Maria-Theresa Okafor, Ph.D., MCG
Designated Federal Officer
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
200 Independence Avenue SW
Washington, DC 20201

August 14, 2026

Re: Request for Comment on the Update to the National Plan to Address Alzheimer's Disease (HHS-ASPE-2026-0298)

Dear Dr. Okafor,

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) appreciate the opportunity to respond to the Request for Comment on the Update to the National Plan to Address Alzheimer's Disease.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Impact Movement (AIM), a separately incorporated advocacy affiliate, is a nonpartisan, nonprofit organization and works to make Alzheimer's a national priority.

Over a decade ago, after the efforts of the Alzheimer's Association, AIM, and bipartisan congressional champions, the National Alzheimer's Project Act (NAPA) (P.L. 111-375) was signed into law. This landmark law has led the way for additional policy victories, including the first National Plan to Address Alzheimer's Disease, with the goal of preventing and effectively treating Alzheimer's by 2025. In addition to the creation of the National Plan, NAPA also directed the Department of Health and Human Services (HHS) to create and convene the Advisory Council on Alzheimer's Research, Care, and Services to advise the Secretary and evaluate implementation of the National Plan, with the Secretary responsible for overseeing the creation and updating of the Plan itself.

Since NAPA and the National Plan, AIM has continued to work with bipartisan congressional champions to secure additional policy achievements that have all been supported by the National Plan and Advisory Council. These include the Alzheimer's Accountability Act, the HOPE for Alzheimer's Act, the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406), the Younger-Onset Alzheimer's Disease Act, the Promoting Alzheimer's Awareness to Prevent Elder Abuse Act (P.L. 116-252), and the Improving HOPE for Alzheimer's Act, as well as unprecedented federal research funding increases, and the development of crucial public health infrastructure.

With much work left to be done, however, we were pleased to champion the bipartisan NAPA Reauthorization Act (P.L. 118-92) and to contribute to the next iteration of the National Plan that will guide our country's approach to all aspects of Alzheimer's and related dementias for the next 10 years.

Below you will find the in-depth suggestions for the vision and goals for the next decade from the Alzheimer's Association and the Alzheimer's Impact Movement.

1. What opportunities or challenges exist in advancing research and development of interventions to prevent or treat AD/ADRD, including translating scientific progress into effective and scalable treatments and care?

In addition to continuing to diversify research pipelines beyond amyloid, the National Plan should prioritize support for the infrastructure to support a combination-therapy pipeline. The initiation and progression of Alzheimer's disease is not completely understood, but evidence suggests they are influenced by a multitude of factors. Aging is the greatest risk factor for Alzheimer's and there are multiple causes of aging-induced brain degeneration. In addition, recent advances in understanding the genetics underlying sporadic Alzheimer's disease point to a number of pathways being involved in increasing the risk of Alzheimer's disease. Targeting these pathways together, in combination, has the potential for synergistic benefit for individuals living with Alzheimer's disease. Research into options for whom the current disease-modifying therapies are less safe (e.g., individuals who carry two copies of the APOE e4 gene allele) and different ways of monitoring and delivering treatments should also be a priority.

Though Alzheimer's disease accounts for 60-80 percent of dementia cases, many individuals have and experience co-pathologies. Therefore, it is imperative that the National Plan reflect a strong commitment to those living with cognitive impairment and dementia beyond Alzheimer's disease, including but not limited to mixed dementia, Lewy body dementia, frontotemporal dementia, and vascular dementia.

The next iteration of the National Plan should also protect research funding to explore the biological underpinnings of the disease and integrity to ensure that today's early-stage trials become the next decade's drug targets as well as include support for longer-horizon, higher-risk science. Consistent with the Alzheimer's Accountability and Investment Act (P.L. 118-93), the National Plan should reference the annual National Institutes of Health (NIH) professional judgment budget for Alzheimer's and dementia research as the benchmark against which federal investment is managed.

As the pipeline for new targets and new potential strategies for therapy advance, the National Plan should prioritize modernizing clinical trial design and recruitment, including adaptive platform trials, decentralized/community-based trial sites, and recruitment of historically underrepresented populations, including Black and Hispanic communities and individuals with Down syndrome, among others. We applaud the work done to date to reach these disproportionately affected communities, particularly at the National Institute on Aging through the implementation of the Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (S. 1548/H.R. 3085 117th Congress), key provisions of which were enacted in the Consolidated Appropriations Act, 2023, and in the U.S. Study to Protect Brain Health through Lifestyle Intervention to Reduce Risk known as U.S. POINTER (AAIC 2025). U.S. POINTER found that healthy lifestyle changes — specifically a combined exercise, nutrition, cognitive engagement, and health monitoring program — can meaningfully protect brain health in diverse communities across the U.S.

This study is the first large-scale, randomized controlled clinical trial to demonstrate that an accessible and sustainable healthy lifestyle intervention can protect cognitive function in diverse populations in communities across the United States. More recently, the promising results of Latin American Initiative for Lifestyle Intervention to Prevent Cognitive Decline (LatAm-FINGERS), discussed below, demonstrate that culturally adapted lifestyle interventions can make a difference in diverse communities.

Finally, we look forward to working with HHS as it works to restore American leadership in biomedical and pharmaceutical innovation through its Operation TrialBlazer initiative.

2. What opportunities or challenges exist in improving risk reduction and promoting brain health across the lifespan?

We are in a new age of opportunity to promote brain health and reduce the risk of cognitive decline. The Council's recognition of this new age is apparent with the addition in 2021 of Goal 6 of the National Plan, which aims to accelerate action to promote healthy aging and reduce risk factors for Alzheimer's disease and related dementia.

Last year, the Alzheimer's Association released the topline results of the U.S. POINTER study. As noted above, U.S. POINTER is the first large-scale, randomized controlled clinical trial to demonstrate that an accessible and sustainable healthy lifestyle intervention can improve cognitive function in diverse populations in communities across the United States. Cognitive scores improved in both study arms, and the structured intervention produced a statistically significantly greater rate of improvement than the self-guided intervention, which was estimated to protect cognition from normal age-related decline for up to two years. More recently, the Alzheimer's Association-funded LatAm-FINGERS reported their findings that two culturally tailored lifestyle interventions (differing in terms of structure and accountability for the participants) improved memory, thinking, and overall cognitive function in older adults at risk of dementia across 11 Latin American countries, with the strongest gains seen in participants receiving structured support and coaching. Participants in the structured arm showed 55 percent greater improvement on a composite measure of global cognition than those in the flexible arm. It is also important to follow the longitudinal cohorts in these and other intervention studies to better understand what may contribute to the prevention of cognitive decline.

These clinical trials show great promise in improving the health of Americans – if they can be delivered in the community. To understand better how to successfully do that requires an investment in implementation studies. We applaud the Centers for Medicare and Medicaid Innovation (CMMI) for the MAHA ELEVATE initiative, particularly by reserving three of the awards for interventions that address dementia. Three interventions, however, will not be enough, and we encourage the Advisory Council to call for additional initiatives on brain health implementation science. Furthermore, for all intents and purposes, successful interventions like U.S. POINTER cannot currently be reimbursed by Medicare. As with most intensive lifestyle interventions, most elements are delivered in the community by entities not eligible for Medicare reimbursement. Lifestyle intervention programs are not delivered out of physician offices, and we should not expect that it would be any different with brain health interventions. We note with gratitude the Request for Information on Intensive Lifestyle Interventions to Slow Progression of Alzheimer's Disease in the Calendar Year 2027 Physician Fee Schedule and applaud the Centers for

Medicare & Medicaid Services' (CMS) prioritization of older Americans. As additional steps, the Advisory Council should work with CMS to explore and develop coverage policies of evidence-based brain health interventions, including a coding and payment system that includes community-based organizations similar to what is currently done with the National Diabetes Prevention Program. To inform that policy, the National Plan should call for a research roadmap developed with NIH, the Centers for Disease Control and Prevention (CDC), and CMS that identifies the evidence needed to support coverage of brain health interventions, including implementation and cost-effectiveness data, beneficiary eligibility criteria, definitions of covered services, quality measures, and payment methodology. We intend to respond separately to the Calendar Year 2027 Physician Fee Schedule Request for Information by its September 14, 2026, deadline and would be happy to share our response with the Council.

The Council should continue to support the Healthy Brain Initiative (HBI), which is a partnership of organizations across the country working collaboratively to improve the understanding of brain health as a central part of public health action. Led by the CDC, the Alzheimer's Association has been a national HBI partner since its inception in 2005. The foundational document of the work is the *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023–2027*. This guidebook identifies 24 actions that state and local public health agencies can take to quickly and strategically address the Alzheimer's crisis. A companion *Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples* includes 13 public health strategies that can help AI/AN communities improve brain health, address dementia, and meet the needs of caregivers.

Lastly, in December 2024, the BOLD Infrastructure for Alzheimer's Reauthorization Act (P.L. 118-142) was signed into law showing the continued commitment of Congress and the Administration to prioritizing brain health as a public health issue. We thank the Council for its leadership in elevating brain health and Alzheimer's and dementia as a public health issue and encourage it to continue as a priority.

3. What barriers or challenges affect early detection and timely diagnosis of AD/ADRD?

Blood-based biomarkers can now identify the underlying biology of Alzheimer's disease years before symptoms appear, and the Food and Drug Administration (FDA) has cleared two tests to aid diagnosis in patients who are already experiencing cognitive symptoms. Scientific progress is moving quickly, and legally, Medicare cannot keep up. Medicare has no authority under current law to cover screening for an asymptomatic population – a gap between scientific innovation and coverage authority that only Congress can close. At the same time, many primary care physicians are not prepared to integrate these tests into routine practice for several reasons, including training, capacity, and reimbursement. In this new landscape, the lack of specialists demands a reimagining of the role of primary care in assessment and diagnosis. Therefore, once passed by Congress, CMS should be prepared to implement coverage policies for screening an asymptomatic Medicare population, such as the Alzheimer's Screening and Prevention (ASAP) Act, which would permit CMS to cover routine blood-based screening tests for Alzheimer's disease and other diseases caused by dementia once the FDA clears them. The National Plan should prioritize support for primary care clinicians to administer these tests, from clinical practice guidelines to training to reimbursement pathways. We would be pleased to work with relevant agencies to develop such guidelines akin to the Alzheimer's Association's Clinical Practice Guideline for Blood-Based Biomarker Tests for specialists.

Once passed by Congress, the Health Resources and Services Administration (HRSA) should be prepared to implement the Accelerating Access to Dementia & Alzheimer's Provider Training (AADAPT) Act, which would empower primary care providers to better diagnose Alzheimer's and other dementia and deliver high-quality, person-centered care in community-based settings through grants to providers participating in structured Alzheimer's and dementia virtual education programs. Additionally, as more of these tests come to market in the future, the National Plan and stakeholders should invest in clear, patient-facing materials to help individuals understand the differences between tests and the possible results. Building from the AADAPT Act, the Advisory Council should consider urging CMS to include updated, widely distributed guidance on appropriate use of Alzheimer's disease and dementia treatments, both symptomatic and disease-modifying, to build confidence among clinicians.

We must also determine how to accelerate the path between an earlier diagnosis and treatment. Early diagnosis means that disease-modifying therapies, if appropriate, are more effective. It also allows individuals to participate in clinical trials, make lifestyle modifications, and plan for the future. Many people, upon diagnosis, are referred to specialists. However, the lack of specialists and, too often, the lack of dementia training among specialists, can end up slowing the path to treatments. We must rethink the role of specialists and what requires a specialist referral to the extent that some drivers of the need for referral can be reduced or eliminated. This is also true for post-diagnosis. Bold thinking is required to reevaluate how primary care can handle more as new tools emerge and treatments evolve (e.g., subcutaneous, at-home administration of treatments) and enable these to be embedded into practice.

4. What are the most significant gaps in dementia care, services, and supports for people living with AD/ADRD and their families, caregivers and care partners, including caregiver well-being?

Access to comprehensive dementia care management, including care navigation, remains a barrier for too many individuals living with dementia and caregivers. In addition to expanding and scaling models like the Guiding an Improved Dementia Experience (GUIDE) Model, discussed below, the National Plan should prioritize expansion of and access to dementia care navigation programs. To encourage and implement more coordinated care models across the country for people living with Alzheimer's and other dementia, the Alzheimer's Association formed an expert workgroup of researchers to create a definition of consistent dementia care navigation and to identify evidence-based principles to provide a framework and standards for dementia care navigation. We have also convened an ongoing Dementia Care Navigation Roundtable and a Dementia Care Navigation Training series for care professionals. We would be pleased to share our experience with the Advisory Council and HHS to close this gap in care and support.

Caregivers themselves face significant, under-addressed gaps in support. Nearly 13 million family members and other unpaid caregivers provided an estimated 19.6 billion hours of care to people living with Alzheimer's or other dementias in 2025, valued at more than $446 billion — yet formal supports for these caregivers remain inconsistent and difficult to access. Respite care, in particular, remains one of the most significant gaps: while models like GUIDE have begun to test respite as a covered benefit, access to affordable, reliable respite is inconsistent across states and often exhausted quickly when it is available at

all. The National Plan should prioritize expanding access to respite care as a component of dementia care support.

Caregivers also lack consistent access to their own health screening and support as part of the care management process. Because dementia caregiving is uniquely long in duration and fluctuates in intensity, caregiver assessment and referral to support services should be built into dementia care navigation models as a standard practice. The Alzheimer's Association's dementia care navigation framework includes caregiver assessment as a core standard, and we would welcome the opportunity to share this work with the Advisory Council as it considers how caregiver well-being can be systematically embedded into care delivery.

5. What models, programs, or practices are currently working well in supporting people living with AD/ADRD and their families, caregivers, and care partners, and what factors contribute to their success (e.g., effectiveness, scalability, or applicability across settings)?

The Alzheimer's Association and AIM appreciate CMMI's continuing commitment to testing the GUIDE Model. Given the robust response to and participation in GUIDE, the agency should be prepared to act on the initial results as they become available and scale any positive outcomes to a broader Medicare population. The agency should also continue to address ongoing challenges to participation, like the respite aspect of GUIDE. The model holds enormous promise to transform dementia care for millions of beneficiaries and caregivers, and every effort toward success should be made. CMMI and CMS should consider how to ensure the services provided by GUIDE are also provided in Medicare Advantage plans.

Beyond GUIDE, CMMI and CMS should also invest in implementation science to understand how to adapt evidence-based programs and explore how to disseminate and adapt these to settings beyond academic medical centers, such as rural health systems, safety-net providers, and small independent practices. We would welcome continued federal investment in implementation science and technical assistance that helps effective models reach the full range of communities and providers serving people with dementia. Additionally, the Alzheimer's Association is a participant in the Rural Health Transformation Program, working with communities to expand brain health awareness and risk-reduction efforts; empower communities to easily find, understand, and access navigation and support resources; and develop the workforce to strengthen the entire care ecosystem. We would be pleased to share our learnings with CMS to develop and scale new models for these communities.

6. What health outcomes and care goals are most meaningful to people living with AD/ADRD and their families, caregivers, and care partners, and how should these be measured and incorporated into care over time?

More time with greater cognition, function, and independence are among the most important outcomes for persons living with AD/ADRD, their families, caregivers, and care partners. Members of the Alzheimer's Association's Early-Stage Advisory Group, individuals living in the early stage of Alzheimer's and dementia, raise these same priorities. As one advisor described it, people living with dementia and their care partners value being able to "continue living lives where they can engage in meaningful activities, giving them the best opportunity to live in an environment where they can preserve independence." These

advisors also stress the urgency of timely access, noting that because the newest treatments are available only in the early stages; a delay of even a few years can leave a person no longer eligible to benefit. This outcome can be advanced and achieved through earlier detection and diagnosis and access to treatments, as discussed above.

As noted, the health and well-being of caregivers themselves is another key outcome. In addition to what is learned about caregiver support through the GUIDE model, HHS should continue to gather evidence to support legislation for paid family leave, tax credits, and flexible workplace policies that are specific to long-duration, non-linear caregiving. Paid Leave Oregon, New York State's Paid Family Leave, and Washington Paid Family & Medical Leave are examples of such policies.

7. What barriers exist to accessing timely, high-quality, person-centered care across different community settings and stages of disease progression?

As suggested above, identifying individuals at the earliest stages, including those without clinical symptoms, is a new frontier in this disease space but remains a challenge, and even more so for persons with younger-onset (e.g., Autosomal Dominant Alzheimer Disease) and persons with Down syndrome. People with younger-onset Alzheimer's who qualify for Social Security Disability Insurance face a five-month wait for cash benefits plus a 24-month Medicare qualifying period which is up to roughly 29 months from disability onset before Medicare coverage begins. Unlike ALS, Alzheimer's carries no statutory exception, and Compassionate Allowance processing speeds the disability determination without shortening either waiting period. Again, these populations should be a priority in the National Plan.

Barriers to access differ by geography and compound as disease progresses. Rural communities, for example, face an acute combination of challenges: limited access to specialists, the frequent need to travel significant distances to imaging sites, or even primary care providers accepting new patients. Supporting rural providers and families means bolstering services that already exist and using telehealth where it can help. Our work in the Rural Health Transformation Program, referenced above, is designed to address these specific access gaps, and we would welcome the opportunity to share what we learn as that work matures.

In addition to being disproportionately affected by the disease itself, stigma remains a barrier in some racial and ethnic populations. The National Plan should continue to support community-level engagement efforts for populations of high risk, tailored to specific cultural contexts, that normalize early evaluation and seeking support.

The availability of home- and community-based services (HCBS) varies widely by state and locality, meaning that a family's ability to keep a loved one safely at home as the disease progresses often depends more on where they live than on clinical need. The National Plan should continue to prioritize the development, implementation, and funding of HCBS to ensure that individuals' and families' needs are met where they are. We would be happy to serve as a resource to the Council as they explore HCBS for the National Plan.

A key barrier to person-centered dementia care is that care decisions and care plans may not fully reflect the goals, preferences, and daily needs of the person living with dementia. In addition, caregivers are not always included as active partners in care planning, creating an additional barrier to providing person-centered care. The National Plan should continue to address these challenges by promoting person-centered care models and dementia care guidelines that encourage providers to incorporate the individual's priorities, cultural background, and desired quality of life into care planning and decision-making. In addition, it should work to expand caregiver education, support, and engagement to encourage shared decision-making and care that aligns with individual values and priorities.

Finally, care transitions across settings, such as hospital discharge, entry into long-term care, and transition to hospice are points where continuity of care most often breaks down. Standard transition protocols are rarely designed around the specific needs of people with dementia and their caregivers, and a family that has built a relationship with a care navigator or comprehensive care team frequently loses that continuity at exactly the moments of highest vulnerability. We encourage the Advisory Council to treat dementia-specific transition planning as a distinct priority.

8. What workforce or infrastructure challenges most affect:

a. AD/ADRD research and intervention development
b. risk reduction activities
c. public health AD/ADRD initiatives
d. delivery of healthcare and long-term care
e. support for families, caregivers, and care partners?

a. AD/ADRD research and intervention development. The National Plan should prioritize investment in community-based trial infrastructure, workforce development at trial sites serving populations of high risk, and training pathways that retain early-career researchers in this field.

b. Risk reduction activities. There is no established workforce or payment infrastructure for delivering evidence-based brain health interventions at scale. As described in response to Question 2, the community-based organizations, lifestyle coaches, exercise professionals, registered dietitians, and community health workers who deliver programs like those tested in U.S. POINTER are largely ineligible for Medicare reimbursement, and few public health agencies have dedicated brain health staffing. The National Plan should prioritize building this delivery workforce, including recognition and payment pathways for community-based providers modeled on the National Diabetes Prevention Program.

c. Public health AD/ADRD initiatives. The National Plan should prioritize sustained BOLD funding and implementation, dedicated dementia capacity in state, local, Tribal, and territorial health agencies, and complete, comparable surveillance data as the foundation for measurable national goals.

d. Delivery of healthcare and long-term care. As discussed above, the traditional roles of primary care clinicians and specialists are an enormous challenge in this new landscape of diagnosis and treatment. The next iteration of the National Plan should prioritize a reimagining of these roles and the education, guidance, and reimbursement that will be required to affect such changes. Primary care itself is undergoing a fundamental shift in what it is expected to manage, and CMS coverage and payment policy

and HRSA program authority should establish sustainable funding mechanisms that support primary care in adapting to this expanded role. This includes expanding and simplifying billing pathways for team-based care so that appropriately trained members of the care team, including nurses, care navigators, and community health workers, can deliver and bill for defined, evidence-based dementia care services, reducing administrative burden on physicians without compromising quality or safety. Any such expansion should be developed in partnership with physician, nursing, and other clinical stakeholder groups to establish appropriate training, competency, and supervision standards. The Plan and the Advisory Council should also continue to promote expansion of specialist pipelines (e.g., geriatricians, neurologists), dementia-specific training in primary care and long-term care, and incentives for direct care and community health workers, among other members of the workforce.

e. Support for families, caregivers, and care partners. The National Plan should prioritize direct care workforce recruitment, training, and retention, including dementia-specific competencies, and should support the caregiver-facing workforce, including care navigators and community-based aging services staff, that connects families to respite, education, and support services.

Thank you for the opportunity to comment. The Alzheimer's Association and AIM would be glad to serve as a resource to ASPE as it considers these important issues and how they relate to individuals living with Alzheimer's and related dementia, and their families. Please contact Laura Thornhill, Director, Regulatory Affairs, at 202-638-7042 or lthornhill@alz-aim.org if you have questions or if we can be of additional assistance.

Sincerely,

Robert Egge
Chief Public Policy Officer, Alzheimer's Association
President, Alzheimer's Impact Movement