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

Virtual Meeting

May 3, 2021

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, Bradley Hyman, Matthew Janicki, Becky Kurtz, Carrie Molke, Maria de los Angeles Ordonez

- *Federal Members Present*: Arlene Bierman (Agency for Healthcare Research and Quality, AHRQ), Ellen Blackwell (Centers for Medicare & Medicaid Services, CMS), Susan Cooley (Department of Veterans Affairs, VA), Bruce Finke (Indian Health Services, IHS), Richard Hodes (National Institutes of Health, NIH), Gavin Kennedy (Office of the Assistant Secretary for Planning and Evaluation, ASPE), Shari Ling (CMS), Erin Long (Administration on Aging, AoA), Lisa McGuire (Centers for Disease Control and Prevention, CDC), Deborah Olster (National Science Foundation, NSF), Cheryl Schmitz (Veterans Health Administration, VHA), Joan Weiss (Health Resources and Services Administration, HRSA)

- *Advisory Council Designated Federal Officer*: Helen Lamont (ASPE)

General Proceedings

Co-Chair Katie Brandt called the meeting to order.

Welcome

Ms. Brandt said the meeting marked the 10th anniversary of the charter, signed May 23, 2011, that established the Council. She thanked the Council and Dr. Lamont for their work over the past year, noting that it continued despite the challenges resulting from the COVID-19 pandemic.

Updates

Dr. Lamont announced that the current Administration's American Jobs Plan proposes allocating $400 billion for long-term supports and services infrastructure. The Administration's American Families Plan proposes direct support for paid family medical leave. ASPE will update the Council about the progress of these proposed plans.

Dr. Levey thanked the NIH for its recent Alzheimer's Research Summit. He said the Food and Drug Administration will decide whether to approve aducanumab for treating Alzheimer's disease in June 2021.

Clinical Care Panels

Introduction of Panels

Mr. Egge noted that COVID-19 was the central focus of dementia care during 2020. He emphasized the importance of equitable access to emerging new screens and treatments. People who experience Alzheimer's disease or related dementias (ADRD) before being eligible for Medicare may lose their jobs and insurance, and be unable to access promising new approaches to care. Caregivers supporting people with ADRD also may have to leave their jobs. For the past decade patients and caregivers have found care navigation confusing and frustrating. They report lacking adequate support services and not knowing what services are available. Addressing these challenges must be a priority.

Panel I: Accelerating Medicare Eligibility for those with Younger Onset Dementia

Leslie Fried, Senior Director, Center for Benefits Access, National Council on Aging
Laura Jones, Former caregiver for person with Alzheimer's disease, advocate

- The mandatory 24-month waiting period for Medicare eligibility for people younger than 65 years was intended to contain program costs and to avoid employer-funded insurance companies' shifting costs to Medicare. The waiting period was waived for people with amyotrophic lateral sclerosis (ALS) effective July 1, 2000. Since, several additional legislative and administration actions have been passed with the intention of increasing access to benefits for people in need.

  During the mandatory waiting period, insurance options are: Affordable Care Act Marketplace plans, Medicaid and Medicaid expansion options, or employer-based coverage through a family member with coverage or continued coverage authorized through the Consolidated Omnibus Budget Reconciliation Act (COBRA). However, COBRA is often prohibitively expensive. Medicaid is only an option for patients with household incomes no higher than 138% of the federal poverty threshold. Research is needed on what Medicare applicants who are younger than 65 years experience during the 24-month waiting period. Research should focus on whether applicants are able to access health care, what costs they incur for care, frequency of medical bankruptcy, as well as how waiving the waiting period would affect the Medicare trust fund. Research should explore approaches to improving Medicare services and coverage.

- Ms. Jones's late husband was diagnosed with Alzheimer's disease at age 50. She was 45 years old and they had a 3-year-old daughter. The illness prevented Mr. Jones from continuing to do his job. The experience was emotionally and physically exhausting for Ms. Jones. Mr. and Ms. Jones became advocates and testified at a hearing to pass the Compassionate Care Act. She had to work in order to retain health insurance coverage and pay living expenses. She sometimes ignored her daughter's and her own medical needs. Parenting is very challenging while caring for a spouse with dementia. It is difficult to learn that a spouse will no longer work, will not recover from illness, and will not have health insurance coverage for 2 years. People younger than 65 are not retired and typically do not have independent adult children. Their spouses have limited time to take the patient, themselves, or other family members for medical appointments. When Medicare coverage becomes available, it does not cover nursing home care. Ms. Jones's bills for residential nursing care totaled $760,000. About 4 years after Mr. Jones's initial diagnosis, Ms. Jones experienced two stress-related heart attacks, which necessitated residential care for Mr. Jones. He remained in residential care until his death 7 years later. Immediate Medicare coverage would facilitate care planning and access to medical care. It would increase opportunities for patients to live with some independence and reduce caregiver stress. Earlier care coverage would reduce need for acute care and the associated costs.

Discussion:

- Dr. Cherry asked what steps the Council could take to eliminate the Medicare waiting period for patients with dementia, and what evidence is necessary to support a recommendation to do so. Ms. Fried said information about how the waiting period affects patients and their families likely would impact Congress' decisions regarding policy. Evidence about potential impact on the Medicare trust fund of waiving the waiting period will be important for considerations regarding policy change. Potential impact could be at least partially inferred from the results of waiving the waiting period for people with ALS. Legislation, which the Council could recommend, is necessary to waive the Medicare waiting period for people with dementia.

  The current national plan to address Alzheimer's disease specifies little regarding meeting the needs of people diagnosed while young, other than noting the need for research on this topic. In 2020 provisions for caregivers in the Older Americans Act expanded to apply to caregivers of people of all ages.

Panel II: Improving Timely Diagnosis of Dementia in Diverse Communities

Kristen Felten, Dementia Specialist, Wisconsin Department of Health Services Office on Aging
Nicole Fowler, PhD, MHSA, Associate Professor, Indiana University School of Medicine
Kate Possin, PhD, Professor in Neurology, University of California, San Francisco

- Early detection is a National Alzheimer's Project Act (NAPA) goal. Primary care providers, people with symptoms of cognitive impairment, their friends and family, community and social workers, interprofessional care team members, and dementia care specialists can contribute to improving timely diagnosis and treatment of dementia. Community-based organizations can conduct screenings and connect patients with treatment. It is important for care models to offer "no wrong door" approaches to connecting patients with screening and care.

Wisconsin's county-based Aging and Disability Resource Centers (ADRC) and Tribes' memory screening program and Wisconsin Alzheimer's Institute's Diagnostic Clinics Network collaborate to offer Wisconsin's Early Detection Engine, which is designed to address barriers to timely diagnosis. Individual-level barriers include stigma, fear of loss of control or status, inability of the person with disease or others to recognize symptoms, lack of awareness of available resources, and worry about dependent family members. Systemic barriers include geographic, physical, financial, cultural, and linguistic barriers to accessing care, lack of providers with necessary skills in diagnosis and referrals to community resources, inadequate reimbursement of time providers spend making a diagnosis, and lack of effective treatments. ADRC staff are trained to perform screens and offer to share results along with a cover letter to primary care providers. Staff encourage clients to discuss screen results and symptoms with their primary care providers. Primary care providers review screens and diagnose, then refer patients to appropriate community resources. The Diagnostic Clinics Network receives referrals for diagnostic evaluation and refers patients diagnosed with dementia to ADRCs. In a pilot test, 96% of patients who were offered a screen accepted. Offering universal screening reduces stigma. A large majority of patients with positive screens (80%) accepted the offer to share results with their primary care providers. Most (62%) of patients with positive screens accepted information and referrals to community resources. Primary care providers conducted diagnostic evaluations for 39.2% of these patients. All but one of those with a dementia diagnosis initiated treatment. Approximately one-third of patients with positive dementia screens lived at home alone. Early detection empowers decision making, facilitates understanding of dementia, and offers an opportunity to discuss available support resources for patients and their families. This approach can be tailored for specific communities. It increases access to services, and increases primary care providers' awareness of community resources as well as of their patients' concerns about cognitive symptoms. The program has a grant for enhancement by certifying dementia care specialists, updating the screening manual, and evaluating the program's statewide impact.

- Primary care providers do not recognize dementia in between 40% and 50% of patients who have it. This causes higher rates of hospitalization; longer inpatient stays; lower quality management of comorbid conditions; increased unsafe activities; reduced likelihood of receiving dementia care or support for caregivers; and increased stress, burden, and isolation for families. While between 80% and 90% of patients consent to screening for dementia symptoms, only 33-53% of those who screen positive agree to diagnostic evaluation. Positive screens are more common among adults aged 80 years or more, those with less than a high school education, those with self-reported forgetfulness, urban residents, and those who have been screened in-person rather than over the telephone. The aging population, emerging pharmacological treatments, evidence of suffering when dementia is not recognized, and benefits for planning how to respond to dementia are reasons for increasing support for early detection. The U.S. Preventive Services Task Force has said evidence for dementia screening is insufficient to recommend for routine care. Researchers should expand the evidence base. Reasons for early detection include being able to identify reversible causes, reducing cognitive burden, health promotion and early intervention initiation, evaluating environmental safety, validating concerns, and supporting care planning. However, screening can induce anxiety and depression, and has the potential to over-burden the health care system. It may also contribute to stigma. Patients do not always want to know whether they have dementia. Without a cure, some critics question the value of early detection.

- Since the Affordable Care Act passage, Medicare annual wellness visits include cognitive impairment screens. Analysis of a random national sample of 2011-2013 Medicare beneficiaries found early detection procedures were not more common among patients receiving wellness visits compared with patients not receiving these visits. The Indiana University Cognitive Health Outcomes Investigation of Comparative Effectiveness of dementia screening (CHOICE) study is a randomized controlled trial of more than 3,000 patients 65 years or older without a dementia diagnosis at enrollment. Outcomes were health-related quality of life, depression and anxiety, health care utilization, and advance care planning. Analysis found neither harms nor benefits to patients of early screening. The research team now is assessing impact of early screening on family members. Interest in follow-up diagnostic screening is associated with perceiving the benefits of planning, and having a relative with Alzheimer’s disease. Lack of interest is associated with living alone, lack of interest in screening for other conditions, passing some parts of the screen, and concern about stigma. Overall, results suggest that early detection contributes to optimal care. It is important to reduce stigma in order to encourage early detection and support optimal care. It also important to increase awareness of the benefits of early screening and to increase access to early screening services.

- Analysis of 2015 California Medicare beneficiary claims data for patients with mild cognitive impairment (MCI) or dementia found that only 23% of non-Hispanic White beneficiaries had been diagnosed at the MCI stage. This was the case for 18% of Hispanic beneficiaries, 16% of Black beneficiaries, and 12% of Asian beneficiaries. Results showed that only 10% of non-Hispanic White beneficiaries received comprehensive evaluations, while 5% of Hispanic beneficiaries, 2% of Black beneficiaries, and 2% of Asian beneficiaries received comprehensive evaluations.

- The Consortium for Detecting Cognitive Impairment, Including Dementia was formed to identify gaps in diagnostic care. The Consortium aims to respond to an ADRD Summit high-priority recommendation to detect whether cognitive impairment is objectively present when a patient, caregiver, or clinician reports behavioral, cognitive, or functional changes. Consortium researchers currently are conducting studies to assess three screening tests in primary care settings.

Studies are assessing the impact of testing on frequency of diagnoses and whether providers order appropriate follow-up tests, prescriptions, and referrals. Primary care providers are essential partners in any effort to improve detection. It is important for diagnostic results to be very easy to access from an electronic health record (EHR). Diagnosis must link to better care. Early detection efforts must address needs of diverse patients and care partners and be flexible enough to address needs of patients who do not have care partners. The Consortium is conducting projects that seek to link diagnosis to better care. In one approach, a dementia care specialist nurse contacts patients and care partners by telephone after their diagnosis to assess needs, provides basic education and referrals, and documents findings in the EHR for the primary care provider. Another approach is telephone-based dementia care navigation, which has improved caregiver well-being and patient quality of life, and reduced hospital visits.

Panel III: Advancing Value-based Reimbursement for Dementia Care

Nora Super, Executive Director, Alliance to Improve Dementia Care, The Milken Institute
Soo Borson, MD, Principal, Dementia Care Research and Consulting
David Reuben, MD, Director, Multicampus Program in Geriatrics Medicine and Gerontology, University of California, Los Angeles

- The Milken Institute Alliance to Improve Dementia Care was formed in July 2020 and comprises 70 member organizations representing advocates, research, health systems, industry, philanthropy, government, community-based organizations, and people living with dementia and their caregivers. Its focus areas are health and economic disparities, workforce development and capacity building, and payment for collaborative dementia care models. It aims to develop partnerships with leaders across multiple sectors and collaborate with federal agencies and policy makers to overcome care barriers and develop public and private sector scalable solutions for dementia care, as well as policies to reduce prevalence and disparities and increase equitable access to care. Current efforts focus on developing an alternative payment model for dementia care, since Medicare fee-for-service does not cover all elements of comprehensive care. Care models should increase opportunities for payment to community-based organizations. They should tailor services to patients' needs.

- There is a current shortage of geriatric medicine and psychiatry providers, which will persist as dementia cases increase over the next decade. Primary care providers make 85% of first diagnoses of dementia and provide 80% of ongoing care. Primary care providers often under-diagnose dementia, often diagnose late, and often offer non-specific diagnoses. There are inequities in detection. Patients diagnosed by their primary care provider often under-utilize CMS benefits. Memory disorder specialists make 15% of first diagnoses and provide less than 10% of ongoing care. They are more likely to conduct standardized assessments and to detect disease in earlier stages. Their care model tends to be disease-focused and less comprehensive than primary care approaches. Inequities in detection are larger for memory care specialists. They are more likely than primary care providers to bill for cognitive assessment and care planning. Primary care is more likely than specialist care to focus on dementia as a chronic condition with psychosocial and functional impact, and to prioritize managing uncertainty and maintaining a relationship between clinician and the patient and family over the course of the disease. Medicare benefits can improve dementia care. However, they are underutilized. Only 32% of 2018 Medicare beneficiaries had wellness visits. In 2019, less than 1% used cognitive assessment and care planning services and 6.7% used chronic care management services. Primary care for dementia is associated with reduced hospitalizations and readmissions within 30 days, and emergency department utilization. Primary care providers are uniquely positioned and motivated to provide dementia care. However, they need better financial systems and resources to provide quality dementia care. Improving primary care should include increasing team-based care and face-to-face time with patients, and decreasing burden of documentation. Primary care assessment and management practices should be simplified. There should be incentives for implementing CMS dementia care benefits. Primary care providers need education that demystifies dementia and shows that treatment is within the scope of primary care. Primary care for dementia focuses on cognitive health, emotional/behavioral health, physical health and function, care partner capacity and needs, and health-related social needs. Managing these domains can reduce crises.

- Research is necessary to test prevailing assumptions about dementia care needs. Alzheimer’s Disease Research Centers and Geriatric Workforce Enhancement Programs should collaborate to test innovative care models.

- Approximately 80% of people with dementia have mild symptoms that do not require hospitalization and only minimal emergency department care. Care models must be appropriate for patients’ levels of need. Research shows that models that address caregivers’ needs, either alone or with patients’ needs, are effective. Providers are more likely to implement these practices if there is a clear relative advantage, the change is compatible with normal workflow and workplace culture, they are easy to understand, they can be tested on a smaller scale, and improvement is observable. Barriers to implementation include inertia and lack of insight, costs, need for training, and challenges in developing partnerships with community-based organizations. Policies should support adequate payment for dementia care, training, integration of community-based services, and care designed to meet needs of underserved and remote patients and their caregivers.

Discussion:

- Dr. Levey asked what the Council should recommend to accelerate availability of comprehensive dementia care models. Panelists said community-based partners should be considered essential. Dr. Finke asked how best to assess the degree to which care is patient-centered. Dr. Borson said current measures are inadequate and the field should develop valid measures. Researchers have attempted to develop measures of dementia care quality for decades. The next step is to identify which stakeholders should be involved with this process and how to engage them. Dr. Ling suggested considering core outcomes other than care utilization, and considering how to consider costs and equity when assessing care quality.

Federal Updates

- ***NIA***. NIA's ADRD research budget has increased steadily since 2008. Between 2015 and 2018 one-third of awardees were new or early-stage investigators; one-fourth were new to the field. Research spans from basic science to late-stage clinical trials. NIA leads the Accelerating Medicines Partnership for Alzheimer's Disease (AMP-AD), which uses big data approaches to identify new targets for treatment. AMP-AD is working to expand multi-omic profiles in brain, blood, and cerebrospinal fluid samples from diverse cohorts; generate longitudinal immunologic profiling data across diverse cohorts; and expand single nucleus/single cell molecular profiling efforts to multiple brain regions and to diverse cohorts. Researchers are applying technology to support remote training, intervention, and monitoring in response to COVID-19. Researchers will continue to use these options after the pandemic in order to reduce participant burden, and to make participation more accessible for diverse populations. The IMBedded Pragmatic ADRD Clinical Trials (IMPACT) Collaboratory will develop infrastructure for pragmatic trials.

- ***ACL***. ACL announced the Alzheimer's Disease Program Initiative, which will fund grants to states and communities to develop "no wrong door" systems to serve high priority populations, including people with intellectual and developmental disabilities and people who live alone. Upcoming funding opportunities include a second round of the states and communities grants and "Dementia Capability in Indian Country." ACL's National Alzheimer's and Dementia Research Center is hosting a series of webinars. The agency has updated its Brain Health web page and continues to support Brain Health education programs in communities across the United States. ACL's Minority Organizations Technical Assistance and Research Program funds five national organizations, each of which serves people who identify as African American, Hispanic, Asian and Pacific Islander, Native American, or LGBT.

- ***CMS***. CMS updated its web page for beneficiaries to include information about available Cognitive Assessment and Care Planning services. The page also links to resources. CMS will add discussion of these benefits to its "Medicare and You" handbook in 2022.

- ***IHS***. Congress appropriated $5 million to IHS in fiscal year 2021 to address Alzheimer's disease. IHS is conferring with Tribal leadership regarding funding allocation, which will align with the National Plan to Address Alzheimer's Disease. IHS expects to have a plan of action by July 2021.

- ***ASPE***. ASPE has released two new reports on people with dementia: "The Impact of COVID-19 on People with Dementia," and "The Risks and Costs of Severe Cognitive Impairment at Older Ages: Literature Review and Projection Analysis." Both are available on the agency website. ASPE published an issue brief on risks and financing associated with long-term supports and services and other briefs about economic hardship issues for older adults.

- ***CDC***. CDC disseminates information about COVID-19 for older adults, their caregivers, and administrators and staff of adult day care centers. The "How Right Now" campaign aims to help older adults address mental health issues related to stress, isolation, and concerns related to the pandemic. CDC collaborated with NORC to assess needs of older adults and their caregivers during public health emergencies and will disseminate information about resources to address these needs. CDC collaborated with the National Association of Chronic Disease Directors to develop rack cards with information about how to reduce risk for cognitive decline. CDC worked with partners to develop the Healthy Brain Initiative Road Map series, which provides information about reducing risk for cognitive decline, and editable templates to support care planning either independently or with health care providers. CDC collaborated with the Alzheimer's Association to develop materials about how to manage hypertension to protect brain and heart health. The agency published a guide for how community health workers can support healthy aging and address dementia.

  CDC's National Center for Chronic Disease Prevention and Health Promotion continues to support a committee to develop a national goal to reduce burden of risk factors in order to prevent or delay onset of ADRD. Committee members have formed workgroups to conduct literature reviews about risk factors, risk reduction, and interventions. The literature review will discuss evidence regarding risk, evidence-based interventions for individuals and the public, public health impact, and potential systems and policy approaches to addressing each risk factor. The group will present recommendations to this Council in July and final recommendations to HHS in August 2021.

Public Comments

- Maria Beers, producer of *Remember Me*, a weekly podcast focusing on frontotemporal degeneration, and associates have interviewed several caregivers about the process of their loved one's diagnosis. All caregivers reported that doctors told them they could do nothing to address the condition. Lack of a cure does not mean no care is valuable. Care providers can listen to patients and caregivers, and provide insight for planning. Ms. Beers urged the Council to support development of tools and education to teach health care providers how to support patients and caregivers with frontotemporal degeneration.

- Judith Illes, Director of Strategic Alliances for the Gerontological Society of America, recommended that the Council and stakeholders prioritize earlier detection and improved recognition and care of neuropsychiatric symptoms. The Society developed a toolkit for comprehensive dementia care and a report about dementia-related psychosis, which is available on the organization’s website.

- Kristen Lees Haggerty, Project Director at Education Development Center, presented comments prepared with Gary Epstein-Lebow of Brown University and David Reuben of University of California, Los Angeles. Existing payment mechanisms often do not support implementation of evidence-based care. Alternative payment models would increase access to effective and comprehensive dementia care. The commenters encourage ASPE and the Council to advance work toward implementing alternative payment models. Commenters expressed support for the Comprehensive Care for Alzheimer’s Act, which was introduced with bipartisan support on April 15, 2021. The Act would require the Center for Medicare and Medicaid Innovation to test an improved payment structure for dementia management, including capitated payment and performance-based incentives to support care planning and coordination, chronic condition management, interdisciplinary care, and caregiver education and support. The Act aims to expand access to comprehensive dementia care to as many Medicare beneficiaries as possible, especially vulnerable, rural, and underserved individuals and communities. The commenters continue to recommend that the Council and ASPE: (1) continue work described in ASPE’s report, “Examining Models for Dementia Care;” (2) convene at least one workgroup to address payment reform for comprehensive dementia care; and (3) monitor and report how inclusion of dementia as a risk adjustment modifier in the CMS hierarchical condition category coding affects the definitions of populations of people living with dementia, the quality and types of care they receive, and their health outcomes. The recommendations align with the National Plan to Address Alzheimer’s Strategy 1E and all Goal 2 strategies, as well as with the Council’s 2020 recommendations.

- Matt Sharp of the Association for Frontotemporal Degeneration (FTD) noted that FTD is the most common cause of dementia among people younger than 60 years, yet few people are aware of the condition. People with the condition are harmed by the mandatory 24-month waiting period for Medicare benefits. As a result of behavioral symptoms and lack of diagnostic resources, many people with FTD lose their jobs before they are diagnosed. Loss of employer-provided insurance is a major barrier to getting health care. Mr. Sharp recommended waiving the waiting period for anyone with a permanently disabling condition.

Concluding Remarks

Dr. Lamont adjourned the meeting at 4:37 p.m. Eastern time.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at https://aspe.hhs.gov/napa-advisory-council-meetings.