

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

Virtual Meeting

October 25, 2021

## Advisory Council Members in Attendance

- *Non-Federal Members Present:* Cynthia Carlsson (Chair), Randall Bateman, Venoreen Browne-Boatswain, Matthew Janicki, Ken Kim, Helen Bundy Medsger, Adrienne Mims, Joe Montminy, María Ortega, Joanne Pike, Rhonda Williams, Carrie Molke
- *Federal Members Present:* Kim Wittenberg (substituting for Arlene Bierman) (Agency for Healthcare Research and Quality, AHRQ), Bruce Finke (Indian Health Services, IHS), Sarah Fontaine (Department of Defense, DoD), Richard Hodes (National Institutes of Health, NIH), Shari Ling (Centers for Medicare & Medicaid Services, 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), Tisamarie Sherry (Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, HHS/ASPE), Joan Weiss (Health Resources and Services Administration, HRSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)

## General Proceedings

Chair Cynthia Carlsson called the meeting to order at 1 p.m. Eastern Daylight Time.

### ***Welcome***

Dr. Carlsson welcomed meeting participants, noting that the central topic would be long-term care and support services. She invited panel members to introduce themselves.

### ***Introduction to Panels***

Dr. Molke observed that the need to increase availability of long-term services and support (LTSS) has been a priority for decades, but that stakeholders have lacked a national strategy for addressing this now urgent need. The aim of panel presentations was to provide insight regarding the experience of providing direct services, provide

data about workforce capacity, and present potential strategies for meeting needs for LTSS.

## **Panel Presentations on Long-Term Services and Support**

### ***“Voices from the Field: Caregivers”***

**Sandra Norder**, NHA, HSE, FACHE, JD, President, Chief Executive Officer, Saint Paul Elder Services, Inc.

- Ms. Norder explained that nursing home direct care staff serve as “expert noticers” who provide clinicians with information relevant to patients’ health. Nursing home caregivers are experts in infection control, preventing its spread in situations and settings that maximize risk due to unavoidable close contact. Caregivers offer companionship, which improves long-term health outcomes. Trained caregivers offer understanding of dementia and effective, respectful approaches for managing symptoms and optimizing patients’ quality of life.
- Challenges to maintaining an adequate nursing home caregiver workforce include recruitment and retention, stress and burnout, and admissions holds and downsizing.
- Potential approaches to making professional caregiving attractive are to: end the COVID-19 public health emergency, recruit people with potential to be excellent professional caregivers, use “smart” technology to serve nursing home patients, and frame caregiving as not just work but as living with patients part time.

### ***“Health Care and Health Support Workforce Outlook”***

**Michelle Washko**, PhD, Director, National Center for Health Workforce Analysis, HRSA

- Across industries, current demand for labor in the United States exceeds supply due to technological advances, changing demographics (e.g., aging population, immigration restrictions), policies, and shifts in behavior among workers. In 2030 all “baby boomers” will be 65 years or older, the segment of the population that uses the most health care services.
- The geographic distribution of the health workforce should allow everyone access to care. Patients should be able to access services when and where they want. The health workforce should be trained and able to provide high-quality care. Health workforce supply should be in equilibrium with demand. Data are essential for assessing health workforce supply and quality.
- The mission of the National Center for Health Workforce Analysis is to “support informed public/private sector decision making on a broad range of issues around the United States health care and health support workforces by expanding the evidence base.” The Center has a mandate to generate, fund,

improve, and disseminate data, analyses, and research findings on the United States health care and health support workforce.

- Current issues include health workforce maldistribution, lack of health equity and health workforce diversity, need for a larger public health workforce, optimizing use of telehealth, obtaining data on the population's needs for health care, health care worker resiliency and burnout, the opioid epidemic, and the COVID-19 epidemic.
- Demand for direct care workers is rising, mostly as a result of the aging population. Data on labor supply are limited but suggest that the current workforce is not adequate to meet demand. The greatest need is for home health and personal care aides. These positions tend to earn low pay and have high turnover rates.
- More data are needed on demand for, quality of, and supply of the health workforce, including data for specific occupations.

### ***“Building Quality Dementia Care through Quality Direct Care Jobs”***

***Stephen McCall, MPA, Data and Policy Analyst, PHI***

- Direct care job quality links directly to dementia care quality. Strong relationships between direct care providers and consumers are an essential component of care quality. These relationships require providers to receive a living wage, high-quality training, and respect for their contributions.
- Nearly 90% of direct care workers are women; 60% are people of color; 25% are immigrants. Historically, direct care labor has been undervalued. For example, direct care labor has been excluded from minimum wage and overtime laws.
- Between 2010 and 2020, the direct care workforce increased by 1.5 million jobs, making it the largest job category in the United States. Most growth occurred in home care. Growth was caused mostly by the increasing population of older adults, consumer preferences for home care, and changes in policies and programs in response to recognition that home care can be more cost effective than nursing home care.
- Across settings, people living with dementia are a large proportion of direct care consumers.
- Direct care workers' wages have stagnated for the past decade at just more than \$13 per hour. One-third of direct care workers work part time. Median annual earnings are \$20,200; 44% of direct care workers live in or near poverty. A total of 45% of direct care workers receive some form of public assistance. Long-term care facilities depend on public funds to invest in the direct care workforce.

- Between 2019 and 2029, the number of direct care jobs is expected to increase by more than 1.2 million, which is higher than the increase projected for any other job category. As people retire or move to other jobs, more than 7.4 million direct care jobs are expected to open between 2019 and 2029. The high demand for direct care workers combined with poor job quality could jeopardize dementia care quality.
- A strategy for addressing need for direct care should include quality training, fair wages, quality supervision and support, respect and recognition, and real opportunity.
- Quality training ensures that all workers acquire the skills, knowledge, and confidence to succeed in their roles. Federal law currently only mandates dementia care training for nursing assistants working in nursing homes. State-level training requirements vary widely. Only 13 states have dementia care training requirements for home health care workers. Stakeholders should promote dementia care training standards that are culturally competent, reflect adult learning principles, are learner-centered, and teach principles of person-centered care. Successful training completion should result in portable credentials. States should provide training infrastructure, such as training registries.
- Fair compensation is defined as supporting financial stability, health, and planning for the future. Wages should align with workers' roles and responsibilities.
- Quality supervision and support allow workers to work safely and effectively. Supervision should be consistent, accessible, and supportive. Workers should have access to peer mentors and networks.
- Direct care workers often spend more time with patients living with dementia than any other health care professional. They offer important knowledge that should be considered in care planning and decision making.
- A quality direct care job offers opportunities for learning, development, and career advancement. Few current direct care jobs offer real opportunity. One way to change this is to create Dementia Care Senior Aide positions, which would require training and earn additional compensation. Dementia Care Senior Aides could educate other workers and family members to identify and address behavioral triggers, provide support through care transitions, and serve as liaisons between frontline and other members of the health care team.

### ***“The Future of LTSS Policy”***

***Damon Terazaghi, MS, Senior Director of LTSS Policy, ADvancing States***

- The American Rescue Plan Act of 2021 provided unprecedented additional Medicaid funding, which has supported most current innovative workforce initiatives. Additional funds included a 10% increase for home and community-based services. States may not reduce state funding as a result of these federal funds, which are intended to expand, enhance, and strengthen home and community-based services. States must submit spending plans and receive CMS approval prior to implementation.
- Analysis of state spending plans showed that current priorities are to expand caregiver support, home modification, assistive technology, and behavioral modification services. Caregiver support efforts include increased payment and burnout prevention. Additional priorities include providing additional “waiver slots” that allow people on waiting lists to receive services; increasing providers’ payment rates; offering bonuses to providers; and conducting studies of payments to providers, provider training and certification, recruitment and retention bonuses, telehealth improvements, LTSS electronic health records, health and welfare technology, housing supports, and behavioral health initiatives.

### ***“The State of Caregiving in Wisconsin”***

***Lisa Pugh, Executive Director, The Arc Wisconsin; Co-Chair, The Survival Coalition***

- Older adult parents often care for adult children with intellectual or developmental disabilities, due to lack of other options for care.
- Family caregivers need access to other direct caregivers so that they can have respite.
- The COVID-19 pandemic has exacerbated the urgent need for direct care workers.
- The gap between need for and availability of caregivers is wider in rural areas than it is in urban communities. This difference is projected to increase over the next two decades.
- Advocates presented the need for additional caregiving as an economic priority for the governor of Wisconsin to address. The governor appointed a bipartisan task force of legislators to address the issue. The task force passed 16 proposals, 12 of which received funding. Funded proposals support funding to reimburse direct, personal, and nursing home care services, as well as dementia care specialist services.
- Funds from the American Rescue Plan Act will support increased provider rates, studying provider rates to determine what is necessary to make wages

competitive, workforce training, and ensuring direct care jobs allow opportunities for career advancement.

- It is important to connect workforce investments with return on investment, such as improved health outcomes and reduced costs for care.
- Data are critical for documenting need for services as well as outcomes.
- Health and labor agencies should collaborate to develop and implement workforce initiatives.
- Investment in career ladder strategies can build and sustain the workforce.

### ***“The State of Caregiving in Wisconsin”***

***Karen Schulmerich, BSN, RN, Director of Nursing Administration, Monroe Community Hospital***

- Long-term care providers are aging and retiring or changing jobs. Staff shortages are increasing the workload, which presents an additional challenge to recruitment and retention.
- Long-term care is highly regulated, which can be a retention challenge.
- Career ladder opportunities can increase recruitment and retention. Potential career paths include: unit aide to certified nursing assistant trainee to certified nursing assistant to senior nursing assistant, or following the same path except to become a hospital mobility technician after serving as a certified nursing assistant; and levels of seniority for licensed practical nurses and registered professional nurses.
- Nursing is physically, emotionally, and intellectually demanding. It is also rewarding to make significant contributions to the community.

### ***Discussion***

- Ms. Medsger said dementia-specific training is critical for providing high-quality direct care, but currently is minimal. She asked what efforts are being made to increase dementia-specific training among the LTSS workforce. Mr. McCall said training is generally lacking, undervalued, and under-regulated. This is partly because workers are not compensated adequately to pay for their own training. The training that is available tends to focus on technical skills rather than relational skills, which are important for care quality.
- Mr. Kim asked how best to measure need among people who are not utilizing LTSS, who may disproportionately represent immigrant and refugee communities. Mr. McCall said one indicator is the number of people with authorization to receive services but are not utilizing those services. It is

challenging to estimate the number of people paying directly for services without documentation through insurance or employment records. Household surveys are a potential method for estimating the number of people obtaining services through this “gray market.” Some states are conducting surveys to estimate the number of available workers. State agencies should coordinate to collect these data.

- Ms. Williams asked whether American Rescue Plan Act provided funds for analyzing impact of implementing states’ plans and whether states are required to monitor and report on implementation. Mr. McCall and Ms. Pugh were unaware of such requirements but said that impact evaluation would be valuable.

***“Behavioral and Social Science Research and Clinical Practice Implications of Preclinical Diagnosis of AD/ADRD: A NASEM Workshop”***

***Reisa Sperling, MD***

- Brain changes associated with Alzheimer’s disease and related dementias (AD/ADRD) begin years prior to clinical impairment. Not everyone who experiences these changes will develop dementia. Further, pace of disease development varies between patients.
- There is debate regarding patients’ rights to their own health data and transparency of research findings versus problems with discussing risks before definitive results with representative populations are available.
- The National Academy of Science, Engineering, and Medicine (NASEM) held a 2-day workshop in June 2021 with participants from diverse disciplines to discuss disclosure of markers of AD/ADRD with patients who have no clinical symptoms.
- Methods for preclinical detection include identifying biomarkers and neuropsychological markers, reviewing medical and financial records, and assessing early and mid-life risk measures. More is known about preclinical indicators of AD/ADRD than other types of dementia. Quantitative metrics are needed to assess vascular risks for dementia, which disproportionately affect people of color. There are currently no validated biomarkers for other neurodegenerative dementias. Cognitive and behavioral markers may be risk indicators for these dementias. Preclinical markers are not used as a clinical diagnosis.
- Participants in studies of biomarkers are mostly White and have high socioeconomic status, which presents issues for generalizability. Discrimination and stress may be unique risk factors that affect people of color. Several chronic diseases are disproportionately prevalent among people of color and may interact with biomarkers to affect clinical outcomes. Genetic risk factors have differential impact by race.

- Barriers to diversity and equity in research include: a legacy of distrust and lack of linkage between communities of color and researchers, less awareness and variable perceptions and beliefs about dementia among communities of color, study inclusion criteria that disproportionately exclude people of color and potentially bias results, cost of procedures such as PET scans and lumbar punctures to detect biomarkers, and ineffective approaches to recruiting diverse research participants.
- Strategies for increasing diversity and equity include: collaborate with communities at all phases of research from determining questions and goals to interpreting and reporting results, with a focus on qualitative results that facilitate understanding community context; conduct research to identify and understand racial differences in biomarkers and social determinants of health, including assessment of heterogeneity between and within racial/ethnic group; use eligibility criteria that maximize inclusiveness; prioritize equity and access; collaborate with community partners; and recruit and train a diverse research workforce.
- Costs of screening and treating all people with risk factors would be very high, though benefits of preventive care also could be valuable.
- Disclosing patients' risk factors is associated with increased likelihood of research participation as well as healthy lifestyle changes.
- Assessing dementia risk must include consideration of multiple factors associated with aging.
- Patients who have received disclosures that they are at risk for AD/ADRD have indicated that it important to gain knowledge and that it is critical for patients to understand that risk changes over time. Patients have expressed concern about confidentiality and whether information about their risk factors could pose a threat to employment or insurance coverage.
- Decisions regarding whether to share information about preclinical markers should be based on whether the information is meaningful or actionable. Disclosure study results indicate that disclosing information about apolipoprotein E (APOE) and amyloid markers can be done effectively and safely. However, studies are conducted with volunteer participants. Results may not be generalizable to the general population, which is more diverse than research samples, and may have additional concerns about stigma and discrimination.
- Patients may view data about their biomarkers in electronic health records before their providers can help with interpretation.
- Because brains are uniquely associated with identity, disclosure of dementia risk poses unique challenges.

- Cognitive decline is typically prolonged, not defined by a discrete event, making delineation of risk difficult.
- Current key ethical issues include: (1) How should stakeholders define the risk-benefit ratio that favors disclosure of dementia risk, while so much remains unknown about individual risk? (2) Do participants from epidemiologic research cohorts who did not sign consent for preclinical marker disclosure want to know their results; should researchers offer the option of learning these results? (3) Should researchers disclose preclinical marker results to individuals whose demographics are not reflected in research cohorts, and therefore whose risk may not be predicted by findings from those cohort studies?
- Major policy questions related to preclinical diagnosis include: (1) How will these diagnostics affect the sustainability of health care spending? (2) How will they affect society's well-being? (3) How will they affect medicine pricing?
- Algorithms that apply biomarkers, genetic risk factors, and early cognitive tests are more than 90% accurate in predicting clinical decline in research settings. Large community-based studies are ongoing. Pragmatic studies and primary prevention trials would be valuable.
- Digital biomarkers may offer a valuable indicator of changes in cognitive functioning. They should be validated with biomarkers and standard clinical assessments. Potential use requires consideration of privacy and regulatory issues.
- Data are not yet adequate to predict individual risk of dementia, especially in the short term. Some people with multiple risks are resilient, while some people without known risk factors experience cognitive decline.
- There currently is no legal protection against discrimination based on biomarkers for AD/ADRD. This is an important consideration as research continues and findings about risk emerge.
- More research is needed on understanding heterogeneity in response to risk factors, including resistance to pathology. Research should be conducted on diverse epidemiologic cohorts and on how risk disclosure affects families as well as health care and economic systems.

### ***Discussion***

- Mr. Montminy asked whether disclosure researchers have considered what kinds of support patients may need after disclosure, and how to ensure patients get this support. Dr. Sperling said more work is needed in this area.

## ***“Reducing the Impact of Dementia in America: A NASEM Decadal Study of the Behavioral and Social Sciences”***

***Elena Fazio, PhD***

- NASEM conducted a consensus study to identify research with the greatest potential for impact toward achieving a specified goal over the next 10 years (decadal survey), in order to inform development of a 10-year research agenda. In August 2021, NASEM released a report of the results of this study on reducing burden of and addressing challenges related to AD/ADRD. An advisory panel of people living with dementia and caregivers for people living with dementia ensured that the expert committee considered these stakeholders’ perspectives while developing priorities and recommendations. Advisory panel input focused on the difficulty of obtaining an accurate and timely dementia diagnosis, problems with obtaining supports and services, challenges in communication with health care providers, and fear and loss.
  
- The report calls for:
  - Identifying modifiable drivers of racial inequality in dementia incidence as well as mechanisms through which socioeconomic factors can affect brain health.
  - Improving the experiences of people living with dementia by supporting their dignity and well-being while balancing safety and autonomy. This effort includes further research that informs guidance to support ethical and responsible decision making by and for people living with dementia. It also calls for development and utilization of outcome measures that reflect perspectives and values of people living with dementia, their care partners, and their communities.
  - Improving family care partners’ experiences through continued support for relevant behavioral and social science research, as well as for innovations, including technology, that address practical and logistical challenges of caregiving.
  - Facilitating development of communities that support people living with dementia and their caregivers, allowing people living with dementia to live independently and maintain social connections, and mitigating past and current socioeconomic and environmental stressors. This should include systematic analysis of characteristics of dementia-friendly communities.
  - Substantially strengthening the quality and structure of health care and long-term care. Potential research topics include clarification of disease trajectories in order to inform care planning and studying effective approaches for integrating and coordinating services across health care systems and community-based organizations.
  - Substantially strengthening dementia care payment mechanisms. Research could include comparison of effects of various financing structures on care quality and health outcomes.

- Improving understanding of the economic impact of dementia and identifying high-value, cost-effective interventions. Research topics include understanding drivers of economic costs related to dementia.
  - Improving research methodology by improving measurement of risk exposures and outcomes, developing systematic approaches to integrating evidence across studies, and increasing diversity of researchers and research participants.
- The National Institute on Aging currently supports several projects that align with priorities identified in the NASEM report. These include research on screening for cognitive impairment; studies of the relationships between education and cognitive impairment; and pilot projects applying artificial intelligence and technology in aging research, pragmatic trials for dementia care and caregiver support, and studies of the health equity implications of the cost of novel treatments for AD/ADRD.

## **Federal Updates**

- Due to time constraints, federal Council members shared their slide presentations on the Council website without making oral presentations at the meeting.
- The website also offers information about relevant programs, projects, and initiatives.

## **Public Comments**

- Esther Kane of the Association for Frontotemporal Degeneration said her organization strongly supports Council recommendations to strengthen support for the direct care workforce. These efforts should consider needs of people with dementias with onset that typically occurs at a young age. Most care options are not designed to address early onset dementia. In addition, staff training should address all types of dementia in order to strengthen ability to offer person-centered care. Frontotemporal degeneration is associated with language and behavioral symptoms, which can be more challenging to care staff than typical symptoms of AD/ADRD.
- William Mobley, neurologist and Associate Dean for Neurosciences Initiatives and Director of the Down Syndrome Center for Research and Treatment at the University of California, San Diego, and Chair of the National Down Syndrome Society's Scientific and Clinical Advisory Board, said that people with Down syndrome are at increased risk for Alzheimer's disease. By age 40, nearly all people with Down syndrome have brain pathology associated with Alzheimer's disease. The average age of dementia diagnosis among people with Down

syndrome is 56. All people with Down syndrome have an extra copy of the gene for amyloid precursor protein, a risk factor for Alzheimer's disease. More research is needed on the biology of Alzheimer's disease among people with Down syndrome. In addition, people with Down syndrome need more access to expert clinical care. Dr. Mobley encouraged the Council to support policies that address these needs.

- Kandi Pickard, President and Chief Executive Officer of the National Down Syndrome Society, said it is critical for the Council to address needs of people with Down syndrome and their families. The organization has written a letter to the Council that provides a detailed discussion of these issues. The letter is available on the organization's website. The lifetime risk for Alzheimer's disease among people with Down syndrome is greater than 90%. Alzheimer's disease is the leading cause of death among people with Down syndrome. People with Down syndrome are the single largest group with early onset dementia due to Alzheimer's disease. The National Down Syndrome Society urges the Council to form a subcommittee to focus on how HHS can improve diagnostic and clinical services available to people with intellectual and developmental disabilities, including Down syndrome. Areas where support is needed are: access to adequate clinical care, increased support for research on Down syndrome associated with Alzheimer's disease, access to new treatments, including people with Down syndrome in clinical trials, and access to LTSS for people with Down syndrome.
- David Egan introduced himself as a person with Down syndrome. He advocated for including people with Down syndrome in clinical trials and ensuring people with Down syndrome have access to clinical treatment for Alzheimer's disease. Program and policy planning should address needs of people with Down syndrome. He pointed out that research on risk factors such as the gene for amyloid precursor protein among people with Down syndrome is likely to provide insights that contribute to reducing the burden of Alzheimer's disease for the general population.
- Matt Sharp, Advocacy Manager for the Association of Frontotemporal Degeneration, said preclinical diagnosis of frontotemporal degeneration would allow patients to plan for the future and help families to make decisions regarding care and research participation. There are few current opportunities to participate in research on frontotemporal degeneration. Clinical research often involves invasive and uncomfortable procedures with no immediate benefit to patients. Participation in genetic treatments for frontotemporal degeneration requires genetic testing, which has potential consequences that should be considered. The early age of frontotemporal degeneration onset has implications for employment, insurance, financial planning, raising children, and access to benefits. The Association of Frontotemporal Degeneration encourages research that focuses not just on Alzheimer's disease, but on all dementias.

- Catharine Krebs of the Physicians' Committee for Responsible Medicine said the organization supports Council recommendations for increasing diversity of dementia research participants. The organization advocates for human-specific, non-animal, preclinical research approaches, such as tissue chips derived from human cells. The organization recommends increasing sharing of, access to, and utilization of human research data and samples. It recommends that NIH identify gaps in tissue sample availability, with emphasis on availability of tissue from diverse donors. The organization recommends that stakeholders advocate for diversity and inclusion in human research data and samples.
- George Vradenberg of UsAgainstAlzheimer's and Sarah Lenz Lock, AARP Senior Vice President of Policy and Brain Health, said their agencies support the Council's recommendation to add the goal of reducing risk factors for AD/ADRD to the National Plan.

## **Concluding Remarks**

The next Advisory Council meeting will focus on clinical care, and will be held on January 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>.