

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

Washington, DC and Virtual Meeting

October 21, 2024

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Adrienne Mims (Chair), Randall Bateman, Deke Cateau, Fawn Cothran, Roberta Cruz, Susan DeMarois, Keun Kim, Helen Bundy Medsger, John-Richard Pagan, Joanna Pike, Yakeel Quiroz, Rhonda Williams
- *Federal Members Present:* Erin Long, Administration for Community Living (ACL); Tisamarie Sherry, Office of the Assistant Secretary for Planning and Evaluation (ASPE); Shari Ling, Centers for Medicare & Medicaid Services (CMS); Sarah Fontaine, Department of Defense (DoD); Teresa Buracchio, Food and Drug Administration (FDA); Bruce Finke, Indian Health Services (IHS), Richard Hodes, National Institutes of Health/National Institute on Aging (NIH/NIA); Rebecca Ferrell, National Science Foundation; Eric Weakly, Substance Abuse and Mental Health Services Administration; Cheryl Schmitz, Department of Veterans Affairs (VA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)
- *Other Federal Representatives Present:* Latrice Vinson, Agency for Healthcare Research and Quality (AHRQ); Maria-Theresa Okafor (ASPE); ; Alisa Etheredge, Centers for Disease Control and Prevention (CDC); Juan Rodriguez (CDC); Heidi Holt (CDC); Jolie Crowder (IHS); Valeria Jones (IHS); Frank Shewmaker, NIH/National Institute of Neurological Disorders and Stroke (NINDS); Melinda Kelley (NIH); James Rudolph (VA)

General Proceedings

The Advisory Council on Alzheimer's Research, Care, and Services was convened for its third meeting of the year at 9:30 a.m. Eastern Standard Time in Washington, D.C., and virtually. Dr. Adrienne Mims, Advisory Council Chair, welcomed meeting participants and reviewed the meeting agenda. The meeting was open to the public.

Federal Updates

For detailed updates, please visit the [Federal Agency Updates](#) presentation slides.

Latrice Vinson, AHRQ. AHRQ shared three updates on funding and publication activities:

- State-based health care extension cooperatives: Notice of funding opportunities (NOFOs) that are relevant to older adults with dementia have been posted, including up to 15 grants through AHRQ's Healthcare Extension Service, two other NOFOs, the National Coordinating Center that will provide technical assistance and guidance on cooperatives' communication and dissemination efforts, and the National Evaluation Center that will assess program implementation and impact.
- Health Level Seven has published the Multiple Chronic Conditions eCare Plan Implementation Guide, and AHRQ has published a paper on the eCare plan methodology. New web links for the publications and the multiple chronic conditions value set library are now available.
- AHRQ paper on person-centered care planning for people living with or at risk for multiple chronic conditions published on October 17, 2024. The paper is highly relevant to persons living with dementia (PLWDs) and includes invited commentary.

Alisha Etheredge, CDC. CDC announced Dr. Juan Rodriguez as the new CDC Healthy Aging Branch Chief. Other announcements included:

- New *Morbidity and Mortality Weekly Report* publication from CDC's Alzheimer's Disease Program; first study to examine changes in the health of caregivers from pre-pandemic to more recent years, using a large population-based sample.
- New NOFO forecasted on Grants.gov: Public Health Strategies to Address Alzheimer's Disease and Related Dementias and is scheduled to be released on January 6, 2025.
- The Alzheimer's Disease program has a new, user-friendly website, and has funded five new projects under CDC's National Partners Cooperative Agreement. Most projects were informed by the NAPA Advisory Council 2023 Recommendations.
- A new, free, interactive public health learning module, *Public Health and Dementia--Part 1: Understanding the Public Health Impact of Dementia*, is now available from the Healthy Brain Initiative at the Alzheimer's Association.
- The Healthy Brain Initiative *Road Map for American Indian and Alaska Native Peoples* is expected to be released November/December 2024.
- UsAgainstAlzheimer's digital media campaign strategy now uses the National Alzheimer's Disease Index and PLACES (a CDC surveillance data set) to identify focus areas for culturally tailored messaging aimed at priority population.

Teresa Buracchio, FDA. FDA will host a 4-hour virtual public workshop on December 10, 2024, to discuss mortality and antipsychotic use in dementia-related behavioral disorders and increased risk among elderly patients, in fulfillment of a Congressional

mandate. Initial analyses that led to the boxed warning (one of the strongest drug label warnings for antipsychotic drugs since around 2005) will be presented, followed by public and stakeholder comments, and a discussion of future steps.

Bruce Finke, IHS. Moving forward, IHS NAPA council activity will transition from Dr. Finke to Dr. Jolie Crowder. Dr. Crowder highlighted new partnerships and funding opportunities with the IHS Office of Quality, and shared key announcements:

- IHS awarded nearly \$1.2 Million in grants to address Alzheimer's Disease.
- New training and education contracted awarded August 2024; new and ongoing workforce development, education, and training, including caregiving support and coaching opportunities and resources were highlighted; participant numbers are high.
- IHS data dashboard and communications infrastructure improvements in progress.
- Mini-Cog videos featuring Indian Health Council staff and grantees published (more are forthcoming); IHS article recently published and highlighted relatively high percentage of younger people (age 55-64) diagnosed with dementia.
- Established an Indian Health System Caregiving Workgroup with clinical and community representation to inform IHS activities.

Richard Hodes, NIA. NIA provided updates on active, completed, and upcoming research.

- 2024 Alzheimer's Research Summit held in October; 1,100 people attended.
- Dr. Hodes highlighted recent findings and updates from active NIA supported Alzheimer's Disease and Related Dementias (AD/ADRD) clinical trials by categories--pharmacologic, non-pharmacologic, dementia care and caregiving, and biomarkers.
- Clinical trial data and biosamples from the Anti-Amyloid Treatment in Asymptomatic Alzheimer's study are now available.
- Research concepts approved at the recent National Advisory Council on Aging meeting have been posted online.
- Eureka Challenge: Five Phase 1 winners announced in September 2024; Phase 2 to launch January 2025.

Frank Shewmaker, NINDS. NINDS shared funding and event announcements.

- The vascular contributions to cognitive impairment and dementia (VCID) Program announced six awards through its A Center Without Walls for VCID funding opportunity.
- NINDS to host its next tri-annual ADRD Summit March 25-26, 2025.
- Dr. Shewmaker shared new findings from a NINDS and NIA supported research study on neurodegeneration in genetic AD.

CLINICAL CARE SUBCOMMITTEE PRESENTATIONS

“Voice of a Person Living with Dementia Experiencing Clinical Care”

Sara Langer, MD

Dr. Langer, a former neurologist living with yet mild Lewy body dementia shared her experience as a PLWD and highlighted differences between her experience and that of her sister, who also has dementia. Dr. Langer followed up as frequently as needed with her doctor in clinic or via patient portal. She felt more informed and proactive in her health care because she engaged in dementia education, online and in-person support groups, sought out dementia advocacy organizations, and attended national and international meetings. Her husband supported these pursuits. She requested and received physical and occupational therapy and psychiatric care, discussed her care, and needs with her doctors, and worked with them to optimize her medications. She experienced significant improvement on her medication and feels that she is living a full, rewarding life, and despite limitations in driving, complex finances, concentration, and general energy. In contrast, her sister did not independently seek out resources or discuss her diagnosis or functional needs with anyone besides her spouse, Dr. Langer, and doctors, and sees her neurologist infrequently. She does not receive much, or optimal therapeutic interventions and care support from her doctor or spouse and has much more functional and cognitive difficulties than Dr. Langer.

Paths diverge sharply for PLWD post-diagnosis based on access to the following:

- Good spousal or family support (or physician suggested active care partners when family members do not seem engaged)
- Access to support groups and community resources (e.g., healthy groceries, education, exercise, art, social programming, transportation, housing, household support) and help with medication access and adherence, and communication devices.

Recommendations:

- Broader integration of conventional physician visits with allied health personnel and community services is needed.
- Every person, upon presenting with cognitive concerns, should be evaluated by an occupational therapist or speech pathologist, psychologist, and social worker to help focus the diagnostic evaluation and to determine what community services, including support groups, might be of most benefit. Reassessment should occur annually.
- Use more of a collaborative approach instead of a top-down approach in clinical care.

“Dementia Ideal Care Map”

Wen Dombrowski, MD, MBA, CATALAIZE

The Ideal Care Map was created to address gaps in best practices put forth by various organizations (academic, government, and industry) these best practices tend to focus on only one part of the patient journey or on one relevant group (e.g., what doctors do or what patients do) and reside in silos of different repositories of information. The Ideal Care Map aims to address these gaps by combining an ecosystem view of ideal care, best practices beyond physicians’ medical decisions, technologies that enhance care, and proposals of new care pathways, processes, and quality measures.

Discussion

- Create tools with intended users, test them, and solicit feedback prior to launch, to avoid technology barriers (e.g., language barriers and health literacy issues).
- Educate and involve children and young adults in learning about healthy lifestyles and brain health early, to engage and challenge them to discuss them with older relatives.
- The Ideal Care Map is comprehensive, but overwhelming. Suggestions on best places to start or focus this work include--creation of an interactive, online version that allows people to filter out information and zoom in on specific sections and creating a revised, updated version specific to certain types of organizations.
- Ideal Care Map Implementation likely feasible over the next 3-5 years. Meaningful outcomes and quality measures of interest are needed. A chart listing different patient-reported outcome measures specific to the quality of life for PLWD is available in the Ideal Care Map publication.

“Dementia Care Provider Presentation--Hospice of the Valley”

Gillian Hamilton, MD, PhD, Hospice of the Valley, University of Arizona College of Medicine

The Supportive Care for Dementia Program is a no-fee program supported by Hospice of the Valley's board, with a census of 800, that serves people living with mild cognitive impairment or any level of dementia. Program services include monthly visits (up to five) from a dementia educator. Administrative and live nurse triage teams answer phones on weekdays, nights, and weekends. The medical director, Dr. Hamilton, and a nurse practitioner review medication, and make suggestions to the patient’s family and primary care doctor. An occupational therapist also provides consultative services. Majority of referrals to the program are from physicians. In the last 3 years, the program has cared for over 4,000 patients (3,800 with caregivers). The program has reported significant reductions in patient aggression, agitation, calling out, wandering, insomnia, and caregiver stress, as well as reductions in patient hospitalizations during the 6 months before and after participation in the program.

Dr. Hamilton also presented case studies, results of programmatic analyses, and experiences as a participant in the CMS-supported Guiding an Improved Dementia Experience (GUIDE) Model.

Discussion

- Navigating stigma of hospice can be challenging; community liaisons outreach to physicians' offices, organizations, and churches, and are the program's primary source of referrals.
- Age of onset and funding do not limit who the program sees. Funding from ACL has been very helpful, and the program is seeing younger and younger individuals living with dementia.
- Dementia trajectory may result in delayed hospice planning or use.
- Hospices creating palliative care programs early on, so that those same patients will go to their hospice suggested as a way other states can successfully implement hospice programs.
- Dr. Lamont invited any Medicare Advantage models that picked up a GUIDE-like program to share information about services they have been providing and reasons why.
- Using some of the new other Medicare codes (Principal Illness Navigation, Community Health Integration Services) may help in replicate the GUIDE model in places that will not be Guide-selected.

“Health System Assessments”

Amy Boehm, Alzheimer's Association

Health system readiness is the ability of a health system to promptly and sustainably adapt its policies, infrastructures, and processes to support the integration of innovation and innovative approaches to care. The Alzheimer's Association health system initiative aims to improve the early and accurate diagnosis of dementia and work with our health systems and our clinical partners to drive the improved quality of care delivered after the time of diagnosis. An Alzheimer's Association survey of clinicians identified lack of knowledge, incentives, capacity, and mindset as barriers to screening and providing quality care after diagnosis.

Boehm provided an overview of the ideal patient journey from awareness of cognitive issues to treatment, highlighted key health system readiness factors (clinical, operational, and technological readiness), and frameworks and tools used to assess system readiness (e.g., SWOT Analysis, ORC Assessment, PEST Analysis, etc.). She reviewed how to leverage data to assess the current state of health systems and make improvements and concluded with a review of how to create an ideal state of health systems.

“Dementia Care Specialists”

Kristen Felten, MSW, APSW, Wisconsin Department of Health Services

Felten described the origins of Dementia Care Specialist (DCS) Program which aims to enhance the quality of life for PLWD and their families, reduce dementia-related crisis events and the burden on systems, and supporting brain health across the lifespan through a whole community and educative approach. The program began as a pilot program among Tribal nations and was later expanded statewide. Currently, the program has about 80 full and part-time DCSs serving Tribal nations, and other counties, including small rural counties. The Program’s three pillars create support for PLWD and their families:

- Dementia capability: DCS and trained frontline staff identify when an individual may need to undergo a memory screening and provide education around resources. Several program participants made changes to their exercise and diet based on education from staff. Program evaluation results will be published in an upcoming article.
- Dementia-friendly communities: DCS develop community coalitions in their counties which help train businesses, including pharmacies and banks, on how to be dementia-friendly. Libraries and memory cafes are also safe, stigma free places that promote programming and offer support.
- Individuals and families: DCS spend most of their time on this pillar, and work one-on-one with family caregivers, including at least two required evidence-based programs (one of which must be for the caregiver or family) Having the same DCS over time is very important to PLWD and their families.

Staci Hannah MEd, CDP, CACTS, **Dina McDonald**, and **Courtney Thompson**, Georgia Department of Human Services

Presenters provided an overview of the Dementia Team, which includes 13 DCS in each of the 12 Area Agencies on Aging, a Georgia Alzheimer's and Related Disease Plan, and Georgia Memory Net connection (a partnership with Emory, where they oversee state funded Georgia assessment clinics). Primary functions of DCS include:

- Creating Dementia Capable Aging Networks through Training, Education, Awareness and Collaboration (e.g., memory cafes).
- Creating Dementia Capable Communities through outreach and partnerships (e.g., working with libraries, high schools and local colleges, private businesses, hospices, restaurants, banks, pharmacies, grocery stores, and establishing local dementia coalitions).
- Supporting PLWD and their families through classes and seminars (e.g., Rosalynn Carter Institute, Teepa Snow classes, virtual dementia tours, and an assisted technology lab).

Discussion

- There may be a need to do similar work in nursing homes and assisted living facilities. However, DCS Programs focus on PLWD and families who do not have access to existing dementia training, care teams, and tools in these facilities.

- There is a need for improvement in program promotion and reaching PLWD and their families, beyond knocking on doors and marketing by local Area Agencies on Aging.
- Both Wisconsin and Milwaukee DCS programs include people of all ages and do outreach to young onset PLWD.
- Recruitment and training up of DCS or their equivalent may be challenging and take time. Wisconsin's Program provides twice monthly opportunities for all DCS to meet virtually for education and office hours. New DCS are connected with a mentor and DCS have self-managed regional meetings on topics of they are choosing. Wisconsin's Program also partners with the Wisconsin Alzheimer's Institute and Wisconsin Alzheimer's Disease Research Center to provide annual research, which are critical in helping dispel myths and inform about new dementia treatments.
- Minimum job requirements for DCS may include college level education and 1 year of experience working with PLWD or family caregivers who are not your family, to allow for a breadth of experience beyond people they know. Tribal nations have different requirements due to challenges with staff turnover and need for Tribal knowledge and sensitivity.

“Bridging Healthcare and Social Services for PLWD and their Caregivers”

Erin Long, MSW, ACL

ACL partnered with Drs. Helen Lamont and Maria-Theresa Okafor of ASPE to develop an issue brief that identifies core components of successful dementia care programs (including those outside of the GUIDE Model) that bridge services from community-based organizations and health care systems, highlights examples from the field, and identifies barriers to and best practices for aligning these systems to deliver comprehensive dementia care. The brief was informed by an environmental scan and interviews with 12 stakeholders from community-based organizations, health care systems, federal and state government agencies, and policy experts.

- Core components of successful dementia programs: early identification of symptoms and referral for further evaluation, individualized care planning, ongoing reassessment of needs, tailored referrals to and assistance accessing resources, caregiver support, and medication management.
- Barriers to systems alignment: workforce challenges, different funding sources and payment structures, lack of organizational buy-in, and communication and data sharing.
- Best practices: improve dementia-specific knowledge of staff, utilize multidisciplinary teams with participation from both systems to aid in the distribution of care tasks across systems, develop and implement care navigation capabilities or programs to serve as a central point of contact for PLWD, caregivers, and the care team, increase business acumen of both systems to facilitate reimbursement, including for non-traditional billers, build structure that facilitate effective data sharing and communication across both systems, and measure the effectiveness of dementia care programs

Discussion

Funding barriers may be a result of trying to get payment systems to do things outside of what they're designed to do, variations between a medical model and social model approach, and the incentive nature of payment models of care. Other countries may have models or best practices that can inform those in the U.S.

Investing in person-centered care models, drawing on lessons learned from IHS grantees, and enabling team-based care, centered around individuals and their needs to thrive may help bridge gaps in services from the two systems.

RISK REDUCTION SUBCOMMITTEE PRESENTATIONS

“Bringing Dementia Risk Reduction Actions to Life by State and Local Public Health”

Elizabeth N. Head, MPH, Georgia Department of Public Health

Head provided an overview of how data from Georgia's Online Analytical Statistical Information System and other sources inform development and targeting of AD/ADRD programming and risk reduction strategies. AD/ADRD efforts highlighted include:

- Partnerships: State agencies, Georgia Governor, academia, PLWD and their care partners, physicians, advocates, non-profits, and businesses.
- Healthy aging: leveraging of CDC BOLD grant and partnerships to promote healthy aging and serve as bridge between communities and service providers (e.g., training and education, identifying acute/emerging topics of interest, policy updates, reducing ADRD stigma, conducting ADRD screenings, etc.):
 - DCS Program.
 - Georgia Alzheimer's and Related Dementia Collaborative.
 - Successful community engagement and initiatives examples: onsite virtual dementia tours, Savvy Caregiver -- care partner program, African American faith-based ALTER program.
 - Think About It -- Statewide ADRD media campaign (billboards, buses, radio, pharmacies, social media, etc.).
- Risk reduction: Practical steps for primary care physicians (i.e., integrating telehealth referrals into their practice and participating in virtual dementia tours), partnership with University of Georgia includes using U.S. Department of Agriculture land grants to promote risk reduction strategies in rural areas and implementation of Cognitive Aging Research Center Program, Fall Prevention Nature Walk through local libraries.
- Strategic direction: Lifespan approach to risk reduction strategies.

Megan Mermal, Greendale Public Health Department

An overview and history of Brain Health Initiatives from the Village of Greendale were provided. Greendale is a part of the Milwaukee metropolitan area, with a population of about 15,000 residents, and a higher percentage of older adults than Milwaukee County and the state of Wisconsin.

- Healthy and successful aging identified as a priority in Wisconsin Community Health Assessment and Community Health Improvement Plan (CHIP) which led to dementia focus. Initial initiatives included a Memory Café, Music and Memory Program, Dementia Focus Resource Guide, Dementia Newsletter, Village Views articles, and memory screenings, which led to dementia-friendly community designation.
- CDC Alzheimer's Healthy Brain Initiative Roadmap for Public Health and grant critical in informing CHIP and developing and implementing the community's dementia-related initiatives.
- Community messaging/outreach: dementia knowledge and attitudes survey, translating outreach material, tables at local events, a brain health webpage, community magazine articles.
- Current programs and initiatives: a bike safety day and helmet program, fall prevention program, mini-grant program that support community groups promoting dementia risk reduction, Boost Your Brain and Memory 8-week brain fitness and education program, produce donation program for older adults, caregiver respite.
- Lessons learned: strong and diverse partnership help expand program reach.
- Biggest challenges: competing public health issues, fighting social and cultural norms, individual readiness, and desire for behavior change earlier in life, and funding.

Public Comments

- **Ron Epps**, *International Association for Indigenous Aging*, highlighted the need for dedicated focus on underserved populations at risk of developing AD/ADRD, including Blacks, Hispanics, those with intellectual and developmental disabilities, American Indians, Alaska Natives, and Hawaiian Natives. While progress has been made to address these disparities, more work needs to be done. Challenges include no word for dementia in many indigenous languages, and no longer having any dedicated resource centers for high-risk populations. Proposed recommendations include the NAPA Advisory Council addressing these disparities in its advice and guidance, continuing the momentum that has been started, and building upon these resource centers for underserved, high-risk populations.
- **Anna Fedewa**, *National Down Syndrome Society*, celebrated several critical pieces of legislation that were recently signed into law -- NAPA Reauthorization Act and the Alzheimer's Investment and Accountability Act and proposed that a representative from the Down syndrome community hold a seat on the NAPA Advisory Council.
- **Matt Janicki**, *University of Illinois and National Task Group on Intellectual Disabilities and Dementia Practices*, proposed two points for consideration by the NAPA Advisory Council as it prepares the 2025 National Plan update:

- Many adults with Down syndrome are high risk for AD/ADRD, with dementia onset around early 50 years of age. The NAPA Advisory Council should prioritize those with younger-onset dementia in the national plan update recommendations related to the use of GUIDE model services.
- The CDC recently issue an advanced NOFO titled Public Health Strategies to Address Alzheimer's Disease and Related Dementias for extending the BOLD Act's participants and programs impact in the United States. The initial phase of this program will end in 2025, including the Components A and B and the BOLD Centers of Excellence. The CDC's new NOFO does not include continuation funding for initiatives targeting underserved populations at high risk for AD/ADRD, including ethnic and cultural communities, indigenous American, and adults with intellectual developmental disabilities. The NAPA Advisory Council should submit statements or guidance to the CDC in advocating for continued inclusion of [funding] support for these populations.
- **Stephanie Monroe**, *UsAgainstAlzheimer's*, commented on the need to focus on populations that are at greatest risk for developing AD/ADRD -- diverse populations and minoritized communities. She highlighted the adoption of Goal 6, to reduce risk factors for AD/ADRD, and provided updates on progress made towards the goal, and additional work needed. She also expressed dismay that the CDC forecasted NOFO left out this precious focus on often overlooked populations -- Black, Latino, Indigenous, and those with disabilities and noted that UsAgainstAlzheimer's is working with the CDC to rearticulate its commitment to these populations. Monroe concluded by urging the NAPA Advisory Council to redouble its efforts to focus on people who need it the most -- people who have historically been overlooked, underserved, and to do so in both our planning and funding.
- **Mary Richards**, *The Heart of the Solution*, shared information on a new project, The Heart of the Solution, a campaign that integrates vascular health and inflammation into our thinking around Alzheimer's and dementia prevention, diagnosis, treatment, and care.

Concluding Remarks

Dr. Carlsson shared information on the Council's next two meetings -- the January 13, 2025 meeting will focus on long-term care services and supports and the April 28, 2025, meeting will focus on research.

The meeting adjourned at 4:30 p.m.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at <https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-advisory-council/napa-advisory-council-meetings>.