August 15, 2026

Maria-Theresa Okafor, Ph.D., MCG
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
U.S. Department of Health and Human Services
Submitted electronically via Regulations.gov

Re: Request for Information — Update to the National Plan to Address Alzheimer's Disease (Docket No. HHS-ASPE-2026-0298; 91 FR 46791)

Dear Dr. Okafor:

On behalf of LeadingAge, we appreciate the opportunity to comment on the update to the National Plan to Address Alzheimer's Disease (National Plan).

Together with our state partners, we represent more than 5,300 nonprofit and mission-driven aging services providers serving older adults and touching millions of lives every day. From our national headquarters in Washington, DC, and in collaboration with state partners whose members are active in 50 states, the District of Columbia, and Puerto Rico, we use advocacy, education, applied research, and community building to make America a better place to grow old. Our membership encompasses the entire continuum of aging services, including skilled nursing, assisted living, memory care, affordable housing, retirement communities, adult day programs, hospice, Programs of All-Inclusive Care for the Elderly (PACE), and home-based care.

Our members serve hundreds of thousands of individuals living with Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) and their families each year. This comment offers the perspective of the direct service delivery system that will implement much of what this updated National Plan sets in motion.

To ground our comments in the operational realities our members face, our response is organized around three challenges that affect every care setting: (1) financing comprehensive, dementia-capable services; (2) funding adequate workforce training; and (3) integrating family caregiver supports into the direct service delivery system rather than treating caregiver support as a separate, parallel system. We address these themes, and the perspectives of nursing home, assisted living, adult day, PACE, and home health providers specifically.

For context, total 2026 payments for health care, long-term care, and hospice services for people age 65 and older with dementia are estimated at $409 billion, and average Medicaid payments for beneficiaries with AD/ADRD are more than 22 times greater than for beneficiaries without these conditions — underscoring how disproportionately the Medicaid program, and the providers who accept Medicaid, carry the cost of caring for this population.

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Question 1: Research and Development of Interventions

LeadingAge supports continued federal investment in translational research that moves scientific discovery into treatments deliverable within real-world LTSS settings. A persistent challenge is the gap between clinical trial populations and the frail, multimorbid, often cognitively and functionally impaired individuals our members serve daily. We encourage HHS to prioritize pragmatic trials and implementation science conducted across the continuum of providers so that new interventions are tested where they will ultimately be delivered. Consideration of operational interventions and comprehensive treatments that can be practically layered in either a residential or community setting to slow decline and improve skill retention.

Question 3: Barriers to Early Detection and Timely Diagnosis

Our members frequently encounter individuals with obvious signs of dementia when the family is in crisis and searching for LTSS. For these families and individuals, many have never received a formal AD/ADRD diagnosis. This delays access to appropriate care planning, caregiver education, and available treatments. Stigma and fear limit individuals and their families from seeking clinical diagnosis. We've also heard stories from members citing interactions with clinicians attributing other medical causes for dementia-related symptom manifestation--- a seeming hesitance to conduct cognitive assessments and establish a formal diagnosis for dementia or Alzheimer's.

Contributing barriers include a shortage of geriatric-trained clinicians and dementia specialists, particularly in rural areas; limited primary care reimbursement for cognitive assessment; and low awareness among primary care providers of available resources to support individuals and families, such as referrals to adult day or PACE programs. We encourage HHS to support broader adoption of brief, validated cognitive screening tools in primary care along with reimbursement policies that support the time required for a thorough diagnostic screening and stronger research and referral mandates. Early introduction to services like adult day and PACE can provide caregiver education and support, stave off more acute and costly treatment, and delay cognitive decline. These combine for a better life experience for the individual living with dementia.

Question 4: Gaps in Dementia Care, Services, and Supports

The most significant gap our members observe is the mismatch between the number of people who need Medicaid-funded LTSS for dementia and the financial capacity of providers across every care setting to serve them well. That gap looks different depending on where care is delivered. Universally across all settings, individuals with significant agitation and behaviors are more costly to provide care and services. As a result, providers are stretched, without adequate reimbursement to cover costs of care. For individuals with significant behaviors and agitation as a symptom of their AD/ADRD, these payment gaps and shortfalls are exacerbated, further jeopardizing and limiting dementia-specialized care.

Nursing Homes

- HHS's own Assistant Secretary for Planning and Evaluation (ASPE) found that Medicaid payment rates for the average nursing home cover only about 82 cents of every dollar of reported cost, and that for roughly 40 percent of nursing homes, Medicaid per diem payments cover 80 percent or less of costs.
- This shortfall directly constrains a facility's ability to hire and retain the dementia-trained nursing staff and optimal or enhanced staffing patterns that residents with behavioral symptoms of dementia often require.
- Facilities that close or sell to private equity investor groups typically serve disproportionately higher shares of Medicaid residents and operate on more severe negative margins prior to sale, further concentrating access problems for lower-income individuals with dementia in already-underserved communities.

Adult Day Services

- Most high-quality adult day programs provide social, emotional, rehabilitative, medical, nutritional, respite, and family caregiving services, allowing safe supervision and engagement of participants while allowing their primary caregiver to work or attend to other life needs. When participants attend adult day programs, their caregivers can go to doctor appointments, maintain their home, and experience brief respite from moment-to-moment caregiving responsibilities.
- Adult day services are a non-mandatory Medicaid HCBS benefit and were treated as non-essential during pandemic-era closures in many states, illustrating how quickly this service line will be deprioritized when state budgets tighten under HR 1 constraints.
- Per-visit or per-diem reimbursement rates frequently do not reflect the true cost of dementia-appropriate staffing, specialized programming, and transportation. Many families pay out of pocket for adult day services for their loved ones demonstrating their integral role in supporting caregivers and individuals living with dementia.
- These financing gaps have contributed to site closures nationally, eliminating one of the few affordable, community-based options that also function as planned respite for family caregivers.

PACE

- PACE programs face regulatory expansion constraints limiting PACE expansion applications pending with CMS and have only quarterly windows for submission of these applications.
- Additionally, enrollment of new participants is limited to the first of the month, meaning a participant with unmanaged conditions may need to wait a full month to be enrolled on the first of the following month, resulting in longer lead-times to services available to stabilize an individual's health, mitigate behaviors and anxieties, access caregiver supports or medications, along with socialization and routine to support stability and emotional wellbeing.
- PACE is not yet available in numerous states, and where it does exist, expansion is often constrained by financing and start-up capital or state budgetary pressures, rather than by demand — despite close to half of PACE participants living with dementia.

Home Health and Home Care

- Industry-wide turnover among home care workers is estimated at roughly 79 percent, with recruitment costs of $2,600 to $5,000 per hire, undermining the continuity of care that is especially important for individuals with dementia, who rely on routine, familiarity, and consistency with caregivers.
- Home health agencies also face Medicare payment reductions taking effect in 2026 and lingering adjustments looming in future years. These compounding financial pressures come at the same time Medicaid HCBS funding faces state-level uncertainty, making additional training for dementia-specific behaviors and experiences a heavier lift to bear for home health and home care agencies.
- Home- and community-based services now account for the majority of Medicaid long-term services and supports spending nationally, yet HCBS remains an optional Medicaid benefit, making it among the first services states scale back when budgets are constrained.

Assisted Living and Memory Care

- Medicaid does not cover room and board in assisted living or memory care, and coverage of services varies widely by state and by whether a community participates in an HCBS waiver; many families exhaust private resources before any Medicaid support becomes available.
- The median monthly cost of memory care in 2026 is approximately $6,690, borne primarily out of pocket, which leaves many families "spending down" savings before Medicaid services can help.
- The result is financing instability for specialized memory care programming: providers cannot count on Medicaid support for the intensive staffing, specialized training, and secure physical environments dementia care requires.
- The HCBS Settings Rule further limits the provision of memory care by requiring extensive documentation for door alarms, locked units, delayed egress, visitation, community engagement, employment counseling among other regulatory citations that impose a one-size-fits-all approach to care planning and aging services provision in the community with little regard to the circumstances of dementia.

Across every setting, caregiver well-being is inseparable from these financing gaps: when Medicaid-funded services are unavailable, delayed, or unaffordable, family caregivers absorb the difference, often at a cost to their own health and ability to remain in the workforce. We recommend the National Plan set explicit, measurable targets for expanding dementia-capable respite and adult day capacity. In conjunction with simple diagnosis and assessment, the availability of funding to support providers caring for individuals with significant behaviors continues to be a barrier to provider financial viability, and therefore the availability of high-quality, engaging, and integrated services for individuals with behaviors associated with their AD/ADRD.

Question 5: Models, Programs, and Practices That Work Well

Several models in current use merit continued federal support and broader replication or expansion:

- **Adult day health centers as a hub model —** where adequately funded, adult day programs combine dementia-specific programming, health monitoring, and built-in caregiver respite, support, and education in a single community-based setting, making them one of the most effective and efficient points of integration between direct service delivery and caregiver support. Opportunities to expand access via funding for adult day would open the service to many more individuals with dementia. Considerations for pilot programs and payment via Medicare could establish a longitudinal service to help people remain independent in their communities with optimal wellbeing that mitigates the need for higher levels of care and increases in acute care utilization.
- **PACE care —** PACE coordinates medical, behavioral, and LTSS for frail dually eligible individuals under a single interdisciplinary team, and close to half of participants have a dementia diagnosis. Continued federal regulatory flexibility and support for financing and technical assistance to expand PACE into the many states and rural areas where it is not yet available would extend this model's benefits to more people living with dementia. Establishing successful PACE programs in truly rural areas is nearly impossible because of stringent regulatory contracting and provider access requirements. While maintaining the core oversight and accountability that is central to PACE success, flexibility could be introduced that allows for specialist contracting substitutions or less onerous physical plant requirements to improve financial viability for necessarily smaller programs in more rural areas with less potential enrollees.
- **The GUIDE Program-** The Guiding an Improved Dementia Experience (GUIDE) pilot through the Center for Medicare and Medicaid Innovation establishes tiered categories of dementia severity, enrolls traditional Medicare participants, and provides caregiver education and resources, along with respite programming and services to fill gaps in the traditional healthcare journey for dementia patients. The GUIDE model integrates already strong providers of dementia services into a more seamless experience for enrollees and their families, intending to prove that the whole is greater than the sum of its parts.
- **Structured family caregiving —** programs that formally recognize, educate, support, and compensate family members as paid caregivers both stabilize the direct care workforce and honor family and cultural preferences for who provides care.
- **Federally funded dementia-capable HCBS grants —** the Administration for Community Living's Alzheimer's Disease Programs Initiative funds states and communities to build dementia-capable HCBS systems, and several states are also directing new Rural Health Transformation Program funds toward rural HCBS access, workforce growth, and caregiver supports. Establishing key performance indicators and quality measures that can be applied to multiple service types, program designs, and provider types will be key to assessing functionality and economy of programs in different states and funding streams. Using these metrics and tools, federal-state partnerships operating promising models can encourage modification to programs with less efficiency and create usable pathways in other states for expanded adoption of successful programs.

Question 6: Meaningful Health Outcomes and Care Goals

For individuals living with AD/ADRD and their caregivers, the outcomes that matter most often differ from standard clinical metrics. We encourage the National Plan to prioritize measures such as retention of functional status and independence, caregiver strain and well-being, avoidable hospitalizations and emergency department use, time spent in the setting of the person's choice, and continuity of relationships with care staff — alongside, not instead of, clinical and biomarker-based outcomes. LTSS providers across the continuum are well positioned to help HHS develop and pilot these measures, since we observe day-to-day functional and quality-of-life trajectories that clinical encounters alone do not capture.

Question 7: Barriers to Timely, High-Quality, Person-Centered Care

- Medicaid reimbursement rates in many states do not reflect the actual cost of delivering dementia-capable care in any setting, whether that is because of nursing facility staffing requirements, assisted living and memory care specialization, adult day per-visit rates, PACE capitation adequacy, or home health/home care wages. Inadequate reimbursement limits the availability of high-quality dementia care across the board.
- Fixed HCBS waiver slot allocations effectively default individuals into institutional settings not because that is their preference but because community-based capacity, including adult day, PACE, and home-based care options are full.
- Geographic gaps compound these barriers: PACE and specialized memory care are concentrated in urban and suburban areas, rural communities face the most acute direct care workforce shortages, and travel distances to specialty diagnostic services remain a persistent obstacle.
- Care transitions between settings are rarely financed or coordinated in a way that carries dementia-specific care plans and caregiver knowledge forward, creating discontinuity at exactly the moments when it is most disruptive for someone living with dementia. Availability and funding of caregiver supports, education, and community groups help family navigate and and understand the dementia-experience of transitions, offering better communication and compassion during difficult transitions.

Question 8: Workforce and Infrastructure Challenges

Workforce capacity is, in our members' experience, the single largest constraint on the entire continuum of AD/ADRD care and services. We highlight two dimensions of the workforce challenge that we believe deserve particular attention in the updated National Plan: funding for dementia-specific training, and the disconnect between family caregiver support funding and the providers who could most efficiently deliver it.

(a) Overall Scale of the Workforce Shortage

- The Administration for Community Living projects that more than 1.3 million new direct care workers will be needed by 2030, consistent with broader industry projections of roughly 9.7 million total direct care job openings between 2024 and 2034 nationally.
- Low wages, physically and emotionally demanding work, and reimbursement models — particularly Medicaid, which finances the majority of LTSS — underlie chronic understaffing and turnover across all settings.

- At least one in five immigrant direct care workers comes from a country currently affected by federal visa pause policies, and recent changes to Temporary Protected Status designations could further reduce the pipeline of workers this sector depends on. We encourage HHS to flag these workforce pipeline risks for other federal agencies as part of the National Plan's implementation. HHS could advocate with other agencies for transition of immigration status to more favorable categories for workers in healthcare and HCBS job categories.

(b) Funding Adequate Workforce Training

- Existing federal investments — including ACL's Direct Care Workforce Strategies Center and Alzheimer's Disease Programs Initiative grants — are valuable but operate at a scale (typically single grants up to roughly $1 million per year for a small number of multi-year state or community projects) that cannot build dementia-specific training infrastructure across the tens of thousands of provider sites nationwide. We encourage both retention of these small-dollar grants for smaller and rural providers, while considering comprehensive expansion to scale large investments in workforces and training of dementia-capable staff.
- Nursing homes must meet federal minimum training requirements but receive no dedicated funding stream for the dementia-specific competencies (managing behavioral expression, communication techniques, person-centered dementia programming) beyond that floor; Medicaid rate inadequacy means paid training time competes directly with the cost of covering direct-care shifts.
- Assisted living and memory care training standards vary widely by state, and Medicaid reimbursement, where it applies at all, rarely funds the paid training hours dementia-capable care requires.
- Adult day and PACE providers increasingly treat dementia training as core infrastructure for quality and safety, given that a large share of participants live with dementia or cognitive impairment, yet no dedicated Medicaid or Medicare payment stream funds that training.
- Home health and home care agencies face the added challenge that staff turnover near 79 percent means training investments are frequently lost before they pay off, discouraging the up-front spending needed to build a dementia-capable workforce.
- We recommend the National Plan encourage states to build dementia-specific training costs directly into Medicaid HCBS and nursing facility rate-setting methodologies — for example, a recognized training cost add-on — rather than relying solely on time-limited, competitively awarded grants that reach a small fraction of providers.

(c) Integration of Family Caregiver Supports

- An estimated 63 million Americans serve as family caregivers, representing roughly 40 percent of U.S. adults who care for an aging or disabled loved one, yet the two primary federal caregiver support programs — the National Family Caregiver Support Program and the Lifespan Respite Care Program — were funded at approximately $209 million and $11 million, respectively, in FY 2026. AARP estimates the value of this caregiving at more than a $1 trillion dollars, leaving gaps in funding measured not by millions, but measurable in exponential terms.

- Caregiver support funding, administered through the Older Americans Act and the Administration for Community Living, flows largely through Area Agencies on Aging — a separate infrastructure from the Medicaid and Medicare payment streams that fund direct LTSS delivery. Adult day, PACE, home health, and residential providers are frequently best positioned to identify caregiver strain in real time and deliver support as part of ongoing care, but they lack dedicated financing to formally integrate caregiver assessment, training, or respite coordination into their care models.
- PACE's interdisciplinary team structure and structured family caregiving programs are promising exceptions that already connect direct service delivery with caregiver support, but both remain limited in scale and geographic availability.
- We recommend HHS lead alignment between OAA-funded caregiver support programs and Medicaid HCBS/PACE payment structures, including explicit recognition and reimbursement of caregiver assessment, training, and respite coordination as billable care coordination activities delivered by LTSS providers themselves, rather than solely as a separately administered caregiver program that providers can only refer families toward. Additionally, HHS should develop metrics to assess program and alignment success and establish policies for restructuring arrangements and programs that are not meeting outcomes or other metrics.

Conclusion

LeadingAge appreciates HHS's continued leadership on the National Plan to Address Alzheimer's Disease and welcomes the opportunity to serve as a resource as the Department develops updated goals and priorities through 2035. We would welcome the opportunity to provide additional data or member examples on any of the topics above. Please contact Georgia Goodman (ggoodman@leadingage.org) with any questions.

Respectfully submitted,

Georgia Goodman
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Selected Sources

The following sources informed the data cited above and are provided consistent with the RFI's request for supporting citations and hyperlinks.

- ASPE — Nursing Home Medicaid Shortfall Findings (via AHCA/NCAL summary)
- PHI — Understanding the Direct Care Workforce: Key Facts & FAQ
- ACL — Strengthening the Direct Care Workforce
- ACL — Alzheimer's Disease Programs Initiative (ADPI) — Dementia Capable States and Communities

- ACL — Lifespan Respite Care Program
- ARCH National Respite Network — FY 2026 Appropriations for Family Caregiver Programs
- KFF — Payment Rates for Medicaid Home Care: States' Responses to Workforce Challenges
- KFF — Who Are Direct Care Workers and How Might Federal Policy Changes Impact the Workforce?
- 2026 Alzheimer's Disease Facts and Figures (NIH/PMC)
- Frontiers in Dementia — Reimagining U.S. Social Care Policy: Medicaid Strategies for Dementia
- ATI Advisory — Key Considerations for Expanding Access to PACE in Underserved Rural Communities