

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

Virtual Meeting

July 20, 2020

## Advisory Council Members in Attendance

- *Non-Federal Members Present:* Katie Brandt (co-chair), Allan Levey (co-chair), Venoreen Browne-Boatswain, Cynthia Carlsson, Debra Cherry, Robert Egge, Brad Hyman, Matthew Janicki, Becky Kurtz, Carrie Molke, Maria Ordonez, Gloria Owens, Cheryl Schmitz
- *Federal Members Present:* Helen Lamont (ASPE, Federal Project Officer), Arlene Bierman (AHRQ), Ellen Blackwell (CMS), Rod Corriveau (NIH), Bruce Finke (IHS), Richard Hodes (NIH), Gavin Kennedy (ASPE), Shari Ling (CMS), Erin Long (ACL), Lisa McGuire (CDC), Emma Nye (ASPE), Deb Olster (National Science Foundation), Arne Owens (ASPE), Joan Weiss (HRSA)

## Welcome and Opening Comments

- Co-Chair Katie Brandt called the meeting to order at 1 p.m. Eastern Daylight Time. Dr. Helen Lamont conducted roll call and described meeting protocol, including how to use the supporting technology. Ms. Brandt welcomed participants to the Council's 38th meeting, noting that it was held virtually due to the COVID-19 pandemic. Ms. Brandt also noted that the pandemic did not interfere with Council members' work. Ms. Brandt introduced Council members and thanked Dr. Lamont for her work.
- Ms. Brandt is Director of Caregiver Support Services at Massachusetts General Hospital Frontotemporal Disorders Unit. In this capacity, she has observed COVID-19 causing loss of loved ones, adult daycare programs, home care services, senior centers, jobs and income, and social connections. Caregivers are often afraid to ask for emergency or routine medical services, since this may increase their loved one's risk of exposure to COVID-19 and because such care is likely to require that caregivers separate from loved ones. This has resulted in greater caregiver burden and social isolation. COVID-19's impact will include long-term changes to care delivery in homes, community-based settings, and skilled nursing facilities. For example, virtual care has dramatically increased since the pandemic onset. However, it can be challenging to ensure that virtual care visits are private. Plans for future care delivery must focus on patients' and caregivers' dignity, values, and

culture. Positive developments in response to the pandemic include increased availability of virtual support groups and online educational resources.

- Co-Chair Dr. Allan Levey concurred with Ms. Brandt's comments. As a clinician, he has recently observed a faster rate of cognitive and behavioral decline among patients than he has observed at any previous time in his career. Patients are challenged to understand or remember the pandemic or associated precautions such as social distancing and hand washing. Adjustments that are difficult for everyone are especially difficult for people with memory or cognitive impairments. Clinicians stress the importance of social interaction after a diagnosis of Alzheimer's disease or related dementias (AD/ADRD). The pandemic has made it difficult to adhere to this recommendation, possibly leading to more rapid decline. Clinical staff have rapidly pivoted to conducting assessments via videoconference. However, not all patients have broadband access, which exacerbates disparities. Dr. Levey said that it has been stressful for clinicians to have 2-3 times as many of their patients die. The pandemic has presented challenges for clinical trials, sometimes blocking patients' access to treatments, such as infusions or anti-amyloid therapy. Many basic research laboratories have had to close and are challenged to reopen while maintaining social distancing. However, many researchers are working remotely and in shifts to ensure work continues. Dr. Levey said the COVID-19 pandemic eventually will end. It also will continue to be urgent to find a neuroprotective treatment for AD/ADRD.
- Dr. Levey reviewed the meeting agenda. Dr. Lamont said the presentations would describe examples of approaches to serving patients with dementia during the COVID-19 pandemic from federal, state, and long-term care facility perspectives. She encouraged Council members to share their experiences and perspectives to support the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in maximizing its impact.

## **Presentations and Discussions about Emergency Preparedness for Persons Living with Dementia: The COVID-19 Pandemic**

### ***At-Risk Individuals Program and COVID-19***

**Cheryl Levine, PhD**

**Director, At-Risk Individuals Program, U.S. Department of Health and Human Services (HHS) Office of Assistant Secretary for Preparedness and Response (ASPR)**

- Dr. Lamont introduced Dr. Cheryl Levine, who serves as a subject matter expert, disseminates promising practices, monitors emerging issues, and leads partner coordination to ensure integration of access and functional needs for at-risk individuals into public health and medical emergency preparedness response and recovery activities. She convenes federal interagency committees; leads national calls and webinars; and designs and delivers training tools, guidance, and requirements for addressing the access and functional needs of at-risk individuals. Her expertise includes assessing and leveraging social services programs to

address policy development and implementation, research and evaluation methods, and survey design to provide high-quality, data-driven solutions in response to policy questions. Dr. Levine is an expert on research regarding disaster housing recovery programs and quality of life issues for people in communities affected by disaster.

- Dr. Levine explained that ASPR is within the Office of the Secretary for HHS. Its mission is to “save lives and protect Americans from 21st century health security threats.” ASPR supports the Secretary in leading coordination of public health emergency responses. ASPR activities include coordinating medical response, deploying teams to provide medical support, providing grant funding to communities, and collaborating with other agencies on medical research. Dr. Levine’s focus is at-risk individuals. She works with the Community Mitigation Workgroup as part of the COVID-19 pandemic response.
- ASPR was created in 2006 in response to Hurricane Katrina, authorized by the Public Health Service Act. In 2019, ASPR was reauthorized under the Pandemic and All-Hazards Preparedness and Advancing Innovation Act, which requires ASPR to address needs of at-risk individuals during public health emergencies. At-risk individuals include children, pregnant women, older adults, people with disabilities, and others with access- or function-based needs. ASPR aims to ensure that everyone has access to support and services needed during a public health emergency or disaster. In 2018, ASPR launched training on term definitions and ASPR’s approach to addressing access and functional needs. The Federal Emergency Management Agency (FEMA) and other partners have adopted this approach, which focuses on addressing needs regardless of diagnosis. The training is available to the public online at no cost. ASPR also offers other resources, such as a fact sheet on discharge planning to support emergency responders in ensuring people who receive institutional care during disasters return to community settings. ASPR coordinated with the Administration for Community Living (ACL), with support from the National Association for County and City Health Officials and the Association of State and Territorial Health Officials, to develop a Capacity Building Toolkit for including aging and disability networks in community planning. The toolkit is designed to support access to emergency response and recovery resources, to engage people in emergency planning, to facilitate community-based organizations’ communication with clients about emergency planning, and to facilitate partnership development among organizations. The toolkit explains emergency management work, such as risk assessment, creating an emergency operations plan, understanding the incident command system, understanding emergency support functions, training exercises, and engaging in consumer advocacy.
- In response to COVID-19, the Community Mitigation Workgroup has fostered relationships with new and existing stakeholders, such as other HHS agencies, FEMA, and the U.S. Department of Housing and Urban Development. The Workgroup has collaborated with partners to create and promote resources and

guidance for emergency responders. It has supported expanding and maintaining nutritional resources, and it has developed journey maps and other resources for providers serving people with access and functional needs.

- Adult day programs often provide meals. Due to the COVID-19 outbreak, they now must provide these meals via home delivery. ASPR synthesized information about nutrition programs into one resource, “Sustaining Nutritional Needs for At-Risk Individuals,” which provides guidance about identifying need, building capability, engaging networks, and creating solutions, and provides information about leading practices and programs. ASPR also developed “Federal Programs to Sustain Nutrition for At-Risk Individuals” and “Returning to Work for Community-Based Organizations.” The office has developed forthcoming resources, including “Adults with Disabilities in Community Settings,” a webinar series on telehealth, web training on addressing the needs of older adults during disasters, and a webinar on replacing Medicare beneficiaries’ durable medical equipment and prescription drugs after a disaster. All resources are available on ASPR’s website.

### ***Nevada COVID-19 Aging Network (CAN) Rapid Response***

**Peter Reed, PhD, MPH**

**Director and Professor, Sanford Center for Aging, University of Nevada,  
Reno School of Medicine**

- Dr. Lamont introduced Dr. Peter Reed. The Sanford Center’s mission is to enhance quality of life and well-being among older adults through research, education, and community outreach. Dr. Reed is the Project Director for a Health Resources and Services Administration (HRSA) Geriatrics Workforce Enhancement Program (GWEP). He is a fellow of the Gerontological Society of America and chairs the Nevada State Taskforce on Alzheimer’s Disease. He helped launch and serves as Co-Director of the Nevada CAN Rapid Response, a statewide mobilization of providers to ensure older adults can stay home, stay safe, and remain connected to needed services.
- Dr. Reed emphasized that Nevada’s response to COVID-19 has been collaborative. He acknowledged the work of Co-Directors Dena Schmidt, Administrator for the Nevada Aging and Disabilities Services Division; Jeff Klein, President and CEO of Nevada Senior Services; and Dr. Jennifer Carson, Director of the Dementia Engagement, Education, and Research Program at the School of Community Health Sciences at the University of Nevada, Reno. Nevada CAN is the work of several organizations. Dr. Reed emphasized that Nevada’s experience may not represent that of other states. Nevada’s total population is about 3 million people. There are about 36,000 cases of COVID-19 in the state, nearly 650 associated deaths, and 287 people currently receiving intensive care unit services. Nevada is one of two states that has experienced a 50% increase in COVID-19 cases between the week preceding the meeting and the week prior to that. The pandemic is getting worse in Nevada. A key goal of the Rapid Response network is to convey the importance of older adults staying home and maintaining social distance. People are less receptive to this message now than they were 3 months ago.

- Nevada CAN is a collaboration of the Nevada Aging Network led by the State Department of Health and Human Services Aging and Disabilities Services Division, launched April 1, 2020. A large proportion of COVID-19-related deaths are among older adults. Older adults need services to stay home and stay safe. The Nevada Aging Network has served high-risk adults for decades. Nevada CAN was developed to mobilize all resources for older adults in the state to meet high priority needs in anticipation of increasing demand during the pandemic. The governor approved and announced the program within 10 days. Dr. Reed sent a resource guide for other states to use as an example. Dr. Reed pointed out that Nevada CAN serves all older adults and was not designed specifically for people living with dementia. However, it is expected to benefit people living with dementia. The development team defined key objectives and highest priority needs, which were medical services, social supports, and essential items of daily life (e.g., food, prescription medication, pet supplies). Nevada CAN's goal was to ensure these needs were met without older adults leaving their homes. Action teams mobilize groups of between 12 and 25 volunteers to obtain and deliver resources. To date, the program has delivered more than 100,000 meals. Nevada CAN delivers services in multiple languages. In the first 3 months of the program, the program recruited and trained more than 100 volunteers and served more than 100 older adults.
- Dr. Klein adopted Rush University's Bridge Program to serve people living with dementia, and to support transition from residential care to at-home care for people living with dementia and COVID-19.
- Nevada CAN offers HIPAA-compliant, interdisciplinary telehealth services, supported by a HRSA GWEP grant, including primary care, dementia care, psychiatry, and care for chronic health problems.
- Nevada CAN's social support action team calls people at home to monitor and respond to their needs and to have conversations. Volunteers also facilitate digital peer social support groups. Volunteers provide support to ensure older adults can access the technology needed to stay connected with services and social support. Services are delivered through phone, text, and the Internet. People can submit requests for assistance through the Nevada CAN website, which offers a checklist menu. Requests are triaged and directed to action teams or, for requests outside the scope of the action teams, to the appropriate agency. Nevada CAN has an inter-organizational referral network.
- Nevada Ensures Support Together Collaborative comprises more than 30 aging and social service organizations that provide volunteer-hosted virtual social support for homebound older adults. The program was designed with input from service providers and people living with dementia, who are contributors as well as beneficiaries of the program. The program recognizes that community is based on reciprocity and a shared sense of belonging.

***Promoting Quality of Life and Well-Being with Nursing Home Residents, Care Partners and Staff During COVID-19***

**Alice Bonner, PhD, RN, FAAN**

**Director, Strategic Partnerships, Capable Program, Johns Hopkins University School of Nursing; Senior Advisor for Aging, Institute for Healthcare Improvement**

**Sheena Bumpas, CNA**

- Dr. Lamont introduced Dr. Alice Bonner, who is a geriatric nurse practitioner with more than 30 years of experience. From 2015-2019 Dr. Bonner served as the State of Massachusetts's Executive Officer for Elder Affairs.
- Dr. Lamont introduced Ms. Sheena Bumpas, who is a board member for the National Association of Healthcare Assistants. She works in a Study of Nasal Insulin to Fight Forgetfulness memory care unit in Oklahoma, at a center where she has worked for nearly 18 years. Ms. Bumpas volunteers for the Oklahoma Alzheimer's Organization. She has won three national Key to Quality awards for attitude, resident family service, and Certified Nursing Assistant (CNA) of the Year.
- Dr. Bonner emphasized that nursing homes are part of their communities. She thanked care providers for their work.
- The Federal Government requires every nursing home to have an emergency preparedness and management plan. The Office of the Inspector General conducted an assessment that found that many nursing homes do not have a plan or have inaccurate, outdated, or misplaced plans. The assessment also identified best practices. It is crucial for plans to be in place and to address the specific needs of people living with dementia.
- Care and quality of life should be improved continually based on available data, such as those collected by the Centers for Medicare & Medicaid Services (CMS) National Partnership to Improve Dementia Care in Nursing Homes. Data-driven quality improvements have included reduced use of anti-psychotic medications in dementia care and The Institute for Healthcare Improvement's National Nursing Home Huddles, supported by the John A. Hartford Foundation, which are convened via teleconference every weekday. For these huddles, about 200 nursing homes from across the United States participate in peer discussions about best practices, ideas, and challenges. Topics are selected based on participant input. Caregiver mental health was a recent topic.
- Many nursing home care providers are people of color who make approximately \$12-\$17 per hour, often working at more than one job.
- Policies should focus on improved emergency and preparedness planning, quality of life for patients and care providers, and equity for care providers.

- Ms. Bumpas confirmed Dr. Bonner’s point that CNAs are underpaid. She also said CNAs with more than one job often lost one as a result of COVID-19. Many CNAs are single parents who lost access to daycare as a result of the pandemic and are unable to bring their children to work. This has led to a major CNA shortage where Ms. Bumpas works. This means elders are not receiving adequate care and that CNAs still working are burning out.
- Mental health is linked to physical health. People with dementia are often frightened at the sight of a care provider in personal protective equipment, which can provoke problem behaviors. Loss of family contact can lead to depression symptoms. Patients sometimes feel forgotten. They are often confused by digital technology used to support remote contact. It is difficult to isolate patients with dementia when they have COVID-19. They tend to wander, sometimes borrowing from other residents. It is difficult, often impossible, to teach patients with dementia to wear masks properly. Social distancing is the most challenging COVID-19 precaution to teach patients with dementia. Patients want to hug and do not understand why they cannot. It is frustrating for care providers to be unable to offer physical comfort to patients who miss their families. Patients are suffering from depression and anxiety. Ms. Bumpas emphasized that patients with dementia are aware that things are not as they should be.

### **Comments & Questions**

- Ms. Brandt thanked Ms. Bumpas for her work.
- Mr. Robert Egge said the COVID-19 crisis requires a systemic solution. He suggested that point-of-care testing could inform decisions weighing the risks of isolation versus exposure. The United States needs an effective call for a national response regarding how to assess these risks. The Council should communicate the urgency of this problem. Dr. Bonner and Ms. Carrie Molke agreed that there is no federal strategy and that the country needs one.
- Ms. Molke said that when the pandemic began people were receptive to learning about and implementing precautions and responded with community-building efforts. This enthusiasm is declining. Some people are resisting information about precautions. People are becoming angry at each other about differences in understanding about how best to respond to the pandemic. A new approach is necessary to end the pandemic.
- Ms. Molke pointed out that there are disparities in disaster outcomes and said policies should address these disparities.
- Dr. Lamont thanked the presenters.

## **Dementia Nomenclature Initiative**

**Angela Taylor**

**Senior Director, Research and Advocacy, Lewy Body Dementia Association**

**Ron Peterson, MD, PhD**

**Co-Chair, Dementia Nomenclature Initiative Steering Committee, Mayo Clinic**

- Ms. Brandt introduced Ms. Angela Taylor, who works in the Lewy Body Dementia Association's Research Center of Excellence program, and also works on patient engagement and education initiatives. Ms. Taylor is a former member of the Advisory Council on Alzheimer's Research, Care, and Services.
- Understanding of dementia has progressed over the past few years, resulting in new terms including terms for recently discovered types of dementia, such as frontotemporal, vascular, and Lewy body dementias. Effective communication requires consistent terminology.
- "Alzheimer's disease" is used to refer to biological processes or clinical symptoms. It is defined as both. It is sometimes used as a synonym for "dementia."
- Psychiatrists have begun to refer to mild and major neurocognitive disorders rather than dementia in response to many people living with AIDS and others experiencing symptoms during the prime of life perceiving the term "dementia" to be associated with stigma.
- The Dementia Nomenclature Initiative began at the 2016 Alzheimer's Disease and Related Dementias (AD/ADRD) Summit, where nomenclature was a central topic of discussion. Participants suggested convening workgroups to identify the needs of researchers, health care providers, and the general public. The topic of how nomenclature affects care and services was addressed at the 2017 Care and Services Summit. Nomenclature was the theme of the 2019 AD/ADRD Summit. The Summit report described the summit as, "a cross-cutting stakeholder discussion on barriers, opportunities, and strategies to develop consistent, accurate, and meaningful language for cognitive impairment and dementia that is useable or at minimum interoperable among scientists, care providers, and the public."
- A steering committee representing diverse disciplines is charged with implementing the strategy developed at the 2019 summit. The committee assigns deliverables to workgroups, secures funding, and plans workshops. The steering committee issued a public call for nominations for workgroup members through the Advisory Council's listserv. Workgroups focus on the needs of each of the three key stakeholders identified at the 2016 summit. Members are federal agency personnel, academics, clinicians, advocates, people living with dementia, and family caregivers. The steering committee has contracted RAND Corporation to facilitate and coordinate steering committee and workgroup meetings and other



communications, support research, plan workshop meetings, support project report development, and disseminate results.

- The steering committee and workgroups have been formed. The committee has identified deliverables and developed a project timeline. The committee is working to solicit sponsors. The committee plans to hold a virtual workshop to discuss preliminary recommendations with the National Institutes of Health (NIH) in early 2021 and an in-person workshop to discuss workgroups' common and unique needs. Later in 2021, the committee will present updated draft recommendations for comment by the end of 2021. The committee will present input from this workshop at the 2022 AD/ADRD summit, then report final recommendations to the Advisory Council on Alzheimer's Research, Care, and Services.
- Initiative sponsors include AARP, Alzheimer's Association, Lewy Body Dementia Association, Association for Frontotemporal Degeneration, Bluefield Project, and Alzheimer's Drug Discovery Foundation. The steering committee would like to recruit more sponsors.
- Dr. Levey thanked Ms. Taylor and Dr. Peterson.

## **NIH Bypass Budget Update**

**Richard Hodes, MD**

**Director, National Institute on Aging (NIA)**

- Dr. Levey introduced Dr. Richard Hodes.
- Dr. Hodes said that NIH bypass budget mandates that, for each fiscal year (FY) through FY 2025, the Director of NIH will prepare and submit directly to the President a budget that indicates the funding needed above current levels in order to achieve the goals of the National Alzheimer's Plan, including identifying effective interventions by 2025. NIH estimates of funds needed are based on input regarding needs and priorities from key summits and from stakeholders in academia, industry, and non-governmental organizations. NIH defines milestones for progress and estimates costs for achieving them, then makes a final budget estimate.
- NIH categorized current needs using the eight Common Alzheimer's Disease Research Ontology (CADRO) categories. CADRO provides the framework for the International Alzheimer's Disease Research Portfolio and will support long-term progress tracking across national and global efforts.
- NIH estimates that approximately \$3.1 billion is needed for FY 2022. Taking into account availability of prior appropriations, approximately \$289 million is needed in addition to the current budget.

- NIH submits a narrative description of scientific advances and a rationale along with the bypass budget.
- COVID-19 has delayed research. NIH will calculate financial implications of delays. NIH has provided supplemental funding for rapid research to address COVID-19-related needs.

### **Comments & Questions**

- Mr. Egge said that in previous years NIH has found ways to create research opportunities regardless of Congress's specific appropriations. He asked if Dr. Hodes expected that this would be the case for FY 2021 and FY 2022. Dr. Hodes said NIH continually works to ensure that the workforce grows, scientific opportunities are available, and outstanding research is conducted.
- Dr. Levey asked if it is typical for NIH to have a year-end budget surplus. Dr. Hodes said it is not.
- Ms. Molke said the Council was likely to recommend expanding opportunities for researchers from minority backgrounds. She asked whether this is a priority for NIH. Dr. Hodes said this is a priority supported by several NIH initiatives.
- Ms. Molke asked whether and how Council recommendations would affect the NIH bypass budget. Dr. Hodes said recommendations being discussed at the current meeting would influence estimates made for FY 2023. NIH's current recommendations already have been submitted to Congress.

## **2020 Advisory Council on Alzheimer's Research, Care, and Services Recommendations**

### ***Subcommittee Cross-Cutting Recommendations***

- Ms. Brandt explained that the Council has three subcommittees: long-term services and support (LTSS), clinical care, and research. Each makes recommendations. This year an additional three recommendations were made that apply across subcommittee areas. These recommendations center on emergency preparedness, risk reduction, and health equity.
- **Cross-Cutting Recommendation 1: HHS and federal partners should improve and expand emergency preparedness, response, and recovery with specific consideration of the needs of individuals living with AD/ADRD and their caregivers.**
  - People living with dementia may be at especially high-risk during disasters and other emergencies, which can increase need for services, care, and research. Emergency plans are incomplete without addressing the risk factors, vulnerabilities, and special needs of people living with AD/ADRD and their caregivers. COVID-19 highlights the vulnerability of this population. Therefore, the Advisory Council recommends the following:
    - Advisory Council subcommittees should examine how emergency preparedness, response, and recovery must be tailored to support the

- domains of research, care and services, and public services for individuals living with AD/ADRD and their caregivers over the next year.
- Subcommittee recommendations should integrate broad input from experts in research, care, and services as well as individuals at risk for or with symptomatic AD/ADRD and their caregivers.
  - The subcommittees should develop recommendations for specific goals for implementation of emergency preparedness response and recovery plans that reflect unique needs in the areas of LTSS, clinical care, and research.
- Federal agencies should monitor and report on activities related to emergency preparedness for people with AD/ADRD and their caregivers, especially enhanced training for essential emergency personnel and first responders, and developing care plans when primary care providers are unavailable.
  - CMS should update its nursing facility, home health, and hospice regulations in light of lessons learned during the COVID-19 pandemic to ensure:
    - Meaningful standards for the necessary staff, training, and equipment to care for residents under emergency circumstances are developed and met.
    - Nursing facility residents have the right to move in with family during emergencies, without losing their ability to return to the facility, if desired.
    - Reasonable accommodations are provided for visitations by family, friends, caregivers, or paid staff to nursing home residents, while maintaining necessary safety and health precautions, including accommodation of virtual visits when necessary.
    - Additional nursing facility/residential care communities resident protections:
      - CMS should authorize states to provide temporary access to Medicaid home and community-based services for those Medicaid-eligible nursing facility residents who move in with family temporarily during emergencies.
      - States should be prepared to activate National Guard and public health personnel in emergency situations where needed to preserve lives and support operations for caring for people living with AD/ADRD in nursing facilities and residential care communities.
  - Consumer/Caregiver/Health Care Provider Education:
    - ACL should develop education materials for individuals living with AD/ADRD and their caregivers as well as training and guidance for the Aging Network and the Protection and Advocacy Network that support dementia-competent emergency preparedness planning for individuals living with AD/ADRD in community settings. These materials should take into consideration cultural context and language differences and should apply a person-centered approach.
    - The Centers for Disease Control and Prevention (CDC) should develop a National Center of Public Health Excellence on Dementia Caregiving

- to support states, political subdivisions of states, tribes, and tribal organizations to translate, disseminate, and implement evidence-informed caregiving information through public health infrastructure.
    - HRSA, in partnership with other federal agencies, should educate and train the health care workforce to prepare for, respond to, and recover from emergencies and disasters.
  - Flexible Research Infrastructure
    - Congress should appropriate additional funding to extend research projects that have been delayed or halted due to the impact of COVID-19.
    - NIH and other federal agencies that fund AD/ADRD research should support innovation in research protocols such as the conversion from paper and pencil to digital surveys and assessments, telephone and video-based interviews, and the use of flexible scheduling to accommodate increased caregiver burden.
  - Access to expert clinical services for diagnosis, symptom management, and care is essential to help individuals living with AD/ADRD and their caregivers to have the best possible quality of life and to make informed care decisions. High-quality health care is essential for maintaining cognitive resilience. Therefore, the Council recommends clinical care expansion:
    - CMS and private health insurance companies should provide reimbursement to ensure continuation and expansion of telehealth services in order to close the gap on access to care.
    - Federal and private payors should promote innovative care applications that include the utilization of multidisciplinary teams and unconventional clinic visits that incorporate opportunities for home visits for community-based individuals; innovative technology applications such as Internet-based consultations, assessments and reviews; and site visits to memory care and skilled nursing facilities when possible.
- **Cross-Cutting Recommendation 2: The Advisory Council and federal partners should develop a national goal to reduce burden of risk factors to prevent or delay onset of AD/ADRD.**
  - The National Alzheimer’s Plan includes a goal to prevent and effectively treat AD/ADRD by 2025. Research has demonstrated that AD/ADRD include a pre-symptomatic phase that lasts for decades, during which time numerous risk factors affect accumulation of brain pathologies and determine symptom progression trajectories. Treating modifiable risk factors can delay onset of dementia.
  - In recognition of advances in understanding risk factors, the long pre-clinical stages of disease, and the heterogeneity of pathologies that cause dementias, the Advisory Council recommends the following:
    - Establish a subcommittee to address risk factor reduction to mitigate the public health burden of AD/ADRD, and to determine specific goals, metrics, and timelines.

- HHS should review existing data on risk reduction and explore setting metrics for monitoring public health impact using a rigorous, open, transparent process.
  - The existing Advisory Council subcommittees should coordinate and seek broad input from experts and individuals at risk for or with asymptomatic AD/ADRD to inform subcommittee recommendations.
  - The subcommittees should identify opportunities for facilitating risk reduction across the spectrum of AD/ADRD research, clinical care, and LTSS.
  - CDC should develop a National Center of Public Health Excellence on Risk Reduction to support states, political subdivisions of states, tribes, and tribal organizations to translate, disseminate, and implement evidence-informed risk reduction interventions through public health infrastructure.
- **Cross-Cutting Recommendation 3: Advance health equity by addressing racial and ethnic disparities in AD/ADRD.**
  - Structural racism is a public health emergency that has developed over centuries. It should be addressed immediately. Equity should be integral to the entire National Alzheimer’s Plan. People of color experience disparities in incidence and prevalence of AD/ADRD in mortality, research participation, medication and other intervention efficacy, quality of care, and utilization of LTSS. Social determinants of health, cultural and linguistic differences, lack of diversity among researchers and service providers, and systemic racism contribute to these disparities. The disparities are well known but there has been insufficient investment in addressing underlying causes. Investments that have been made frequently focus on individual health behaviors or utilizations, ignoring approximately half of the factors that contribute to health outcomes. The recommendation aims to encourage the nation to address social determinants of dementia by encouraging the transformation of research, clinical care, and LTSS by shifting power over decision-making and policy development.
  - The Council recommends that HHS analyze all LTSS programs and services in terms of health equity to identify barriers to inclusiveness and access to care.
  - The Council recommends incentivizing use of the National Standards for Culturally and Linguistically Appropriate Services (CLAS). Many providers do not adhere to these standards; some are unaware of the CLAS standards.
  - CMS should expand LTSS that affect families, not just individuals, to eligible caregivers of people with dementia.
  - Federal agencies should develop and implement strategies to increase access to and quality of long-term, facility-based, and community-based care for people of color.
  - CMS should develop funding strategies to increase diversity of care providers, which has been demonstrated to contribute to culturally competent care.

- HHS should encourage training long-term care and health care professionals to practice cultural humility.
- The National Alzheimer's Project Act (NAPA) requires including ethnic and racial populations who are at higher risk for AD/ADRD in clinical research and service efforts for the purpose of reducing disparities. The Council recommends monitoring and reporting on adherence to this requirement, including reporting on initiatives, results, and plans to ensure progress. Evaluation should include significant input from people of color.
- Advisory Council meetings should include presentations about health equity and social determinants of health to ensure recommendations respond to needs of all people living with AD/ADRD and their caregivers.
- ACL and other federal agencies should provide technical assistance to support health equity issues related to dementia, including understanding the needs of underserved populations.
- Indian Health Services (IHS) should fund efforts to enhance care for tribal elders with AD/ADRD.
- NIH should fund community-based participatory research that involves people of color in project development and implementation, participant recruitment, and results interpretation and reporting.
- Congress should appropriate funds to support interventions demonstrated to be best practices for addressing disparities in dementia care quality and access.
- NIH should increase funding for research on how social determinants of health influence prevalence and incidence of dementia among people of color, as well as on strategies for responding to these social determinants.
- Congress should appropriate funding for research focusing on experiences of discrimination by long-term care and health care providers among people with AD/ADRD and their family caregivers. Research should assess the impact of discrimination and effective strategies for addressing this problem.
- It is critical to increase the pool of research investigators from diverse racial and ethnic backgrounds. Congress should appropriate funds for the NIA to expand Resource Centers for Minority Aging Research.
- ACL and CDC should identify and expand effective outreach strategies for underserved populations affected by AD/ADRD. HHS should ensure that grantees and contracted providers tailor outreach materials and strategies to underserved populations. HRSA's GWEP should continue to require grantees to educate and train the health care workforce on how to care for older adults within the context of social determinants of health, cultural competence, health literacy, and health equity. HHS should identify current health promotion work targeting racial and ethnic disparities to which dementia-specific strategies could be added.

### **Comments & Questions**

- Ms. Becky Kurtz said she is interested in the impact of Medicaid estate recovery on racial disparities and access to Medicaid LTSS. She would like this to be

addressed in HHS's analysis of policies that affect equity in AD/ADRD-related policies.

- Dr. Arlene Bierman said the Agency for Healthcare Research and Quality (AHRQ) could contribute to risk reduction and health equity through its efforts to train clinicians and transform health systems.
- Dr. Cynthia Carlsson said federal agencies could provide feedback regarding health equity efforts during the grant review process.
- Dr. Hodes offered assistance in navigating NIH priorities and efforts relevant to diversity and equity.

### ***LTSS Subcommittee Recommendations***

- Subcommittee Chair Dr. Debra Cherry presented a roster of subcommittee members and thanked them for their work to develop recommendations. Dr. Cherry said that people diagnosed with AD/ADRD are rarely referred to educational resources. This is especially the case for people with minority racial or ethnic or lower socioeconomic status backgrounds.
- **Recommendation 1: Decrease disparities and expand access to LTSS, including home and community-based services.** Public funding for LTSS is primarily through Medicaid. Other federal programs could contribute to addressing unmet need for LTSS. By 2025, Congress should increase funding for the ACL Alzheimer's Disease Program Initiatives, National Family Caregiver Support Program, and respite programs, as well as Aging and Disability Resource Centers to increase capacity to serve people with dementia. HHS should improve tailoring of existing programs to better serve diverse, underserved, and high-risk dementia populations.
  - ASPE should evaluate state models that expand access to LTSS and disseminate best practices.
  - It is important to protect the family caregivers' financial security, some of whom impoverish themselves as a result of caregiving efforts. Therefore, Congress should expand the Family Medical Leave Act to cover care of any family member. States should expand supports for paid family caregiving leave and should consider creating long-term care savings accounts. Congress and states should expand tax credits for caregivers. Congress should sustain protections against spousal impoverishment.
  - A federal entity should monitor Medicare innovations to determine whether they are offered and assess their impact on care quality or cost.
  - HHS, especially CMS, should provide guidance and informational bulletins to encourage states, payors, and providers to address LTSS needs of people living with AD/ADRD.
  - Federal agencies should deliver annual training for providers about the HIPAA regulations, which are often misinterpreted as prohibiting health information even when doing so is necessary and lawful.

- **Recommendation 2: Improve integration of clinical care with home and community-based services.**
  - Providers do not assess cognitive functioning or diagnose cognitive impairment as often as they should, resulting in people not getting necessary services or supports. By 2025, 30% of hospitals and primary care practices serving people living with AD/ADRD should have in place procedures to:
    - Identify cognitive impairment and integrate management of cognitive impairment into care plans.
    - Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well-coordinated care pathways and referral processes.
    - Identify and document a caregiver or authorized health care proxy to delineate and document individuals' goals of care and to better assure implementation of steps toward goal achievement.
    - Co-design person-centered and family-centered plans with individuals and caregivers or authorized health care proxies so that plans are concordant with the individuals' goals of care and can be supported in the community or other long-term care setting.
    - Involve the individual living with AD/ADRD and a caregiver or authorized health care proxy when undertaking discharge planning from a facility, so as to lessen risk of re-hospitalization or other adverse events.
    - Assess the LTSS needs of persons living with AD/ADRD and their caregivers, provide them with disease education, caregiver training and home and community-based services, and/or refer them to community-based services.
  - By 2025, CMS should have quality measures in place that will encourage health care systems and plans to implement Recommendation 2. The National Movement for Age-Friendly Healthcare Systems is supporting and measuring progress toward this goal and the subcommittee's other recommendations.
  
- **Recommendation 3: Provide high-quality person-centered and family-centered LTSS.** The National Quality Forum reports that the extent to which patients and their family caregivers are involved in care decisions and feel prepared to manage their conditions is critical to improving care quality and reducing costs. Most people want care that is culturally competent and understood by the consumer. Many care plans are not culturally competent or understandable to the consumer. In many cases plans are not even shared with the consumer.
  - There is a growing body of evidence-based dementia and caregiving interventions that produce meaningful outcomes. Federal agencies and other public and private funders should:
    - Fund research to study implementation of evidence-based dementia and caregiving interventions.
    - Disseminate promising evidence-supported interventions and person-centered and family-centered care planning models.



- Convene representatives from professional societies to develop and harmonize practice guidelines related to care planning, caregiver support, and home and community-based services.
  - People from racial or ethnic minority, underserved, or high-risk dementia populations and their caregivers often are underrepresented in evidence-supported dementia and caregiver programs. To expand applicability of these programs, NIH should establish a repository of assessment and outcome tools validated for use with culturally and linguistically disparate populations, including electronic health record-compatible tools in the public domain. NIH also should fund efforts to translate, culturally adapt, and validate evidence-supported caregiver and patient interventions for diverse, underserved, and high-risk dementia populations.
  - CMS and other federal payors should create care or payment models for use of effective evidence-supported interventions, and for person-centered and family-centered care planning.
  - Federal agencies, states, and others should build workforce capacity to provide culturally competent dementia-capable LTSS.
- **Recommendation 4: Address behavioral and psychological symptoms of AD/ADRD across care settings.** These common symptoms can increase morbidity, reduce quality of life, increase care costs, and increase burden. Providers often treat these symptoms with off-label anti-psychotic medications that can produce adverse side effects. Federal agencies and other organizations should build workforce capacity to deliver person-centered care and use promising and/or evidence-informed non-pharmacological interventions for behavioral and psychological symptoms of dementia before relying on anti-psychotic medication.
- **Recommendation 5: Advance brain health through development and enhancement of the public health and health care workforces.** There have been scientific advances in approaches to decreasing risk of cognitive decline. The subcommittee recommends that federal agencies, especially CDC and HRSA, and non-federal organizations educate the general public, people living with AD/ADRD and their caregivers, and the workforce about evidence-informed strategies for potentially reducing risk for cognitive impairment.

#### ***Clinical Care Subcommittee Recommendations***

- Subcommittee Chair Mr. Egge presented a list of subcommittee members and thanked them for their work.
- **Recommendation 1: Advance the themes and recommendations of the 2017 and 2020 National Research Summits on Care, Services, and Supports for Persons with Dementia and their Caregivers.**
- **Recommendation 2: Educate the public about early detection of AD/ADRD, person-centered care planning, and the importance of and ways to enter into research.**

- **Recommendation 3: Enhance the current and future workforce through education to better address the needs of persons living with AD/ADRD and their caregivers.**
- **Recommendation 4: Determine a process for reaching consensus on definitions of best practices for comprehensive care of AD/ADRD at all disease stages.** This should be accomplished by stakeholders outside of the Federal Government.
- **Recommendation 5: Encourage further development, evaluation, and use of health care models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.**

#### ***Research Subcommittee Recommendations***

- Subcommittee Chair Dr. Brad Hyman presented a list of subcommittee members and thanked them for their work.
- **Recommendation 1: The 2020 National Plan should encourage a sense of urgency about providing a robust, comprehensive, and collaborative and transformative scientific road map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025, as well as continuous progress and improvement thereafter.**
- **Recommendation 2: A top priority remains the urgent need for Congress to continue to increase annual federal research funding to be sufficient to meet these prevention and treatment goals across biomedical, clinical, LTSS, and public health domains.**
- **Recommendation 3: Emphasis should be given to the standardization of terminology across the spectrum of cognition in neurocognitive disorders by all agencies involved in the National Plan to reduce ambiguity and confusing or overlapping terms, to reduce stigma associated with AD/ADRD, to increase public awareness of AD/ADRD, and to increase public access to relevant resources and services.**
- **Recommendation 4: A major area of emphasis by all federal agencies involved in the National Plan should be the enhancement of recruitment efforts for research involving those with or at risk for AD/ADRD.** Individual differences in disease drivers should be taken into account.
- **Recommendation 5: Federal agencies should develop a strategy and infrastructure to increase ethical and open sharing of, access to, and utilization of research data and samples.** There should be a continued emphasis on ethics in collaboration with academia, the pharmaceutical industry,

and biotech and information system industries. This strategy should accelerate the pace of scientific discovery in AD/ADRD science by addressing a comprehensive range of issues including cross-sector data and biosample (fluid and autopsy) sharing practices and policies, data harmonization and interoperability, and the training of data scientists and biobanking experts in AD/ADRD research.

- The field should emphasize methods for early disease recognition and for studying disease progression that apply cutting edge technologies and establish biobanks of cells and biofluids from well phenotyped, diverse individuals to reflect the heterogeneity of AD/ADRD.
  - Brain autopsy tissue is needed to support AD/ADRD research programs, which should harmonize data and sample sharing and consent protocols to address gaps in tissue availability for research.
- **Recommendation 6: All federal and non-governmental agencies funding AD/ADRD research along with the Patient-Centered Outcomes Research Institute, academia, and industry, should establish the engagement of the AD/ADRD community as a standard practice in both participating in setting national research priorities for AD/ADRD and throughout all stages of clinical research and care, and LTSS research.**

### Comments & Questions

- Ms. Brandt, Dr. Levey, and Dr. Lamont thanked the subcommittees for their work.
- Ms. Venoreen Browne-Boatswain asked whether any of the research subcommittees' recommendations were to recruit people of color to conduct research. Dr. Hyman said the committee recommends recruiting and developing a diverse research workforce that includes people of color. The committee also recommends recruiting diverse research participants. Ms. Browne-Boatswain said the latter was clear, but not the former. Dr. Carlsson said the recommendation to recruit a diverse workforce is part of Cross-Cutting Recommendation 3, but that it could be valuable to emphasize this point in the research subcommittee recommendations as well. Ms. Molke agreed with Dr. Carlsson's point.
- Ms. Brandt said the Council will gather information related to the recommendations over the next year. The Council should invite researchers and clinicians of color to make presentations about effectively engaging a diverse workforce.
- Ms. Molke said the Council should solicit advice on how to overcome effects of historical mistreatment in research, which has undermined trust. Ms. Browne-Boatswain agreed that this is an issue, but said it is sometimes used as an excuse for lack of diversity among people who conduct or participate in research. She said researchers must address systemic racism as a critical step toward building trusting relationships with people of color. Ms. Brandt said this could be a presentation topic for an upcoming meeting. Dr. Matthew Janicki said NIH includes an institute that focuses on research on minorities. It may be useful for NIH to offer funding to encourage people of color to become dementia researchers. Dr. Hodes said NIH offers programs to recruit researchers from early through later stages of training to conduct AD/ADRD with the purpose of increasing workforce diversity. NIA works closely with the National Institute on Mental Health Disparities. Dr.

Hodes volunteered to help Council members understand relevant NIH programs and discuss what more NIH can do to address this issue.

### ***Votes on Recommendations***

- Dr. Levey reminded meeting participants that only non-federal Council members are authorized to vote on recommendations. He also asked Council members to vote to give recommendation authors the authority to update recommendations based on discussion during the meeting. He asked members to vote by raising their hands. All recommendations were approved unanimously, with authorization to authors to edit based on meeting discussion.

### **Public Comments**

- Michael Ellenbogen said that he is living a full life with dementia. He recalled asking the Council approximately 5-6 years ago to solicit input from people living with dementia, and being surprised when the Council agreed. He thanked the Council for doing so and commended them for accepting input through the Internet. He said he is resigning from his role and expressed hope that other people with dementia will accept this role. He stressed the importance of people living with dementia advocating for themselves.

Mr. Ellenbogen said that some people living with dementia in residential settings depend on family caregivers to feed them because it can require a lot of time. These visitors are not allowed during the COVID-19 pandemic, resulting in many people not getting adequate nourishment. He asked the Council to try to address this problem. He thanked several Council members for their support.

- Ann Lam introduced herself as the Medical Research Program Director for the Physicians Committee for Responsible Medicine (PCRM), a non-profit health advocacy group based in Washington, DC, with more than 12,000 physician members. Dr. Lam said disparities in AD/ADRD care and research have widened as a result of the COVID-19 pandemic. PCRM called on the Council to recommend immediate NIH action to integrate diversity and equity as priorities throughout the therapeutic development process, starting with human-based research in the therapeutic discovery phase, not only for population and precision medicine or cross-cutting themes of the National Plan. Addressing needs of a diverse population will require human-based approaches rather than animal models. PCRM has six calls to action: (1) report the number of animal model grants and shift funding to toward human-based methods of research focused on diversity; (2) create funding for dedicated human-based neuroscience research, basic science, and pre-clinical AD/ADRD research that acknowledges human diversity; (3) change the research review process to include human diversity as a numerically scored criterion; (4) coordinate new partnerships that increase availability of diverse human bio-specimen repositories and set a timeline for ensuring groups affected by disparities are included; (5) create human-based training programs for

established and emerging researchers on integrating a focus on diversity into research; training programs should include partnerships with communities experiencing health disparities; and (6) create a Diversity and Human-based Research taskforce to formulate and solicit stakeholder input and begin to enact a national action plan by the next AD/ADRD summit. Dr. Lam said that PCRM offers to support the Council in setting research priorities.

- Lezlie Poole introduced herself as a Program Manager and Training and Implementation Specialist at the Rosalynn Carter Institute for Caregiving, which serves and advocates for caregivers. COVID-19 has thrust some people into the role of caregiver and has increased social isolation as people quarantine at home. Many caregivers do not identify as such. Caregiving for people living with AD/ADRD is rewarding, challenging, and lonely. The Rosalynn Carter Institute for Caregiving works to reach and support caregivers, including those with limited access to the Internet, health care, and other critical resources. The Institute offers coaching to empower caregivers, increase their resilience, and facilitate self-care. Healthy caregivers provide better care. Supporting caregivers benefits communities. Supporting unpaid caregivers should be a national health priority.
- Nora Super, Senior Director of the Milken Institute Center for the Future of Aging, announced creation of the Alliance to Improve Dementia Care, for which she will serve as Executive Director. In November 2019, the Milken Institute released a report that includes 25 recommendations for reducing costs and risks of dementia. The recommendations align with the Advisory Council's goals, especially the cross-cutting recommendations presented at the meeting today. The Alliance was formed to support implementation of the recommendations in its report. The Alliance includes members from health systems, industry, research, advocacy, philanthropy, and government with the purpose of collaborating to advance recommendations to improve dementia care. The Alliance will contribute to building workforce capacity and implementation of comprehensive dementia care models that identify people at risk for or living with dementia, tailor services to meet their needs and those of their caregivers, and ensure they receive appropriate care when needed. The Alliance hopes to collaborate with the Advisory Council. Founding members of the Alliance include AARP, the Alzheimer's Association, Bank of America, Biogen, and the John A. Hartford Foundation. Alliance goals are to optimize the workforce, build system capacity, and integrate services and support. The Alliance is committed to developing and promoting policies that reduce disparities in dementia prevalence and access to services for populations most at risk for dementia, including women and communities of color. The Alliance is accepting new members and supporters.
- Kristen Lees Haggerty, Project Director at Education Development Center, presented comments prepared with Dr. Gary Epstein-Lubow of Brown University and Dr. David Reuben of University of California, Los Angeles. This group made public comments at the Advisory Council meeting indicating that the Council and ASPE must address payment reform for dementia care and treatment. At least six

working models of dementia care in the United States improve care quality and result in improved clinical outcomes for people living with dementia and their caregivers. Some of these models lower costs of care. Care that applies these models is not widely available. A November 2019 1-day seminar in Washington, DC, convened more than 50 clinicians, researchers, payors, advocates, and other experts in dementia care and payment focused on models for comprehensive dementia care. The convention was supported by the John A. Hartford Foundation, Center to Advance Palliative Care, and Education Development Center. Participants reviewed short-term solutions for payment reform and discussed how to accelerate implementation. The *Journal of the American Geriatric Society* will publish a manuscript based on seminar discussions that yielded recommendations for improving access to comprehensive dementia care through payment reform, research, education, and advancement of a population health approach to health care coverage based on risk and need. HHS should consider these recommendations, which will likely be published in August 2020. HHS should advance payment reform by continuing to examine models of dementia care and how the COVID-19 pandemic has affected them, convening at least one workgroup to address comprehensive dementia care, and monitoring how the inclusion of dementia as a risk adjustment modifier in CMS hierarchical condition category coding affects definitions of populations of people living with dementia, quality and types of care received, and health outcomes. These recommendations align with the National Plan to Address Alzheimer's Disease Strategy 1.E and all strategies for achieving Goal 2.

- Drs. Lamont and Levey thanked public commenters.

## **Concluding Remarks**

Dr. Levey said the Council's next meeting will be held on Monday, October 19. (This meeting date could be changed.) He adjourned the meeting at 4:47 p.m.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at <http://aspe.hhs.gov/daltcp/napa/>.