

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

Washington, DC and Virtual Meeting

July 25, 2022

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Cynthia Carlsson (Chair), Randall Bateman, Venoreen Browne-Boatswain, Matthew Janicki, Keun Kim, Helen Bundy Medsger, Adrienne Mims, Carrie Molke, Joe Montminy, Maria Ortega, Joanne Pike, Rhonda Williams
- *Federal Members Present:* Ellen Blackwell (Centers for Medicare & Medicaid Services, CMS), Roderick Corriveau (National Institute of Neurological Disorders and Stroke, NINDS), Rebecca Ferrell (National Science Foundation), Bruce Finke (Indian Health Services, IHS), Richard Hodes (National Institutes of Health, National Institute on Aging, NIH/NIA), Shari Ling (CMS), Erin Long (Administration on Aging), Lisa McGuire (Centers for Disease Control and Prevention, CDC), Joan Weiss (Health Resources and Services Administration, HRSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, HHS/ASPE)

General Proceedings

Chair Cynthia Carlsson called the meeting to order at 9:30 a.m. Eastern Daylight Time (EDT).

Welcome and Introductions

Dr. Carlsson welcomed meeting participants and reviewed the meeting agenda. Council members introduced themselves.

Update on National Plan Anniversary Activities

Helen Lamont, PhD

Dr. Lamont said that on May 16, 2022, HHS launched a web page about the 10th Anniversary of the National Plan to Address Alzheimer's Disease. HHS also issued a press release and made announcements via social media regarding resources, modifiable risk factors, and federal efforts to address Alzheimer's disease and related dementias (AD/ADRD). HHS convened or participated in several events held to support improved dementia care and policy, as well as produced and disseminated videos and blogs. These activities illustrated both the progress that has been made and the work still to be done. Current priority areas are addressing racial and ethnic disparities in AD/ADRD and expanding the National Plan to states and communities. The NAPA Reauthorization Act was introduced in the House and Senate in May. If passed, the Act will extend the Plan to 2035; add focus on healthy aging and risk reduction; and add representation from several federal agencies, an additional researcher, and a person living with AD/ADRD to the Advisory Council.

Discussion

- Round tables are an effective way for federal agencies to learn about state and local activities related to AD/ADRD, and to learn how federal agencies can support state and local efforts.
- It may be useful for the Council to invite state agency representatives to meetings, and possibly to join the Council, in order to facilitate communication.
- State and county leaders would likely benefit from technical assistance from health agency leaders.
- Individuals can support passage of the NAPA Reauthorization Act by contacting their congressional representatives.

Federal Efforts to Address Racial and Ethnic Disparities in Alzheimer's Disease and Related Dementias

Emma Nye, MPA, Program Analyst, ASPE

The National Alzheimer's Project Act (NAPA) requires inclusion of ethnic and racial populations at higher risk for AD/ADRD or who experience reduced likelihood of receiving care in clinical, research, and service efforts that aim to address AD/ADRD. At the Council's request, in June 2022 ASPE produced and published an issue brief on racial and ethnic disparities in AD/ADRD research, care, and services, as well as an inventory of federal efforts to address these disparities.

Black Americans are twice as likely and Hispanic Americans are 1.5 times as likely as White Americans to have AD/ADRD. AD/ADRD diagnosis is less prevalent among Asian Americans and Native Americans, possibly due to underdiagnosis. Reasons for disparities include bias and discrimination within the health care system, diagnostic

measurement tool bias, lack of culturally competent care, and underrepresentation of ethnic and racial minorities in clinical trials. Members of racial and ethnic minorities are more likely than White people to report perceiving that their health care providers dismiss or condescend to them. Discrimination by health care providers is associated with poorer health outcomes. Currently available diagnostic tools are less accurate for racial and ethnic minorities, even after controlling for other demographic factors. A large proportion of racial and ethnic minorities have reported that culturally competent AD/ADRD care is important, but few are confident that it is available. Black and Hispanic people are more likely than other racial and ethnic groups to perceive AD/ADRD symptoms as a normal part of aging. Providers typically are not trained to understand and respond to cultural differences in perceiving and reporting AD/ADRD symptoms. Reasons for underrepresentation in clinical trials include exclusion due to comorbid conditions, exclusion for not being fluent in English, physical distance from clinical trial location, lack of compensation for participation, difficulty taking time off work, distrust of clinical research, and experience with health care system discrimination and bias.

Federal efforts to address disparities focus on research, clinical care, long-term services and supports (LTSS), public education, and risk reduction. Research focus areas include intramural efforts to identify disparities, funding extramural efforts to identify disparities, and efforts to improve recruitment of racial and ethnic minorities to participate in research. Efforts to reduce disparities in clinical care and LTSS include training health care providers and caregivers to provide culturally competent care for AD/ADRD and improving data collection to better inform AD/ADRD care. Public education and risk reduction efforts include education and awareness campaigns, community and system investments, and individual-level behavior change.

Discussion

- Efforts proposed to facilitate federal, state, and local communication and collaboration to support the National Plan also could be applied to addressing AD/ADRD disparities.
- Lessons learned about social determinants of health can be applied to reducing AD/ADRD disparities.
- Efforts to address AD/ADRD must consider how to serve patients without access to digital technology.
- Public education efforts are needed to address people's fears of participating in clinical trials.
- It is critical for clinicians to learn how to deliver culturally competent AD/ADRD care, including understanding potential bias in diagnostic tests, overcoming language barriers, and understanding how culture affects patients' perspectives on AD/ADRD.
- Many informal caregivers of people with AD/ADRD are unaware of available support resources and deal with the stress of caregiving in unhealthy ways, such as smoking or excessive alcohol use. This stress is especially difficult when the person they care for is experiencing symptoms of AD/ADRD but has not been diagnosed. Health care providers should be trained not only in culturally

competent diagnosis, but also to identify informal caregivers and provide them with appropriate resources. The National Plan should prioritize addressing this issue.

Efforts are needed to improve communication between researchers and clinicians. It is important for clinicians to understand the necessity of research for identifying best clinical care practices. Due to lack of understanding, some clinicians do not provide necessary support, such as providing patients' blood samples, for research participation. It is crucial to address this barrier.

- Research is needed on the effects of the COVID-19 pandemic on vulnerable communities' health service utilization, including whether patients attend recommended appointments and the specific barriers to seeking recommended care.

Federal Updates

- **Richard Hodes** provided an overview of NIH's proposed budget and research priorities for fiscal year 2024. Priorities include longitudinal studies of the effects of social determinants of health on AD/ADRD, research on AD/ADRD risk and prevention, studying genetic influence on risk and development of AD/ADRD, proof-of-principle studies of novel immunotherapies to treat neurodegenerative diseases, developing clinical tools for differentiating dementia types, enhancing digital data on risk and resilience factors, large-scale pragmatic trials of prevention approaches, and applying artificial intelligence to accelerate drug development. NIH will establish a research consortium to consider how to address barriers to integrated care. The agency will fund research on how to incentivize optimal dementia care and will support improving research infrastructure and development of translational research tools. NIH prioritizes equity and inclusion. The agency will expand efforts to understand causes and consequences of health disparities, work to increase community engagement in research, increase diversity of research participants, and establish career development programs in dementia research.
- **Shari Ling** reported that CMS recently revised its interpretive guidance to enhance nursing home quality and oversight. Revisions aim to improve care for people who need care for mental health problems or substance use disorder and to address situations in which patients are inaccurately diagnosed. Guidance clarifies rights of and behavioral health services available for patients with mental health or substance abuse needs.
- **Bruce Finke** said IHS will fund grants and programs to address AD/ADRD in Indian Country, as well as education and training, outreach, and data and infrastructure. Support and education for caregivers is a priority, as is raising awareness of AD/ADRD. The Indian Health Geriatrics Pilot project currently is recruiting participants. IHS is collaborating with the New York University Building

Our Largest Dementia (BOLD) Infrastructure Public Health Center of Excellence in Early Detection of Dementia to develop strategies for early detection in Tribal communities and referring people to necessary services regardless of whether they are diagnosed with dementia. IHS also collaborates with the Northwest Portland Indian Health Board and the Eastern Band of Cherokee Indians to deliver a dementia Project ECHO program to reach the primary care workforce. IHS is seeking geriatric emergency department accreditation for Tribal facilities. A Council member suggested that IHS's budget for these activities is relatively small and that the Council should advocate for increasing it.

- **Lisa McGuire** reported that CDC recently published a *Morbidity and Mortality Weekly Report* on modifiable risk factors for AD/ADRD among people aged 45 years or older. Results also are presented on the CDC website and a podcast. In June 2022, CDC convened a conference of BOLD Centers of Excellence on Dementia Caregiving and has planned several educational events for the next year, including a workshop on addressing dementia risk through social determinants of health, a summit on dementia risk reduction, and a symposium on public health action to advance early detection of dementia. CDC also disseminated findings about memory loss among caregivers through an article, web feature, and podcast. In early 2022, CDC launched a Healthy Brain Resource Center, which provides a searchable database of CDC-verified information and materials. Dr. McGuire invited submissions. CDC collaborated with the Association of State and Territorial Health Officials to develop the Healthy Brain Road Map Module to support public health agencies in identifying priorities and planning action. State and local public health departments provided input via listening sessions. The public comment period for updating the Healthy Brain Road Map Module is July 15-August 15, 2022. Dr. McGuire encouraged meeting participants to provide comments. BOLD grantees are implementing actions recommended by the Road Map. There are 5 Healthy Brain Road Map work groups, each of which focuses on a priority topic: risk reduction; early detection, diagnosis, and management; caregiving; health equity; and community linkages. The updated module will be available in summer 2023. A Council member emphasized the importance of soliciting public comment starting at the very beginning of recommendations development processes.

U.S. Department of Justice (DoJ) Elder Justice Efforts

Andy Mao, JD, Deputy Director, Civil Fraud, Commercial Litigation, DoJ

DoJ's Elder Abuse Initiative aims to combat elder abuse, neglect, and fraud by promoting justice, helping victims and their families, enhancing state and local efforts through training and resources, and supporting research that can inform policy and practice. The Elder Justice Act of 2010 established the Elder Justice Coordinating Council, which comprises leads of federal departments with responsibility for addressing needs of older adults, with the purpose of coordinating efforts. The Elder Abuse

Prevention and Prosecution Act of 2017 created a position at DoJ for a person to advise the Attorney General and coordinate department activities, and an Elder Justice Coordinator for each federal district. The act also requires DoJ to develop best practices training and resources for elder justice professionals. Enforcement efforts have included prosecuting nursing homes that use psychoactive drugs to restrain patients with AD/DRD rather than hire staff trained to serve these patients, as well as elder fraud.

Older adults' capacity to make decisions is frequently an issue in court proceedings. DoJ hosted a symposium on this issue in April 2022. The department collaborated with the National Center on Elder Abuse at the University of Southern California to develop a Judicial Guardianship Evaluation Worksheet to help judges can make informed decisions about imposing guardianship.

DoJ offers Safe Accessible Forensic interviewing for Elders training for law enforcement officials and others who have to conduct interviews, including interviews with people living with dementia. The training describes types of dementia and their symptoms, disease stages, and implications for forensic interviewing such as how time of day can affect cognitive functioning for people with dementia. Training materials are available on DoJ's website. DoJ hosts the Elder Fraud Hotline, which is answered by people trained to work with older adults.

A panel member asked whether DoJ is working to address abuse, neglect, and fraud committed against younger people living with dementia. Mr. Mao said that DoJ prioritizes all abuse, neglect, and fraud, regardless of victims' age and that training for serving people with dementia applies to all age groups. Mr. Mao agreed that training should mention that some people living with dementia are younger than 65 years.

Panel Discussion: Enhancing the Diversity of the Aging Research Workforce through the Resource Centers for Minority Aging Research (RCMAR) Program

“Alzheimer’s Disease-related Resource Centers for Minority Aging Research (AD-RCMAR)”

Melissa Gerald, PhD, NIA

The main objectives of RCMARs are to increase the diversity of researchers who study aging by offering career development mentoring to scientists from underrepresented groups and to increase capacity in the field of aging research by developing infrastructure and increasing the number of trained researchers. NIA's Health Disparities Research Framework identifies several priority populations, which include racial and ethnic minorities, socioeconomically disadvantaged groups, rural populations, people with disabilities, and gender and sexual minorities. AD-RCMARs focus on social, behavioral, and economic factors in relation to AD/DRD. Current priority areas include health disparities and inequities, epidemiology, behavioral and social pathways, early

psychological changes, prevention, research on caregiving, and dementia care. RCMARs both conduct research and train researchers. A national RCMAR Coordinating Center provides logistical support, facilitates communication, oversees information dissemination, and maintains program data. RCMARs offer several resources including a YouTube channel, webinars, and a web-based networking tool. Reducing disparities requires adequate support for scholars and public awareness. The program was recently renewed for 5 more years, and more AD-RCMARs will be funded during the next funding round.

“Michigan Center for Contextual Factors in Alzheimer’s Disease (MCCFAD)”

Kristine Ajourch, PhD, Eastern Michigan University

The AD-RCMAR MCCFAD aims to eradicate disparities related to Alzheimer’s disease by conducting research on risk factors and prevention. The Center attributes its success, in part, to interdisciplinary research teams. Priority populations are Middle Eastern/Arab American and Latino communities, which experience greater risk and prevalence than White Americans. Both communities include many immigrants, have strong family ties, and experience similar stressors. Both groups are underrepresented in research samples. Studying these groups presents an opportunity to identify new paths of risk and resilience. MCCFAD works to increase representation of these priority populations in AD/ADRD research and to train a skilled AD/ADRD workforce. MCCFAD has developed a research volunteer directory of 424 Middle Eastern/Arab Americans and 321 Latino Americans. Community-based scientists led efforts to recruit volunteers. These scientists have earned community trust and understand local culture, allowing them to allay concerns about research and convey the importance of participation. MCCFAD has trained 17 research scientists from diverse racial/ethnic backgrounds over the past 5 years. Collectively, these trainees have won 39 grants and published 144 manuscripts.

“Ready to Launch: Experiences of a Johns Hopkins Alzheimer’s Disease-RCMAR Scholar”

Chanee Fabius, PhD, MA, Johns Hopkins University

Dr. Fabius surveyed agencies that provide dementia care services in Maryland about their current practices, as well as barriers and opportunities to improving training for care providers. Her study also assessed variability in organizational characteristics and care recipients’ quality of life outcomes. The study found that caregivers of people with dementia were more likely to feel stressed, overwhelmed, or unable to continue caregiving than caregivers of people without dementia. Caregivers working in home and community-based care experienced lower stress than the general population of caregivers. Two-thirds of care recipients, with and without dementia, had experienced low levels of social engagement. Qualitative data indicate that caregivers would benefit from more orientation to what is needed by specific care recipients and their families.

Findings indicate that policy makers should strengthen home and community-based care systems.

RCMAR faculty offer mentorship, community liaison and recruitment support, and analytic support on this project. RCMARs also facilitate engagement with peer scholars.

Tracking National Plan Progress: Examples from Healthy People 2030

Helen Lamont, PhD

Healthy People 2030 includes objectives to increase the number of older adults with dementia who know they have it, reduce the number of preventable hospitalizations among older adults with dementia, and increase the number of older adults with subjective cognitive decline who discuss it with their physician. Several Healthy People 2030 objectives are related to risk factors for dementia, such as reducing the proportion of adults with hypertension, diabetes, and obesity. Dr. Lamont invited the Council to consider whether Healthy People 2030 data are ideal for tracking data on dementia and whether dementia lends itself to public health surveillance. Current national survey tracking efforts provide an infrastructure for data collection on dementia. Dr. Lamont noted the importance of considering costs and benefits of any data collection approach. Accurate dementia diagnosis requires multiple medical procedures. Tracking this process through public health surveys would be very costly and time consuming. She noted that current surveys determine whether respondents have a history of any condition by asking only for self-reports of whether a doctor has told the respondent they have been diagnosed with a given condition.

Discussion

- The National Health and Nutrition Examination Survey included the Montreal Cognitive Assessment (MOCA) in 2019 and 2020; CDC has proposed to include MOCA again in 2024. Previously, adding the MOCA cost approximately \$1 million annually.
- While Dr. Lamont believes current surveillance systems to be excellent, they have not led to measurable improvements in conditions such as obesity or other individual health behaviors. In order to track risk reduction, it might be useful to track measures of health condition management and healthcare quality. ASPE looks to the Advisory Council for information about priorities for tracking progress.

Recommendation Presentations and Voting

Dr. Carlsson noted that the current NAPA reauthorization bill does not mention HRSA or ASPE as partners and invited the Council to consider whether that should change, since these agencies have been important partners. If members agree that this is the case, the Council could include a recommendation that these agencies be included along with the others proposed by Congress.

“2022 Research Recommendations”

Randall J. Bateman, MD

The research subcommittee recommendations were:

1. Increase synergies among all federal agencies involved in the National Plan to facilitate faster and more comprehensive translation of research into clinical practice of evidence-based advancements and approved diagnostic, treatment, and care paradigms to improve outcomes for people with dementia.
2. By the end of 2022, NAPA federal agencies should investigate and propose successful models for increasing involvement of people with AD/ADRD in clinical research studies, including trials. The proposal should evaluate how clinical care can be synergized with research participation to accelerate scientific advancements that can be quickly translated into clinical practice. The goal should be for all people with AD/ADRD to be offered opportunities to participate in research.
3. A top priority remains the urgent need for Congress to continue to increase annual federal research and implementation science funding (by NIH and other agencies) sufficient to meet NAPA goals across biomedical, clinical, LTSS, and public health settings.
4. Representation and diversity in AD/ADRD clinical trials should continue to be increased to address health equity and representation in research.
5. Research into implementation of dementia care to provide best care models should continue to be increased.
6. An understudied area that should be prioritized is the impact of stigma related to dementia on health-seeking behaviors to improve access to health services.
7. A cross-cutting recommendation across all NAPA subcommittees is to increase research into neurological effects of COVID-19 and development of emergency preparedness programs for the safety and wellness of older adults and people with AD/ADRD.

“2022 Clinical Care Recommendations”

Maria Ortega, DNP, APRN, GNP-BC, PMHNP-BC, CDP, FAANP, FAAN

The clinical care subcommittee recommendations were:

1. Educate the public about the importance of risk reduction, early detection, and accurate diagnosis of AD/ADRD care models for person-centered and family-centered care, resource access and utilization.
2. Expand and enhance the current and future clinical care workforce through training, continuing education, mandated standards, and remuneration to address better the needs of persons living with AD/ADRD and their families/caregivers.
3. Using the best available evidence, stakeholders should reach consensus on guidance for best practices for diagnosis, management, and integration of family

- caregivers into the care team. For developing comprehensive multi-stage care of AD/ADRD, consideration should include the uniqueness of different populations.
4. Encourage further development, evaluation, and implementation of person-centered and family-centered health care models for AD/ADRD that align performance measures and payment models. These models should incorporate the lived experience of care of persons living with AD/ADRD of all ages and their caregivers, always considering diversity.
 5. To assure health equity, remove any barriers for the receipt of, and payment for, clinical and care services, and LTSS for adults living with dementia who are under the age of 65.
 6. Accelerate efforts to promote healthy aging, reduce risk factors for AD/ADRD, and intervene early in clinical care.

Discussion

- The subcommittee's discussion of Recommendation 1 suggested clarifying the U.S. Preventive Services Task Force statement on cognitive impairment in older adults to explain reasons for early diagnosis and assessment. Dr. Bierman explained that the Task Force is an independent entity, and that "I" (insufficient) ratings indicate that current evidence is insufficient to assess costs and benefits. These ratings can change in response to new or expanded research evidence.

"2022 LTSS Recommendations"

Carrie Molke, MS

The LTSS subcommittee recommended:

1. Improve access to LTSS for people with dementia and their unpaid caregivers.
2. Implement solutions to address the LTSS workforce crisis.
3. Ensure that family and unpaid caregivers of people with dementia have the support they need.
4. Implement new payment models to make long-term care more affordable and eliminate gaps in coverage among government programs that support people with dementia.
5. Implement strategies that support coordination, integration, and dementia capability.

"2022 Risk Reduction Recommendations"

Joanne Pike, DrPH

The risk reduction subcommittee recommended:

1. Identify priorities and specific milestones that would make progress toward addressing risk factors for cognitive decline and dementia.
2. Accelerate public health and aging network action on addressing the risk factors with the strongest evidence of beneficial impact on dementia prevalence, particularly for communities at greatest risk.

3. Identify and accelerate efforts to reduce risk and intervene early in clinical care.
4. Initiate and fund research to strengthen the strategies for addressing the potential risk factors for dementia.
5. Appropriate non-federal entities and private sector organizations should work to improve health in general and brain health specifically by targeting vulnerable, disadvantaged, and marginalized populations; persons compromised by lifelong conditions; and those who would benefit from special focus on and orientation to healthy lifestyles and avoidance of risk across the lifespan.

Non-federal Council members voted to pass all recommendations. A Council member suggested including the recommendations with the Update to the National Plan to Address Alzheimer's Disease. Dr. Lamont agreed to do so.

Public Comments

- Laura Cohen of Eli Lilly said the potential benefits of amyloid plaque-targeted therapies can only be realized when all patients have timely and equitable access to diagnostic and therapeutic options, a goal of NAPA and the National Plan. Eli Lilly applauds CMS's recent decision to open reconsideration of its national coverage determination for amyloid beta PET scans. The determination was made nearly 10 years ago and does not reflect developments in Alzheimer's disease treatment made since. Currently, Medicare beneficiaries receive coverage for only one amyloid PET scan per lifetime and must be enrolled in a clinical trial to access this diagnostic test. Eli Lilly supports eliminating the lifetime limit now that there are treatment options that require confirmatory amyloid beta PET scans. Amyloid beta PET scans have demonstrated clinical utility and should be covered regardless of whether a patient is enrolled in a clinical trial.
- Diana Cose is the Executive Director of Lorenzo's House, which aims to empower families of people living with younger onset dementia. The organization works to raise awareness, remove stigma, and provide resources and support. Ms. Cose asked the Council to support efforts of Lorenzo's House and other organizations with similar missions.
- Sonja Rasmussen, MD, shared the story of her brother, who had Down syndrome and was diagnosed with Alzheimer's disease at age 56. He died at age 60. While life expectancy for people with Down syndrome has increased dramatically over the past 40 years, Alzheimer's disease is halting this progress, with average age of Alzheimer's disease onset among people with Down syndrome being 54 years. Efforts to improve prevention and treatment of Alzheimer's disease should prioritize this vulnerable population. Dr. Rasmussen urged the Council to advocate for inclusion of people with Down syndrome or otherwise at genetic risk in clinical trials.

- Charlotte Woodward of the National Down Syndrome Society reminded the Council that people with Down syndrome have a chromosomal abnormality that elevates risk for Alzheimer's disease and that people with Down syndrome are more at risk than others who also have this chromosomal abnormality. She pointed out that people frequently underestimate the abilities of people with Down syndrome and noted that she lives with this disability and also graduated from college with honors. More research is needed on the connection between Alzheimer's disease and Down syndrome. Previous requests have been made for the Council to form a subcommittee on how to improve support for people with intellectual and developmental disabilities. Ms. Woodward urged the Council to form this subcommittee and to advocate for and support research on the connection between Alzheimer's disease and Down syndrome, to prevent Alzheimer's disease among people with Down syndrome, and to ensure people with Down syndrome and Alzheimer's disease have access to the best available treatments.
- Bradford Grems spoke on behalf of NIA's and NINDS's All Frontotemporal Dementia (FTD) Study, which focuses on most types of frontotemporal lobar degeneration (FTLD), a disorder that typically has a young age of onset. Mr. Grems's family has been affected by FTD and he is a study participant. Research findings on FTLD can inform efforts to treat other forms of dementia as well. Mr. Grems serves on a board of study participants and their caregivers, who provide feedback on research and advice regarding patient and family priorities. The All FTD Study team requests support for continued funding for this study beyond the current project end date in 2024, expanded research on FTLD and other young onset, rare, and atypical dementias, and improved education for health care providers about diagnosing FTLD. Misdiagnosis and lack of understanding are common. Early diagnosis is important for connecting with support, resources, research participation, and health care planning.

Concluding Remarks

Dr. Carlsson noted that the Council's next meeting should be held on October 24, 2022.

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>.