

# ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

## SUMMARY OF MEETING

April 27, 2026

The Advisory Council on Alzheimer's Research, Care, and Services held its second meeting of the year at 1:00 p.m. Eastern Daylight Time in Washington, DC, and virtually. The Council convened in a closed session from 10:00 a.m. to 1:00 p.m. Eastern Daylight Time that included a subcommittee overview and breakout sessions, followed by a public session beginning at 1:00 p.m. Michelle Branham, Advisory Council Chair, welcomed meeting attendees and reviewed the meeting agenda. The meeting was open to the public.

### **Advisory Council Members Present**

- *Non-Federal Members:* Michelle Branham (Chair); Kathryn Newkirk (Vice-Chair); Randall Bateman; John D. Couris; Ricardo A. Hanel; James S. Hartsell; Michael Mayo; Kristi Putnam; Gina Waterhouse; Steve Waterhouse; Jonathan Weiss
- *Federal Members:* Erin Long, Administration for Community Living (ACL); Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation (ASPE); Maria-Theresa Okafor (ASPE); Fleetwood Loustalot, Centers for Disease Control and Prevention (CDC); Shari Ling, Centers for Medicare & Medicaid Services (CMS); Dwayne Taliaferro, Department of War (DOW); Teresa Buracchio, Food and Drug Administration (FDA); Jolie Crowder, Indian Health Service (IHS); Richard J. Hodes, National Institutes of Health (NIH); Rebecca J. Ferrell, National Science Foundation (NSF); Eric Weakly, Substance Abuse and Mental Health Services Administration (SAMHSA); Robert Weathers, Social Security Administration (SSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Maria-Theresa Okafor (ASPE)

**Other Federal Representatives Present:** Mary Lazare (ACL); David Kashihara, Agency for Healthcare Research and Quality (AHRQ); Leyi Lin (AHRQ); Cynthia Goss (ASPE); Romeo Galang (CDC); Lenise Cummings-Vaughn (CMS); Valentina Mantua (FDA); Jill Beaver, NIH/National Institute on Aging (NIA); Elena M. Fazio (NIH/NIA); Amy Bany Adams, NIH/National Institute of Neurological Disorders and Stroke (NINDS); Frank Shewmaker (NIH/NINDS); Alynda Wood (NIH/NINDS); Michael Goldstein (SSA); Meghan Reeves (SSA)

## **General Proceedings**

For detailed information, please visit the [April 27, 2026 Advisory Council](#) presentation slides and written updates.

## **FEDERAL PROGRESS**

### **[Federal Agency Updates](#)**

#### ***NIH (NIA and NINDS) - Richard J. Hodes and Amy Bany Adams***

- An NIA-funded study found that receiving the herpes zoster (shingles) vaccine reduced dementia diagnoses by 20 percent over a seven-year follow-up period. Further research found that herpes zoster vaccination significantly reduced diagnoses of mild cognitive impairment and deaths among patients living with dementia.
- NIH launched the PREPARE (Pioneering Research for Early Prediction of Alzheimer's Disease and Related Dementias [ADRD]) EUREKA Challenge to discover the best data, methods, and strategies for the early prediction of ADRD. Phase 3 winners are developing methods that use speech patterns and demographic data to improve early detection of dementia.
- The 2026 Dementia Care and Caregiving Research Summit was held virtually from March 17–19. Recordings and final report will be posted on the [Care Summit website](#).
- NIH research is identifying new therapeutic targets, including restoring fatty acid levels to protect neurons and using lymphatic vessel endothelial growth factor after a traumatic brain injury to reduce brain lymphatic damage and protect against tau pathology and cognitive decline.
- The Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act calls for an integrated national plan to prevent, diagnose, treat, and cure Parkinson's; ameliorate its symptoms; and slow or stop progression. The first meeting of the [Advisory Council on Parkinson's Research, Care, and Services](#) is on June 29 from 10:00 a.m.–4:00 p.m. ET. The meeting will be virtual and open to the public.

#### ***ACL - Erin Long***

- May 2026 is Older Americans Month, which promotes prevention, wellness, and personal responsibility as cornerstones of healthy aging.

- ACL's Alzheimer's Disease Programs Initiative includes multiple grants, programs supporting dementia care capacity, and the National Alzheimer's and Dementia Resource Center (NADRC).
- Upcoming NADRC webinars will feature [an overview of a new strengths-based group support model](#) and [information on addressing cognitive impairment and dementia among homeless and housing-insecure seniors](#).
- ACL's Caregiver AI Prize Challenge will award up to \$2.5 million to as many as 20 winners to develop, test, and scale AI-enabled tools to support family caregivers and the direct care workforce.

**AHRQ – Kevin Chaney (*written update submitted prior to meeting*)**

- AHRQ published a systematic evidence review in March 2026, [Medical Care for Adults With Down Syndrome](#), which found that adults with Down syndrome have a markedly higher prevalence of Alzheimer's disease compared to the general population, alongside several other co-occurring conditions.
- Of 36 studies examining treatment interventions, 16 focused on dementia (including Alzheimer's disease), representing the largest body of evidence among clinical areas reviewed.
- Across all clinical areas reviewed, including ADRD, evidence was insufficient to determine the effectiveness of interventions. Significant evidence gaps remain, highlighting a need for further research on ADRD diagnosis, treatment, and care strategies for adults with Down Syndrome.

**CDC - Fleetwood Loustalot**

- CDC's Building Our Largest Dementia (BOLD) Infrastructure and National Healthy Brain Initiative (NHBI) have deployed \$41.5 million for fiscal year 2026. These initiatives fund 43 state, tribal, and local health departments and three centers of excellence that focus on early detection, risk reduction, and caregiving.
- CDC is continuing to fund the International Association of Indian Aging to adapt the NHBI Road Map for tribal elders.
- CDC's Behavioral Risk Factors Surveillance System will continue to include modules capturing cognitive decline and caregiver trends. Currently, 32 states collect data on cognitive decline, and 27 states collect data on caregiver trends.
- CDC is also expanding the Alzheimer's Disease and Healthy Aging Data Portal to include county-level data on risk factors, which can be used to compare data in different geographies.

### ***DOW - Dwayne Taliaferro***

- The Congressionally Directed Medical Research Programs (CDMRP) Alzheimer's Research Program was appropriated \$15 million for fiscal year 2026. The solutions-oriented program aims to develop new capabilities to help the DOW understand, prevent, and assess ADRD.
- CDMRP plans to release three funding announcements—the Transforming Care Award, Transforming Research Award, and Transforming Diagnosis Award—in the next few months.

### ***SSA - Michael Goldstein***

- On April 9, 2026, SSA met with the National Academies of Science, Engineering, and Medicine to discuss recent advancements in the diagnosis, categorization, and prognosis of Alzheimer's disease, and the implications for SSA's procedures in determining beneficiary capability.
- SSA updated the Compassionate Allowances impairment summary for early-onset Alzheimer's Disease to reflect current medical testing and terminology, including renaming the condition to Young-onset Alzheimer's Disease.

### ***IHS - Jolie Crowder ([written update submitted prior to meeting](#))***

- IHS created a series of videos on advanced care planning, early detection, and screening. Video links and additional information will be shared with ASPE and posted on the NAPA website after the meeting.
- In March 2026, 223 participants attended the Elder Care and Alzheimer's Workforce Summit.
- IHS plans to release a funding announcement in the next few months. The funding announcement will include options for (1) caregiver training services and supports national resource center for tribal and urban Indian communities and (2) Dementia Cares, a national center to fund mini-grants, build a champion network, and gather data to inform IHS' work.

### ***CMS - Shari Ling***

- CMS and FDA recently announced the Regulatory Alignment for Predictable and Immediate Device coverage pathway to support innovation, product development, and the usefulness of products for the Medicare population.

## **ADVANCEMENTS IN LONG-TERM SERVICES AND SUPPORTS (LTSS) AND ALZHEIMER'S DISEASE CARE**

### **“Advancing Early Diagnosis and Dementia Care Through Policy and Advocacy”**

#### **Robert Egge, Alzheimer's Association**

- Early detection of Alzheimer's is critical because current treatments are most effective with mild cognitive impairment (MCI), yet 90 percent of people living with MCI are undiagnosed. Blood-based tests now exist and are widely acceptable to patients, but Medicare cannot cover testing for asymptomatic individuals without congressional action.
- The proposed Alzheimer's Screening and Prevention Act (ASAP) Act would enable Medicare to cover FDA-approved blood-based screening tests and establish a pathway for implementation, similar to how Congress enabled coverage for mammography and multi-cancer early detection tests.
- Expanding early detection could improve access to care and encourage lifestyle changes and care planning, helping patients take a more active role in managing their condition even before more advanced treatments are available.

### **“Navigating Aging Needs Navigator (NAN) Tool”**

#### **Dr. Rosemary Laird, NAN Navigator, Inc**

- The NAN model provides each caregiver with a dedicated navigator to offer ongoing guidance, personalized support, and risk assessment. The technology support platform is AI-enabled and HIPAA-compliant.
- Randomized controlled quality improvement studies found a 67 percent reduction in hospitalization among Alzheimer's patients whose caregivers were enrolled in the program.
- The model highlights the need to build a broader dementia navigation workforce and infrastructure to scale, support, and better integrate caregiver-focused services into the healthcare system.

### **“Respite for All”**

#### **Daphne Johnston, Respite for All Foundation**

- Respite for All is a volunteer-led, faith- and community-based respite care program. The model follows a social model of care, providing four hours of connection for people living with dementia and four hours of respite for their caregivers.

- Respite for All is currently in 72 communities across 19 states. The program is low-cost, does not require medical personnel, and is highly sustainable. After 13 years, Respite for All has a 92 percent sustainability rate.

### “GUIDE Model: Implementation and Early Insights”

#### **John Wilkinson, Five Star Home Health Care, and Jodi Lyons, CareBrains**

- The Guiding an Improved Dementia Experience (GUIDE) Model is a nationwide model testing the impact of comprehensive dementia care—including care coordination and management, caregiver support, and respite—on people living with dementia and their caregivers.
- After one year implementing the GUIDE Model, Five Star Home Health Care patients have had 84 percent fewer skilled nursing facility long-term care admissions and 29 percent lower total per capita costs than similar patients.
- The GUIDE model has shown that longitudinal care is effective and saves money. However, the model may start too late in the disease process and not provide enough respite to caregivers.

#### **Public Comment**

- **Ian Kremer (LEAD Coalition)** called for increased federal funding and support for key legislation—including the ASAP, Concentrating on High-Value Alzheimer’s Needs to Get to an End (CHANGE), and Bridging Relief in Delayed Government Enrollment (BRIDGE) for Young-Onset Alzheimer’s Disease Acts—to improve access to cognitive assessment and quality care, particularly for adults under age 65.
- **Carrie Edwards (Association for Frontotemporal Degeneration [FTD])** shared personal experience with FTD and advocated for the Healthy Brain Act. Edwards stressed the need to track environmental exposures to better understand and prevent cognitive decline.
- **Dr. Sudhir Sivakumaran (Lewy Body Dementia Association)** emphasized that dementia is a spectrum with overlapping pathologies that are often underdiagnosed. Dr. Sivakumaran called for the next phase of NAPA to focus on mixed-pathology research and patient experience.
- **Dashiell Meier (Disability rights advocate)** called for the inclusion of people living with Down syndrome in Alzheimer’s research and policy, noting their higher risk for Alzheimer’s and earlier onset compared with the general population. Meier highlighted that studying this population could advance understanding of Alzheimer’s for all people.

- **Dr. Keith Fargo (Lewy Body Dementia Association)** noted that Lewy body dementia is the second most common form of dementia and that most patients have multiple pathologies. Dr. Fargo called for continued research across diseases to improve diagnostics and treatments.
- **Laurie Reynolds (Caregiver)** described gaps in care for people living with Down syndrome and Alzheimer's, including lack of trained providers and limited long-term care options. Reynolds urged more inclusive systems and earlier support for families.
- **Ron Eppes (International Association for Indigenous Aging)** highlighted efforts to support brain health in Indigenous communities through the CDC Healthy Brain Initiative. Eppes emphasized ongoing access challenges and the need to include Indigenous populations in national strategies.

### **Concluding Remarks**

- Michelle Branham, Advisory Council Chair, thanked meeting attendees for their participation and adjourned the meeting at 5:10 p.m.