thought to be most commonly caused by Alzheimer's disease (AD),¹ multiple etiologies often coexist.² Collectively, Alzheimer's disease and related dementias (ADRD) cause progressive brain failure, increasing dramatically in prevalence with the rapid growth of the older population. With estimated prevalence in the United States of about 5 million in 2008,³ ADRD prevalence is expected to exceed 10 million by 2050 and to account for over \$1 trillion in overall costs.^{4,5} Its broad impact on lives, health care delivery, quality, and costs provide strong impetus for public health action to achieve systemic improvements in detection, management, and outcomes. As a first step toward a population health approach to ADRD, we focus here on improving early detection as a public health priority.

Multi-year delays from symptom onset to clinical recognition of Alzheimer's disease and related dementias (ADRD) are common, and over half of affected individuals have not (or do not know they have) been diagnosed with dementia.^{6,7} Diagnostic delay and avoidance can originate at the patient, family, clinician, and/or health system level and are reinforced by low confidence among primary care providers, false beliefs that early diagnosis is harmful or futile, and misplaced emphasis on biomedical therapies as the defining value in clinical care.^{1,8-10} These attitudes perpetuate nihilistic postures that leave patients and families without evidence-informed strategies to best manage the impact of dementia on their lives, health, and well-being. Some populations are disproportionately affected by delays in diagnosis and barriers to dementia-relevant care. Demographic disparities exist in perceptions of cognitive decline and ADRD as a disease, access to information,¹¹⁻¹⁴ and the relationship between perceived and objective cognitive impairment.¹⁵ Black and Hispanic populations have higher reported rates of ADRD than non-Hispanic White populations, yet are diagnosed at later stages and less often seen by specialists.^{12,13,16,17} They are also less likely to have a Medicare Annual Wellness Visit (AWV),^{18,19} a preventive health visit that requires detection of existing cognitive impairment. Practices caring for medically underserved, often minoritized, groups are less likely to offer the AWV,²⁰ yet broad implementation can markedly increase overall diagnosis rates and diminish ethnic disparities in detection.¹⁸

Rural populations are also affected by gaps in medical, public health, and social service infrastructure for dementia care,²¹ with few health professionals prepared to detect and diagnose cognitive disorders in rural populations. Lack of reliable transportation often prevents access to urban or regional centers, and local digital services are often not sufficiently robust for telehealth or remotely delivered supportive services.^{22,23}

1.1 | Configuring a National Public Health Approach to Improving the Detection of ADRD

The core functions and tools of public health service—surveillance, monitoring of population burden, effective communication, and educa-

RESEARCH IN CONTEXT

- 1. Systematic review:** We traced dementia detection as a population health goal through the states' Alzheimer's disease and related dementia (ADRD) plans.
- 2. Interpretation:** States increasingly prioritized ADRD detection as part of health care but largely lacked financing, accountability, and capacity for action. Federal legislation in 2018—Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act—enabled the Centers for Disease Control and Prevention (CDC) to fund a national Public Health Center of Excellence on Early Detection and nearly two dozen state-/county-level ADRD initiatives tasked with planning or implementing improvements.
- 3. Future directions:** A national public health infrastructure for improving the detection of ADRD is evolving. To promote sustainability, we recommend four stabilizing policy steps: a permanent federal authority for ADRD population health; reportable quality measures for dementia detection and care; new collaborations between public health departments, educators, payers, health care systems, and philanthropy; and coordinated sharing of information and implementation strategies across all national agencies and organizations with an ADRD portfolio.

tion campaigns around primary prevention and early diagnosis—could play a major role in mitigating overall and inequitable population and community impacts of ADRD. However, the issue is complex: the multiplicity of key stakeholders, lack of incentives, and established pathways for sustained cross-sector collaboration (between public health departments, community organizations, and health care systems), and wide variation in policy and practice across the United States challenge the translation of knowledge into practice on a national scale. To identify possible solutions, we trace the evolution of current national public health framework for ADRD detection and health care delivery, laying out key developmental steps and critical and complementary policy and practice efforts that led us here (Figure 1). We first briefly discuss the Healthy Brain Initiative (HBI), initiated in 2005; the National Alzheimer's Project Act (NAPA), Advisory Council, and Plan of 2011; and actions taken by the Centers for Medicare & Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA) to enable clinical practice improvement. These national initiatives provide context for assessing the evolution of state and territory dementia plans (state or territory plans [STPs]) and were stepping stones toward passage of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2018. Here we review how STPs specifically iterate the health care values articulated in NAPA priorities and expressed in these national capacity-building initiatives around early detection.

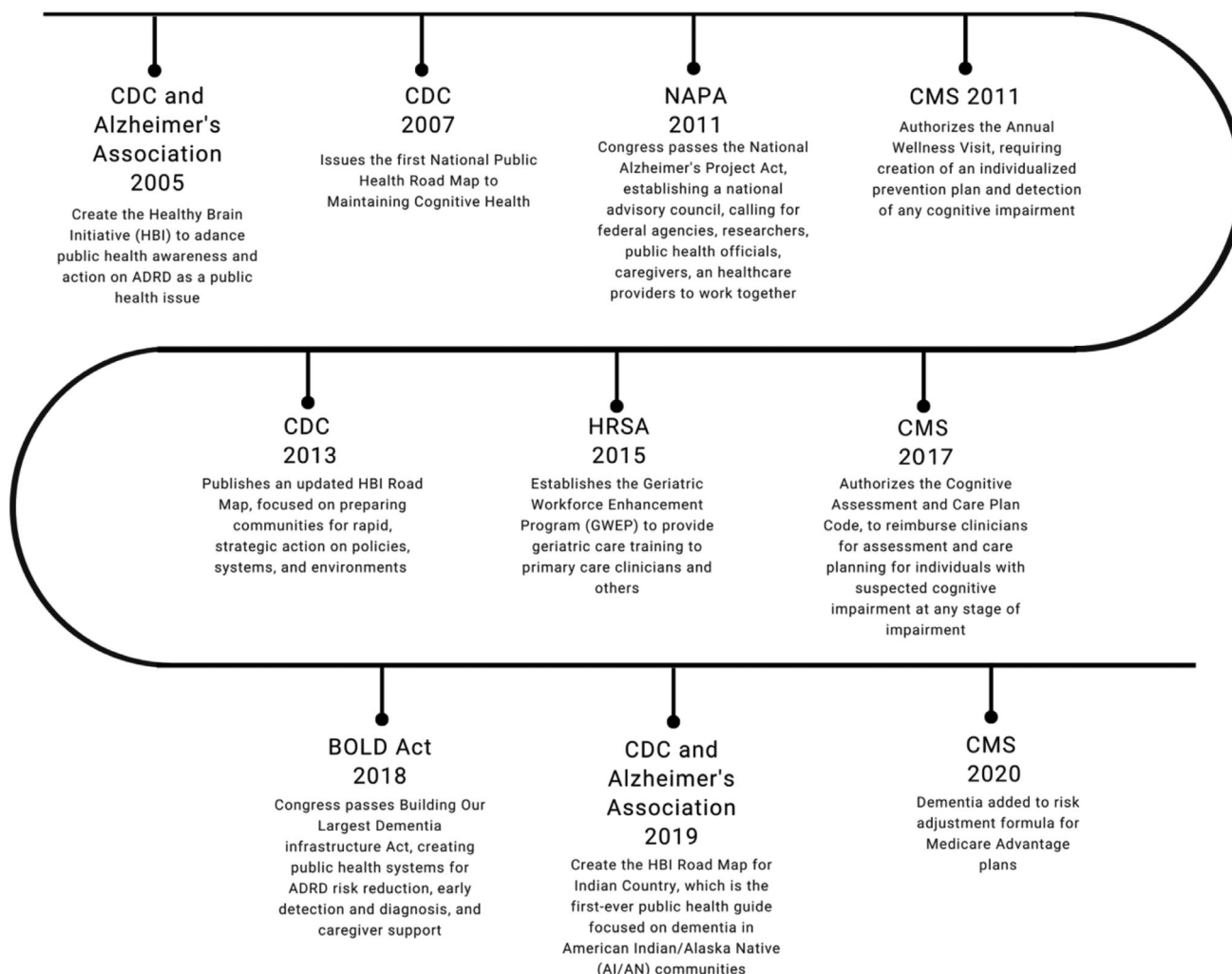


FIGURE 1 Timeline: National ADRD Policy and Practice Initiatives. Timeline depicts key events that influenced policies and practices up to 2020. ADRD, Alzheimer's disease and related dementias; BOLD: Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act; CDC: Centers for Disease Control And Prevention; CMS: Centers for Medicare & Medicaid Services; HRSA: Health Resources and Services Administration; NAPA: National Alzheimer's Project Act.

1.2 | Healthy Brain Initiative

In 2005, the Centers for Disease Control and Prevention (CDC), in partnership with the Alzheimer's Association, amplified the national conversation about ADRD through the HBI, designed to advance awareness and promote public health action.²⁴ In 2007, the CDC's first National Roadmap to Maintaining Cognitive Health charted a path to tangible public health action, and the second version (2013) prepared communities to act quickly and strategically through a three-part framework focused on systems, environments, and policies.²⁵ Aligning the HBI Road Map actions with the Essential Services of Public Health was a key step in facilitating efficient incorporation of ADRD initiatives into existing public health activities.²⁶ The current version (HBI 2018–2023 Road Map) includes definitions, diagrams, and actions applicable to a national audience by promoting State and Local Public Health Partnerships to Address Dementia.²⁷ A fourth iteration of the Road Map has now been released (June 2023).

1.3 | The National Alzheimer's Project Act (NAPA), Advisory Council, and Plan

In 2011, a seminal publication defined new criteria for diagnosis of AD,²⁸ based on AD's distinctive biological features, identified as biomarkers, that differentiate it from other causes of dementia. This new approach has been foundational for subsequent biomedical research on AD and helped to leverage passage of NAPA. NAPA supports efforts to create and maintain an integrated national plan, coordinate ADRD research and services across all federal agencies and with international bodies, accelerate development of treatments, improve early diagnosis and coordination of care for affected individuals, and reduce ethnic and racial minority disparities. The law establishes a multi-stakeholder Advisory Council on Alzheimer's Research, Care and Services and requires the Council, together with the secretary of the U.S. Department of Health and Human Services, to create and maintain a national ADRD plan. The Council's work is regularly reported and

featured in a series of national summits showcasing research and other relevant advances.

1.4 | The BOLD Infrastructure for Alzheimer's Act

Passed in 2018, the BOLD Infrastructure Act directed the CDC to establish three ADRD Public Health Centers of Excellence, each focused on a distinctive dimension of ADRD: (1) risk reduction/primary prevention, (2) early detection, and (3) caregiving.²⁹ These centers, established in 2020, seek to promote awareness, collate and disseminate evidence-based practices, and stimulate collaboration through creation of national partner networks. Through a competitive application process, additional BOLD Act provisions support state, county, and/or local public health departments to increase ADRD planning, implement programs, and improve data collection and timely analysis. "Core Capacity" awards support the creation of state or local dementia coalitions and ADRD strategic plans for their jurisdictions, using the Road Maps as a guide. "Enhanced Capacity" recipients have an existing strategic plan and are charged with implementing it in line with Road Map actions.³⁰

1.5 | Building essential clinical capacity for ADRD care: Centers for Medicare & Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA)

In 2011, CMS introduced the AWW, a reimbursable preventive service aimed at promoting the health of Medicare beneficiaries through a comprehensive health risk assessment that includes detection of any existing cognitive impairment. This assessment serves as the basis for a personalized prevention plan to be created and shared with the beneficiary. Four years later, in 2015, the HRSA launched the Geriatric Workforce Enhancement Program³¹ to enhance and disseminate geriatric clinical skills and capacity to care for an aging population, whose special health risks had been enumerated in the elements of the AWW. The competitively-funded GWEPs all (now numbering 48 across the United States) must include in their plans some form of dementia education, but have broad latitude to choose how they will meet this goal.³² In 2017, CMS introduced the Cognitive Assessment and Care Plan benefit, intended for use in fee-for-service (traditional) Medicare with individuals who may have dementia or be at risk for cognitive impairment from any cause. This benefit added new psychosocial components to traditional medical assessments and legitimated a significant departure from Medicare's previous "patient-only" focus by requiring, for the first time, the participation of an independent historian (e.g., a family care partner) in a clinical visit. Recognizing the defining effect of ADRD on cognition—and the resulting threat to individuals' ability to provide accurate and detailed health-related information and follow through on treatment plans the care partner's role is to supplement information about the patient, participate in developing a care plan, support its execution at home, and identify their own needs for additional sup-

port. In 2020, CMS authorized a new dementia risk-adjusted additional payment for Medicare Advantage plans (which do not specify cognitive assessment and care planning as a covered benefit) to compensate for the higher costs of the complex care often required by beneficiaries with dementia.

1.6 | State and territory plans: Local framing of ADRD needs and gaps

Over the past 50 years, states have experienced a marked increase in their discretionary authority to choose what health problems they prioritize and invest in.³³ Nearly all states and territories have published their own ADRD plans or STPs; these plans identify many needs for improving ADRD education, care, and services, and establish local and regional priorities as vetted by a range of stakeholders. Our review focuses specifically on how state plans have addressed three NAPA priorities³⁴ that are most relevant to health care delivery today: (1) improving rates and timeliness of ADRD detection and diagnosis; (2) developing the primary care workforce for dementia detection and care; and (3) promoting equity for populations disproportionately affected by ADRD.³

2 | METHODS

We identified STPs ($n = 49$) through publicly available websites, most through the Alzheimer's Association (<https://www.alz.org/professionals/public-health/state-overview>) and searched plan details for all 50 states, the District of Columbia, and Puerto Rico. We supplemented this strategy with Google searches using state/territory name followed by "Alzheimer's State Plan." Three reviewers (S.V., S.B., J.W.) examined plan structure and priorities. We then created a uniform variable structure, including the year of initial STP development, to identify common priority-relevant objectives across plans, highlight key recommendations within each objective, and collate commonalities across plans. Because the three NAPA priorities are broad and can be operationalized variably, we identified objectives within each of the three key priority categories.

To characterize the quality of STPs, we determined whether each NAPA health care priority was identified as a problem with a goal for improvement, and whether any specific strategies or action steps were proposed to achieve that improvement. Three researchers (S.V., S.B., J.C.) independently rated each strategy on a scale of 0 to 3 (0 = none; 1 = vague or general; 2 = specific, but insufficient for replication; and 3 = specific, replicable actions) and created a consensus score for each strategy. We examined STPs that included actionable strategies to see if plans included criteria for evaluating results. We also examined the overall composition of each plan's stakeholder working groups and the extent to which public health entities (Departments of Public Health) were integrated into the planning process. We used Dedoose coding software to record all abstracted data and scores.³⁵

3 | RESULTS

Tables 1 and 2 summarize STPs by epochs before and after passage of NAPA legislation in 2011, showing a rapid post-passage increase in numbers of states creating ADRD plans that specifically addressed health care objectives, with progressive diversification and specificity over time: before NAPA (2002–2011), only 11 STPs addressed any health care priority; afterward, 39 did.

3.1 | Before NAPA (2007–2011)

3.1.1 | Early detection and diagnosis

STPs focused on statewide campaigns (6 of 11 plans) to increase public awareness and understanding of rising ADRD prevalence and its relationship to aging, by educating the public about brain health, early signs of cognitive decline, and warning signs of dementia, with the aim of reducing stigma and encouraging diagnostic evaluation. Some states created grass-roots campaigns, but many leveraged the Alzheimer's Association's national campaign and dissemination engine for local use.

3.2 | Clinician workforce development

All “early-adopter” STPs made clinical workforce development a priority; 8 of 11 states called for health care provider education in ADRD recognition (in South Carolina, the goal was mandatory clinician education). Many states (6 of 11) identified dissemination of “best practices,” through incorporating cognitive assessment into routine annual visits and use of screening tools (e.g., Ascertain Dementia 8 [AD-8], Mini-Cog) in clinical settings, or proposing state-funded specialized ADRD diagnostic centers of excellence. Some states (e.g., Colorado) proposed scholarships and loan repayment programs for medical students and residents electing specialized geriatric training. Almost half (5/11) identified partnerships with existing medical education providers or organizations as important in promoting early detection and diagnosis.

3.2.1 | Health equity for disproportionately affected populations

Health equity was a minor focus (3 of 11) before NAPA and when included, it varied from public messaging tailored for diverse cultural groups, languages, and literacy levels to creating telemedicine outreach.

3.3 | Since NAPA 2011–2020

3.3.1 | Early detection and diagnosis

The introduction of CMS's Medicare AWW in 2012 made detection an explicit target for clinical improvement. Arizona identified cognitive impairment as a “vital sign” for health assessment of older people. Part-

nering with existing educational venues remained important (14 of 39 STPs), with an emerging focus on including ADRD in medical training curricula.

3.3.2 | Clinician workforce development

The most common priority for STPs (33 of 39) was education about the importance of ADRD detection and dissemination of best practices in health care settings, addressing treatment, care coordination, and patient/family access to social services support and community resources.

3.3.3 | Health equity for underserved communities

With mounting epidemiological evidence of the disproportionate impact of ADRD on sociodemographically disadvantaged groups, HBI-supported states intensified efforts to build awareness within minoritized communities. Health equity emerged as a distinct focus for more than two-thirds of STPs (27 of 39) created after 2011. Many (15 of 27) identified the need to build culturally tailored information into ongoing ADRD awareness campaigns and communication strategies, emphasizing rural, Hispanic/Latino, and Native American tribal communities and non-English-speaking individuals. Telemedicine re-emerged in an equity context, as did diversifying racial, ethnic, and rural population inclusion in research.

3.3.4 | Stakeholder engagement in the state planning process

STP workgroups included a broad range of stakeholders (data not shown), with health and other care providers most strongly represented both pre- and post-NAPA. Although state public health officials may have contributed behind the scenes, few public health departments were formally named or integrated into plan development before the BOLD Act made them central to ADRD public health development efforts in 2020.

3.3.5 | Plan Quality and Impact Assessment

Most STPs ($n = 30$ and 31 , respectively) identified early detection/diagnosis and workforce development as important and many ($n = 25$ and 18 , respectively) developed explicit goals for these two priorities (data not shown). Most STPs identified health inequity as a problem but typically embedded it in the first two NAPA priorities (early detection/diagnosis and workforce development) without differentiation. As a result, STP equity goals could not be analyzed separately. Newer STPs—especially those from East and West Coast states—tended to include more explicit goals, action steps, and evaluation plans. Overall, most STPs lacked blueprints for action and plans for evaluating their state's progress until the BOLD Act provided national funding to do so.

TABLE 1 State Plans Published Before 2011 (N = 11).

Key Priorities	Objectives	n	Key Recommendations Extracted from State Plans
Early detection and diagnosis (n = 8)	Public awareness campaign	6	<ul style="list-style-type: none"> – Strategic public/private partnerships for implementation of statewide public awareness campaign. (LA) – Design a broad-based dementia and brain health public information campaign. (VT) – Leverage the National Alzheimer's Association's public awareness campaign and disseminate through various media outlets. (CO)
	Annual wellness visit	2	<ul style="list-style-type: none"> – Encourage health care providers to make brain health check-ups standard practice part of annual physicals visits. (MS) – Increase awareness of cognitive screening, assess access to care during annual visits. (NY)
Clinician workforce development (n = 11)	Educational programming	8	<ul style="list-style-type: none"> – Develop and implement continuing education programs that improve the ability of health care providers to detect and diagnose dementia. (MS) – Mandatory training modules and continuing education on ADRD for current and future clinicians. (SC)
	Dissemination of best practices	6	<ul style="list-style-type: none"> – Statewide campaign to educate providers about early detection instruments. (IA) – Pilot-test statewide dementia assessments using validated tools. (MO)
	Incentives for students and providers	2	<ul style="list-style-type: none"> – Scholarships and loan repayment programs through the National Health Service Corps (NHSC) and the Colorado Health Service Corps. (CO)
	Holistic care development (long-term care, community organizations, hospice, adult day care)	3	<ul style="list-style-type: none"> – Coordinated care management codes and transitional care management for health care providers. (MS)
(SC)	Partner with educational program or organization	5	<ul style="list-style-type: none"> – Study potential opportunities and benefits of interdisciplinary approach including social workers, physician assistants, nurse practitioners, physical therapists, neurologists, psychologists, psychiatrists, and primary care physicians. (TN) – Apply for a federal grant to create at least one new Geriatric Education Center in Colorado. (CO) – Work with universities to develop dementia specific training and recruitment options. (NY)
Health equity (n = 3)	Multicultural/multi lingual campaigns	2	<ul style="list-style-type: none"> – Culturally appropriate communication campaigns. (TN)
	Targeted populations	3	<ul style="list-style-type: none"> – Culturally sensitive informational materials and educational programs to increase research diversity and participation from underrepresented communities. (MS) – Explore telemedicine technology applications in research recruitment efforts to reach rural populations and remote communities. (MS)
	Telemedicine	1	<ul style="list-style-type: none"> – Develop a regional care team to support access to dementia care for rural and remote populations. (VT) – Explore the use of telemedicine technology applications in research recruitment efforts to reach rural communities. (MS)

Note: States represented: CO, Colorado; IA, Iowa; KY, Kentucky; LA, Louisiana; MS, Mississippi; MO, Missouri; ND, North Dakota; NY, New York; SC, South Carolina; TN, Tennessee; VT, Vermont. n, number of plans identifying each objective; ADRD, Alzheimer's disease and related dementias.

TABLE 2 State Plans Published 2011–2020 (N = 39).

Key Priorities	Objectives	n	Key Recommendations		
Increase early detection and diagnosis (n = 29)	Public awareness campaigns	17	<ul style="list-style-type: none"> – Long-term media campaign about benefits of early diagnosis, advance health care and financial planning, and available resources. (SD) – Public awareness campaigns to reduce conflicting messages, decrease stigma, and promote early diagnosis. (IL) – Increase public awareness about brain health, dementia, and risk factors. (MI) 		
	Annual wellness visit	13	<ul style="list-style-type: none"> – Promote cognition as an essential “vital sign” to be assessed during patients’ AWW. (AZ) – Increase use of dementia screening and tracking cognitive changes in primary care settings. (AK) – Recommend cognitive health and depression assessments in annual routine physical exams. (PA) – Include screening for cognitive function and mood using validated assessment tools as a regular part of Medicare AWW. (TX) – Include screening for cognitive function and mood using validated assessment tools as a regular part of Medicare AWW. (TX) 		
Clinician workforce development (n = 33)	Educational programming	33	<ul style="list-style-type: none"> – Integrate Alzheimer’s disease awareness training into existing urban and rural public health and community health centers. (AZ) – Train at least 300 health services providers on early diagnosis and pharmacological and nonpharmacological therapies. (PR) – Improve training of health care workers by providing information regarding recognition of the signs of dementia. (MT) – Mandate competency-based training for employees in hospitals nursing homes, and for home care workers and first responders. (TX) – Establish minimum dementia education requirements for all trainees in health-related. (MD) 		
			Dissemination of best practices	27	<ul style="list-style-type: none"> – Disseminate evidence-based guidelines for Alzheimer’s disease management to primary care providers to improve early diagnostic evaluation, treatment, care coordination, and follow-up support of patients. (DE) – Identify best practices in specific areas, e.g., expansion of Memory Mobile or other programs. (FL)
			Incentives for students and providers	11	<ul style="list-style-type: none"> – Create toolbox for persons with ADRD to encourage early screening and diagnosis. (AK) – Student loan forgiveness program or tuition assistance for medical and nursing students specializing in geriatrics. (VA)
					<ul style="list-style-type: none"> – Provide incentives and recognition for outstanding facilities that have effectively implemented care pathways. (NV)
–	Holistic care development (long-term care, community organizations, hospice, adult day care)	11	<ul style="list-style-type: none"> – Provide incentives for primary care providers (PCPs) to appropriately diagnose cognitive disorders. (WA) – Dementia Care Manager to coordinate care, manage individual cases, and develop formal mechanisms for referral. (CA) – Increase education for health care and social service professionals by increasing licensure training requirements. (DE) – Develop formal mechanisms for referral to care facilities that offer social supports and mental health services. (TX) 		
			Partner with educational program or organization	14	<ul style="list-style-type: none"> – Expand education and training through collaborations among state and private universities. (NM) – Partner with a geriatric education center for increasing primary care provider education in areas of high demand. (VA) – Partner with licensing boards to promote continuing education on evidence-based practices. (WA)

(Continues)

TABLE 2 (Continued)

Key Priorities	Objectives	n	Key Recommendations
Improve health equity (n = 27)	Multicultural/Multilingual Campaigns	15	- Develop plans for a multilingual, multicultural AWW awareness campaign for consumers and professionals. (MA)
	Targeted populations	11	- Increase educational reach in rural areas, non-English-speaking and Native American tribal communities. (UT) - Increase access for Hispanics/Latinos, African Americans, and rural communities. (FL) - Provide underserved areas and underrepresented groups with equitable access to quality services. (MI) - Engage and collaborate with community and cultural leaders to support diverse communities and rural populations. (KS)
	Transportation	1	- Develop creative transportation and incentive programs options for both rural and urban areas. (MT)
	Research involvement	4	- Increase participation of diverse populations in research studies. (CA) - Increase research participation of minorities, individuals with disabilities, and rural communities. (VA) - Promote participation in clinical trials, ensuring inclusion of underserved and rural populations. (PA) - Promote early detection and diagnosis and opportunities to participate in clinical research. (MI)
	Telemedicine	4	- Create a work group to identify ways to expand utilization of telemedicine to increase access in rural areas. (OR) - Explore telehealth to provide education and support to underserved regions. (AL)

Note: States represented: AK, Alaska; AR, Arkansas; AL, Alabama; AZ, Arizona; CA, California; CT, Connecticut; DE, Delaware; FL, Florida; GA, Georgia; HI, Hawaii; ID, Idaho; IL, Illinois; IN, Indiana; KS, Kansas; MA, Massachusetts; MD, Maryland; ME, Maine; MI, Michigan; MN, Minnesota; MT, Montana; NC, North Carolina; NE, Nebraska; NH, New Hampshire; NJ, New Jersey; NM, New Mexico; NV, Nevada; OK, Oklahoma; OR, Oregon; PA, Pennsylvania; PR, Puerto Rico; RI, Rhode Island; SD, South Dakota; TX, Texas; UT, Utah; VA, Virginia; WA, Washington; WV, West Virginia; WY, Wyoming; n, number of plans identifying each objective.

4 | DISCUSSION

The HBI, created in 2005 through a partnership between the Alzheimer's Association and the CDC, laid a path to legislation that established ADRD as a population health priority under NAPA. To understand how this aspirational goal has evolved into action, we focused on how states—the primary entities governing public health practice in the United States—developed ADRD plans as the foundation for improving early detection, implementing standardized care pathways, and reducing inequities. We found a consistent emphasis on education, although to date, there is little evidence that education and awareness campaigns have created substantial public demand or adoption of strategies to improve dementia detection or care. Only a third of eligible Medicare beneficiaries have had an AWW²⁰ and less than 1% of beneficiaries with a dementia diagnosis have had a documented care planning visit.³⁶ Considering the historical ineffectiveness of education campaigns, other approaches might more effectively scale up early detection and implement dementia-capable care (including caregiver support). Telemedicine could be a viable approach³⁷; the coronavirus disease 2019 (COVID-19) pandemic has made virtual visits routine for many clinical problems. Although there is no evidence it has improved

dementia diagnosis rates,³⁸ a relatively modest investment in standardized, practical ADRD training for primary care providers and interprofessional audiences could increase workforce capability.^{39,40}

State ADRD plans have effectively described local concerns, identified needed improvements, and formulated broad aims that inform public awareness campaigns, educate decision-makers, and build momentum for state administrative and legislative action. However, states' funding has been dedicated mainly to convening stakeholders, not implementing action. States' central locus of authority and sponsored effort around ADRD is not always clear (lying variably within chronic disease, aging and disabilities, or other state administrative divisions). We conclude that the primary role of state plans has been to prepare locally for a consolidated national public health infrastructure to address ADRD, first imagined nearly 20 years ago and now coming into being with the implementation of the BOLD Act.

5 | CONCLUSION AND RECOMMENDATIONS

Despite the promise of the BOLD Act, sustainable efforts to fill gaps in the public health response and infrastructure to address ADRD will

remain dependent on political will at the federal, state, and local levels, and on partnerships for funding and accountability.

We offer the following four recommendations:

1. *Establish a permanent national ADRD authority dedicated to population health.*

BOLD funding in 2020 gave the CDC federal authority to oversee a true public health response to ADRD, providing support to public health departments to chart a course for their own states and local constituencies. The BOLD Act provides competitively awarded support for public health action at the state and local levels and creates a national platform for dissemination of these efforts through its Centers of Excellence. The three national BOLD Public Health Centers of Excellence collate, disseminate, and promote evidence-based practices, and nearly two dozen state and local public health departments are now responsible for developing concrete ADRD plans and/or implementing specific action steps and measuring impact. However, there is no comparable national authority with incentives and oversight to implement health care improvement, require collaboration between public health and health care delivery organizations, or craft effective strategies to measurably improve equitable dementia detection and care.

2. *Develop standardized reportable measures of ADRD detection, care and quality.*

Medicare benefits introduced over the past decade provide opportunities for clinician reimbursement to detect, assess, and care for persons living with dementia.³⁶ For the first time, caregivers are rightfully seen as essential partners who provide crucial information and contribute to the care planning required by the CMS's reimbursable cognitive assessment and care planning code. However, use of this code is voluntary; health care systems and clinicians have not embraced a population health approach to ADRD, and no regulatory body specifies a standard of dementia care or requires action to improve quality. Moreover, health care systems commonly lack resources in clinical information and staffing to implement best practices in detection and care. A national collaborative of health care providers, public health researchers, persons living with dementia and their care partners, and service organizations should be convened and charged with developing reportable measures for dementia detection, care pathway implementation, and clinical outcomes, with special attention to population inequities in access, utilization, and care quality.

3. *Explore new opportunities for sustainable public health funding.*

By centralizing the conversation on ADRD, the BOLD Act has rallied new stakeholders and increased funding for public health efforts; this could in turn spur new research on clinical care and outcomes. However, underfunding and workforce shortages common to public health departments threaten sustainability, unless novel partnerships, for example, with health care payers and delivery systems,⁴¹ can be formed to promote optimal health care for people with dementia and their caregivers.

4. *Require collaboration between all national agencies and organizations that have ADRD components.*

The BOLD Act will continue to promote national visibility for state and local departments of health, HBI programs, and innovations resulting from funded projects. But the distinctive strengths of ADRD advocacy organizations and national programs overseen by other authorities, such as GWEPs (HRSA), Alzheimer's Disease Research Centers (National Institute on Aging [NIA]), Medicare and Medicaid (CMS), and US Aging and its Area Agencies on Aging (Administration for Community Living) must also be leveraged for sustainability. Detailed data from the dementia workforce development training programs HRSA supports should be collated and published. CMS should build mechanisms for supporting health system adoption of the benefits it creates, such as quality measure development, infrastructure supplements, stronger and more user-friendly incentives to provide dementia-relevant health care, and expanded support to integrate care across health care and community sectors within all Medicare program categories and payment models.

5.1 | Conclusion: Opportunities for accelerating improvement in health care for persons living with ADRD

We have illustrated the evolutionary process by which public health action has been galvanized around ADRD by consecutive and complementary efforts of legislation, non-profit organizations, and state-based, cross-sector working groups. We see a progressive articulation of national ADRD goals under NAPA and the HBI. ADRD is now recognized as an important clinical challenge requiring new Medicare benefits to support improvement in detection and care, knowledge, and skills dissemination through focused HRSA-supported clinician education, and now, federally supported public health action to drive sustainable improvement across the country. The BOLD Act is a key step in creating a uniform national public health infrastructure to mitigate ADRD. Yet, much work remains to create an enduring national standard that improves care for people living with ADRD and those who care for them.

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CONFLICT OF INTEREST STATEMENT

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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