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

Washington, DC and Virtual Meeting

October 24, 2022

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Cynthia Carlsson (Chair), Randall Bateman, Venoreen Browne-Boatswain, Matthew Janicki, Keun Kim, Helen Bundy Medsger, Adrienne Mims, Carrie Molke, Joe Montminy, Maria Ortega, Joanne Pike, Rhonda Williams

- *Federal Members Present*: Arlene Bierman (Agency for Healthcare Research and Quality, AHRQ), Roderick Corriveau (National Institute of Neurological Disorders and Stroke, NINDS), Bruce Finke (Indian Health Services, IHS), Scotte Hartronft (U.S. Department of Veterans Affairs), Richard Hodes (National Institute on Aging, NIA), Shari Ling (Centers for Medicare & Medicaid Services, CMS), Lisa McGuire (Centers for Disease Control and Prevention, CDC), Eric Weakly (Substance Abuse and Mental Health Services Administration, SAMHSA), Joan Weiss (Health Resources and Services Administration)

- *Quorum present?* Yes

- *Advisory Council Designated Federal Officer*: Helen Lamont (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, HHS/ASPE)

General Proceedings

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

Welcome and Introductions

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

Threads Across Subcommittees

***Cindy Carlsson**, MD, MS*

Dr. Carlsson said that the four subcommittees--clinical care, long-term services and supports (LTSS), research, and risk reduction--all strive to respond to the needs of people from diverse racial, ethnic, and cultural backgrounds; people at all stages and with all types of dementia; and people with other conditions, such as Down syndrome. She acknowledged that it would be helpful to have the capacity to form additional specialized subcommittees to focus on each priority population and priority issues such as health equity, impact assessment, and information dissemination. However, current capacity supports only the four existing subcommittees to share in addressing these priorities.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the National Strategy to Support Family Caregivers

***Greg Link**, MA, and **Alan Stevens**, PhD*

The RAISE Act became law in January 2018 and established a Family Caregiving Advisory Council. The act requires annual reports to Congress and requires the development of a national strategy to support family caregivers, to be updated biennially. Implementation of the Act is supported by approximately $400,000 in annual federal appropriations and a John A. Hartford Foundation grant. The initial report to Congress was published in September 2021 and informed development of the national strategy, which identifies five priority areas: (1) awareness and outreach; (2) engagement of family caregivers as partners in health care and LTSS; (3) services and supports for family caregivers; (4) financial and workplace security; and (5) research, data, and evidence-informed practices. The strategy's four components are: (1) a summary of goals and target outcomes; (2) key principles to be applied in efforts to support family caregivers; (3) recommended federal actions; and (4) recommended actions for state, community, and other stakeholders. The key principles are: (1) place the person and family at the center of all interactions; (2) address trauma and its impact on families; (3) advance equity, accessibility, and inclusion for family caregivers in underserved communities; and (4) elevate direct care workers as family caregiving partners. The Council solicited input on the report and strategy through requests for information; focus groups; listening sessions; and key informant interviews with stakeholders including state and local government agencies, employers and unions, health care and LTSS providers, respite providers, and community and faith-based organizations, and philanthropic organizations. Several federal agencies are represented on or otherwise support the Council. The strategy is intended to be implemented by diverse stakeholders, including policy makers at all levels of government, health care and LTSS providers, employers, advocates, researchers, family caregivers, care recipients, and the general public. The Council is accepting public comments on updating the National Strategy between October 1 and November 30, 2022. The Family Caregiving Advisory Council would like its work to align with that of the Advisory Council on Alzheimer's Research, Care, and Services and for the councils to support each other. Supporting family caregivers is essential for supporting care recipients. Research is needed on the number of family caregivers, their needs, and how best to address these needs.

Discussion

- Families' needs vary. For example, LGBTQ family caregivers may rely on peers more than families of origin for support. Older adults with dementia may need support from adult children who live far away.
- The Family Caregiving Council contacted several stakeholder organizations that serve underserved populations to solicit input on the National Strategy. Mr. Link shared a link to a site where users can provide input.
- One of the National Strategy's current recommendations is to add standard fields to electronic health records that identify and assess needs of family caregivers.
- The U.S. Department of Labor is evaluating workplace policies regarding family caregiving.
- The National Academy for State Health Policy developed a template for organizational stakeholders to use to assess how the National Strategy can benefit their clients. The guide also suggests potential actions organizations can take to implement the strategy.

Voice of a Caregiver

Helen Medsger

Ms. Medsger has been a caregiver for two generations of family members with Lewy body dementia (LBD). Her father experienced severe psychosis that resulted in violent behaviors and required residential psychiatric care. Ms. Medsger's family had 3 days from the time of diagnosis to find a care facility before Medicare stopped paying for acute care. They did not have an advanced care plan and were not offered assistance in developing one nor any referrals to other services. At the time, Ms. Medsger was in her 30s and had a young family as well as a full-time job, from which she had to resign. After spending down family assets, Ms. Medsger's father qualified for California Medicaid coverage. As the end of Ms. Medsger's father's life approached, the skilled nursing facility where he lived resisted working with hospice care providers. The only services he received were visits with a hospice nurse and medical equipment deliveries until he died in the late 1980s. The family received no support services following his death. Six years later, Ms. Medsger's sister began to exhibit LBD symptoms. LTSS, palliative, and hospice care were more readily available than when Ms. Medsger's father needed them. Ms. Medsger's sister benefited from speech, cognitive, physical, psychological, and occupational therapies. She was able to express and document her wishes regarding the end of her life. Ms. Medsger was referred to services and resources for family caregivers. During hospice care, Ms. Medsger and her family needed to challenge standard protocols and advocate for proper medication and medical equipment to relieve the patient’s pain related to co-occurring Parkinson’s disease as well as loss of swallow reflex.

During the past month, Ms. Medsger has interviewed family caregivers of patients in hospice or palliative care about their experiences and needs. Key issues they have faced include: patients confusing palliative care with hospice care, thus being afraid to use services because this will signal the end of their lives; health care providers being unfamiliar with severe contractions and associated pain experienced by patients with Parkinson’s disease and being unprepared to support managing this pain; difficulties understanding options for selecting health care providers; lack of communication regarding the possibility of losing access to medical equipment when hospice status is revoked; the necessity of fighting for access to services and treatment; variability in service availability; and challenges navigating the health care system. Ms. Medsger recommended expanding palliative and end-of-life care to respond to patients’ diverse needs and to improve on current models that assume end-of-life lasts no longer than 6 months.

Addressing the Palliative Care Needs of People Living with Dementia and their Caregivers

***Christine Ritchie**, MD, MSPH*

One-third of people aged 65 years and older die with dementia, which affects their end-of-life experience regardless of the primary cause of death. Currently, 5.8 million people in the United States are living with Alzheimer’s disease and related dementias (AD/ADRD), and this is expected to increase to 14 million people by the year 2060. Cases among Hispanic people are expected to increase at seven times the current rate; cases among Black Americans are expected to increase at four times the current rate. On average, family caregivers of people living with dementia provide caregiving services for 22 hours per week over a period of 3 years. During the last year of a patient’s life, families spend an average of $66,000 on health care, making dementia the costliest condition to manage. Currently, more than 2 million Americans live at home with moderate to severe dementia.

Dr. Ritchie and colleagues conducted interviews with 61 people, including people living with mild to moderate dementia, active and bereaved family caregivers, and memory care clinicians. Participants identified several gaps in available services for dementia, including: diagnosis and diagnostic disclosure, anticipatory guidance and dementia competence, caregiver support, care coordination, navigation of behavioral symptoms, and treatment decisions and advanced care planning. Health care providers are often insensitive when disclosing a dementia diagnosis and are unaware of the need for support following the diagnosis. Caregivers are often advised to take care of themselves, without acknowledgement of the challenges of self-care while caring for a loved one with dementia. Care gaps are exacerbated in racial/ethnic minority populations.

Palliative care is based on patient needs, not prognosis. It should be a core service for people living with dementia. Palliative care prioritizes patients' dignity and comfort, and it supports family caregivers.

Discussion

- Primary caregivers need training and resources to help them understand and address the issue of caregiver burden and burnout.
- Current palliative care is largely based on lessons learned from caring for people with cancer. It should be tailored to improve care for people with dementia.
- Palliative care should be integrated into health care delivery and not require a specialist.

2014-15 Panel on Advanced Dementia: Recommendations Review and Discussion

Susan Mitchell*, MD, MPH*

Researchers coordinated with the National Center for Palliative Care Research to advocate for the National Plan to Address Alzheimer's Disease to include convening expert panels to assess research, policy, and practice relevant to providing care to people living with advanced dementia and their families, and to make recommendations to HHS and the Advisory Council on Alzheimer's Research, Care, and Services.

The research panel concluded that most work was descriptive rather than focused on intervention outcomes. Most studies assessed nursing populations, not hospital or community settings. Results identified problems and areas for improving care. Feeding and infections were the most common clinical complications. Research showed that tube feeding has no benefits and antibiotics are overused. Hospice services were shown to be beneficial but underutilized. Hospital use was shown to be common, costly, burdensome, and avoidable. Skilled nursing facility services were frequently misused. Research showed disparities in advanced dementia care.

The clinical practice panel concluded that promising practices are slow to expand and replicate. The panel identified a need for more program evaluation. Programs need good leaders and appropriate culture to succeed. The panel recommended implementation of policies and regulations with potential to facilitate implementation of promising practices.

The policy panel concluded that there are complex policy issues related to advanced dementia and that policies often have a high likelihood of unintended consequences. The panel found that there is inadequate access to palliative care. Complex fiscal and regulatory policies create misaligned incentives that promote poor care. Hospice care is difficult to access. Little is known about the needs of people with dementia who live at home or in community care, or about how to address these needs. While people frequently use the services of acute and subacute care settings, care often is not beneficial. There are several issues related to quality metrics that are unique to assessing advanced dementia care.

Based on these conclusions, the core group of experts recommended ensuring access to high-quality palliative care across all settings; preparing a workforce that is competent to deliver care to patients with advanced dementia and their families; incentivizing documentation and tracking of cognitive and functional status in order to identify people with advanced dementia; supporting research, evaluation, and dissemination of models of care to meet the needs of people with advanced dementia and their families; leveraging policy to ensure access to high-quality care for people with advanced dementia and their families; and supporting quality metrics that ensure transparency and accountability for the care of people with advanced dementia and their families.

Events that have affected responses to these recommendations include allocation of a large budget for the NIA to support research on AD/ADRD; changes in policies that aim to reduce long stays in hospice care; evolution and uptake of electronic health records; development of a national partnership to address needs for care of people with dementia; an approximately 45% increase in the number of people with dementia enrolling in Medicare Advantage; AHRQ and National Academies of Science, Engineering, and Medicine reports on dementia interventions; and the COVID-19 pandemic.

Black people living with advanced dementia receive poorer quality palliative care. This disparity can be addressed through standardized training in cultural competence, standardized training in advanced dementia, and integration of goal-directed care.

Since these recommendations were made, hospice and palliative care utilization have increased, research on evidence-based models of care has increased, and some quality metrics have been developed. There remains a need to train the health care workforce to understand advanced dementia and to develop better data and documentation on advanced dementia. Current priorities are to address disparities, offer palliative care at earlier stages of dementia, improve care coordination, increase knowledge among workforce members, produce evidence to support effective and scale care programs, and address limitations in the health care system that present barriers to evaluation and adaptation of promising models of care.

Discussion

- A patient-centered, holistic approach that provides palliative care early is likely the most promising approach to improving care for patients with advanced dementia and their families.

Panel: End-of-Life Care that Honors Diversity and Culture

End-of-Life Care that Honors Diversity and Culture Indigenous Perspectives on End-of-Life

***J. Neil Henderson**, PhD*

The presentation focused on perspectives of indigenous North Americans, comprising 574 federally recognized American Indian Tribes and Alaska Native villages who speak more than 175 languages. Indigenous cultures are diverse within and between Tribes. Individual indigenous people vary in degrees of acculturation, norms, values, and beliefs. Individual cosmology often combines Tribal and colonial beliefs, and the ways in which beliefs are combined vary widely. For example, Comanche Methodist churches participate in traditions of both Comanche culture and Methodist worship. There is no single culturally appropriate approach to discussing end-of-life issues with indigenous North Americans. Care providers should make an effort to learn individuals' understanding of and perspective on end-of-life. Examples of beliefs that distinguish some Tribal cultures include belief that the body should remain intact after death, which can influence a person's willingness to donate organs, and belief that ancestors will come to retrieve a dying person. Traditional activities during end-of-life include singing songs that welcome ancestors who come to retrieve the dying and songs to support people as they die, holding feasts to honor the dead, and keeping bones or cremation remains as mementos of people who have died. Learning about an individual's beliefs requires expressing sincere and respectful interest. Asking about a person's "way" of understanding indicates holistic interest in that person's experiences, including spirituality. Asking a person to share some of their perspective is a way of demonstrating respect for privacy and potential hesitancy to disclose detailed information about personal beliefs. Providing end-of-life care to an indigenous person may include asking whether the provider should contact a traditional healer or elder.

Community-based Approaches to Reduce Inequities in Palliative and End-of-Life Care Through Partnerships with the Black Church

***Danetta Sloan**, PhD, MSW, MA*

Faith and community leaders serve as community gatekeepers. Community partners can help ensure community members find out about and benefit from research results as soon as they are available. Researchers must consider community priorities, ensure community input, and be aware of their own biases and expectations. In community-based participatory research, community members are involved with planning and decision making, budget negotiation, implementation, and dissemination. Research projects should accommodate community members' needs and preferences as much as possible. Project activities should include identifying and meeting with community leaders and stakeholders, establishing a community advisory board, ensuring transparency, reporting to community leaders throughout the project, and increasing visibility of participating community organizations. Researchers must understand that community members may not trust researchers; they may not expect research to benefit their community and may believe that researchers typically benefit from projects more than community members.

Faith-based organizations can serve as liaisons between Black communities, and health care providers and health educators. Dr. Sloan surveyed members of two churches with African American congregations to assess knowledge about palliative and end-of-life care as well as interest in learning more about these topics in order to identify family caregivers and to identify people who had lost a loved one. Nearly all participants wanted more information about palliative and end-of-life care. Participants indicated that places of worship should serve as supports for community programs. Based on these findings, Dr. Sloan coordinated with faith-based organizations to offer a program that provides education and facilitates discussions about advanced care planning.

Cultural Considerations in End-of-Life Care for the Latino Community

***David Munoz**, MD*

Latino people in the United States are 1.5 times more likely than others to get AD/ADRD. Only 7% of Latino people use hospice care, while 17% of non-Latino people in the United States use hospice services. Latino subcultures vary by factors such as country of origin, dialect, and number of generations a family has lived in the United States. Mothers and oldest daughters are typically family caregivers. Fathers and older sons may be primarily responsible for health care decisions. Clergy may also be involved with health care decisions. Latino people may participate in folk health traditions, which they may hesitate to discuss with mainstream health care providers. It is important for health care providers to discuss this openly and respectfully in order to ensure prescribed medication does not interact with folk medicine to produce harmful effects. Non-verbal communication sometimes differs between Latino and other cultures. For example, nodding often indicates respect or understanding rather than agreement; and social distance is typically half of that of non-Hispanic Americans. Decisions may be based on how a family member’s death will affect other family members more than on the individual patient’s interests. For some Latino subcultures, there is a strong cultural belief that eating is essential throughout life, which sometimes leads to family members feeding patients who are unable to eat due to medical issues. Many Latino subcultures also hold the belief that speaking of death can precipitate death, as well as the belief that miraculous recovery is always possible. Teamwork and intentional understanding are necessary for delivering culturally competent, patient-centered care.

Promoting Equitable and Inclusive End-of-Life Care for Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) Older Adults

***Sherrill Wayland**, MSW*

LGBTQ people with dementia are more likely than others to live alone and to age without a partner, and less likely to have a child who provides support. They also often face barriers to obtaining high-quality health care and support, including discrimination and lack of culturally competent care providers. Many LGBTQ older adults have experienced stigma and discrimination from health care providers, which has led to avoidance of health care or supportive services, resulting in health disparities. When people do not designate power of attorney and it is necessary to assign it for health care decisions, it is assigned to next of kin. Many LGBTQ people do not have good relationships with their next of kin, so designating durable power of attorney is an especially important part of advanced care planning. Designating visitor lists, rights of sepulcher, and documents specifying gender identity of transgender people are important legal concerns. It is important to address these concerns prior to onset of dementia. Some attorneys specialize in serving these needs for LGBTQ clients and should be consulted when these issues arise. Health care providers should ensure that LGBTQ patients' intake forms are current and indicate who should be involved with care and care decisions, including specifying emergency contacts rather than next of kin. Forms should indicate whether patients have legal documentation of their wishes. Providers should ask for patients' names and pronouns, which may not match legal documents, and support patients in ensuring that preferred names and pronouns are used during end-of-life care and final rites. It is critical for health care providers to listen to patients and provide emotional support. This includes respecting the privacy of patients who are not openly LGBTQ and offering to engage an LGBTQ-welcoming hospice chaplain.

Role of the Long-Term Services and Supports (LTSS) System in Providing End-of-Life Care

***Diane Meier**, MD*

Patients with needs after doctors' office hours are typically advised to call 911, resulting in increased and often preventable emergency and hospital service use. Palliative care is often more appropriate and is covered by many insurance plans. The palliative care services offered by Dr. Meier's team include house visits, pain management, continuously available phone contact with health care providers, caregiver support, and connection to Meals on Wheels and friendly visitor services. This approach has resulted in decreased utilization of emergency and hospital services. Research has shown that nursing home patients who receive palliative care consultations have fewer emergency department visits and hospitalizations, and experience lower rates of depression than patients who do not receive these services.

In the United States, it is easier for patients to access emergency and hospital visits than palliative care, though palliative care should be the standard within the health care system. LTSS, including in palliative care, are critical for reducing hospitalizations. The most important predictor of successful palliative care is patients having continuous available phone access to health care providers. Other predictors include high-touch personalized care relationships, a focus on social and behavioral health, and integrating social supports with medical services. Clinicians often lack training in palliative care and pain management. Palliative care is appropriate for all ages, diagnoses, and prognoses, and at any stage of a serious illness. Palliative care improves health care quality and value. Effective palliative care requires adequate numbers of trained staff in all relevant settings, screening and prioritizing highest risk people, asking people what they want and developing a plan that reflects these preferences, supporting family and other caregivers, delivering expert pain and symptom management, and continuous ability to contact care providers in all settings. Currently, no payment models support this model of care. Most large hospitals and hospices offer palliative care, but palliative care is rarely available to people who live at home or in residential care facilities. Policies should be changed to address this gap in care. Policy reform should include basing eligibility for care on need rather than prognosis; requiring providers to meet competency standards; use of quality standards not based on condition improvement; applying quality standards to all providers, including Medicare Advantage vendors; including prioritization of patient-centered goals in quality measures; and supporting payment models that incentivize care coordination and palliative care at home and in nursing homes as well as reduce incentives for intensive and skilled care and hospitalizations that are unlikely to benefit patients. The Alzheimer's Association website presents a proposed alternative payment model for dementia care management.

Medicaid and LTSS comprise the primary system of care for people with dementia. Care costs are higher for older patients with dementia than for those without dementia. The high costs of care for people with dementia will lead to a financial crisis if care models do not change, through efforts such as implementing and supporting effective palliative care programs. Currently, the only feasible model of funding palliative care is to contract with a payer, such as Medicare Advantage or an institutional special needs plan. Other options are scarcely available and include fee-for-service palliative care consultants, care delivered by a trained medical director, and care provided by an expert geriatric specialized medical group.

Nursing homes are often understaffed and otherwise under-resourced; offer poor pain management; and require frequent, burdensome care transitions. Just more than half of people with dementia in nursing homes die within 18 months of moving in. During the last year of life in residential care, people with dementia experience high rates of dyspnea, pain, pressure ulcers, aspiration, and agitation. Palliative care is needed in nursing homes as well as in home and community-based settings.

Development of evidence-based models for palliative care delivery requires payment models that will reimburse for services. Current care quality measures assume that declining health--an inevitable occurrence for people in nursing homes--is an indicator of poor care. Improved care can only be demonstrated with measurement models that do not assume disease reversal is possible for all patients. Due to uncertain prognosis, many people with dementia are not eligible for hospice care. Due to concerns about CMS and Office of the Inspector General penalties for longer stays, many hospice care facilities are reluctant to care for patients with dementia.

Discussion

- Nursing homes typically consider preventing progression of dementia to be the standard of care and focus on prolonging life rather than quality of life.
- CMS requires health care providers to meet minimum standards for health and safety, with some flexibility regarding which services most benefit individual patients. Research evidence and professional guidelines that define targeted outcomes that focus on quality of life and acknowledge limits on reversing disease can support change in practice.

Federal Updates

- **Bruce Finke** reported that IHS has awarded four grants to Tribal health organizations to address dementia in Indian Country through developing models of comprehensive and sustainable care and services. All grantee programs offer support for family caregivers and prioritize early diagnosis and services. IHS is supporting a Geriatric Scholars pilot program to train 18 scholars. The agency has issued a request for proposals for Early Detection Initiative grants to oral health professional training programs. Currently, 11 IHS and Tribal emergency departments are seeking accreditation through the IHS Geriatric Emergency Department Accreditation Initiative.

- **Lisa McGuire** announced that CDC will host a symposium on Public Health Action to Advance Early Detection of Dementia on October 25-27, 2022, and a dementia risk reduction summit on May 16-17, 2023. In the near future, CDC will offer continuing education on modifiable risk factors for AD/ADRD among adults aged 45 years or older. The agency’s website now includes a feature on reducing risk for AD/ADRD, which will soon be available in Spanish. CDC is funding a Risk Reduction Thematic Network from 2022-2024. The three collaborating centers implement evidence-informed interventions targeting modifiable risk factors among highest risk populations, and work to increase collaboration to reduce risk. CDC hosts the online Healthy Brain Resource Center, which offers verified resources relevant to implementing the Healthy Brain Road Map. CDC updates resources regularly and accepts submissions. The agency will continue to support the University of Washington in implementing the Cognition in Primary Care program, which plans to improve and expand over the next 2 years. CDC recently began a 3-year dementia data modernization project. CDC continues to fund grants to develop Healthy Brain Road Map strategies.

- **Shari Ling** said CMS is conducting a study to inform establishment of minimum nursing home staffing standards. Medicaid has increased funding to support enhancement and expansion of home and community-based services. Medicaid's Money Follows the Person demonstration program grantees will develop plans to increase access to these services.

- **Arlene Bierman** announced that AHRQ has issued a request for information on person-centered care and care planning for people with or at risk for multiple chronic conditions, accepting responses until November 15, 2022. AHRQ is collaborating with the National Institute of Diabetes and Digestive and Kidney Diseases to develop an interoperable electronic care plan that facilitates data aggregation and sharing across multiple settings for people with multiple chronic conditions. A technical expert panel has identified a set of core data elements on people living with Long COVID.

- **Helen Lamont** reported that ASPE recently released multiple reports on long-term care and nursing facilities.

- **Eric Weakly** said that SAMHSA is collaborating with CMS to develop the Center of Excellence for Behavioral Health in Nursing Facilities, which will serve as a national model for expanding capacity.

- **Richard Hodes** reported that NIA updated its research priority areas in September 2022. NIA will host a Healthy Aging Start-up Challenge and Bootcamp for researchers and entrepreneurs in order to foster diversity and accelerate innovation. The agency developed a video series on AD/ADRD, recently sponsored a workshop on links between AD/ADRD and cancer, and held a dedication ceremony for the Roy Blunt Center for Alzheimer's Disease and Related Diseases Research. Recent NIA-funded research shows that COVID-19 significantly elevates biomarkers and risk for AD/ADRD. Recent research also has shown that anti-amyloid antibody lecanemab is associated with slowed cognitive decline. The 2023 Caregiver and Caregiving Research Summit will be held March 20-22, 2023. The Geroscience Summit will be held April 24-26, 2023.

- **Roderick Corriveau** announced that NINDS has issued announcements for several funding opportunities related to AD/ADRD. Topics include workforce diversity, social determinants of health, modifiable risks, clinical trials, and others.

Update on the 2023 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers

***Elena Fazio**, PhD*

The summit will facilitate discussion of the state of the science relative to milestones, potential future research, and high priority needs for research. It also will provide opportunities for people with dementia and their caregivers to offer input. Nine sessions are planned on the following topics: living well with AD/ADRD; disparities in dementia care; dementia care models and coordination of care; support for care partners and caregivers; impact of detection and diagnosis on people and their care partners; improving rigor, reproducibility, and opportunity for intervention dissemination; dementia care workforce; economic impacts, implications, and approaches; and approaches to participatory research, diverse recruitment, and retention in dementia care research. Council members suggested that it would be valuable to include discussion on adapting models of care for diverse communities, including indigenous communities, and engaging community leaders in research and information dissemination.

Memorial for Eric Sokol

Ian Kremer, Phil Cronin, Richard Hodes, and others expressed appreciation for the contributions of Eric Sokol, an AD/ADRD advocate who recently passed away.

Public Comments

- **Dawn Ducca** of the Association for Frontotemporal Degeneration said the health care workforce should be trained to understand different types of dementia. Many workforce members have not heard of frontotemporal degeneration. Care providers should be better equipped to handle younger patients with cognitive impairment and eligibility requirements should make services more accessible for younger patients.

- **Michael Ellenbogen** recommended forming public/private partnerships led by the Federal Government with the purpose of accelerating efforts to address dementia. He also recommended developing dissemination mechanisms that identify credible sources and using strategic approaches to ensure critical information about dementia reaches a broad audience of key stakeholders. He encouraged implementation of policies that allow people with dementia to make choices that reduce end-of-life suffering.

- **Melissa Fisher** of the Association for Frontotemporal Degeneration described extreme difficulties finding appropriate care for her father, who had the disease. Professional care options are essentially absent, and family care is inadequate. One-on-one care is prohibitively expensive.

- **Rachel Grimm** of the National Down Syndrome Society said there are inadequate services available and policies in effect to meet the needs of older adults with Down syndrome. She encouraged the council to establish a subcommittee on improving care for people with intellectual and developmental disabilities. She said that her organization would like a partnership with the council.

- **Matthew Sharp** of the Association for Frontotemporal Degeneration announced that the organization will offer pilot grants in the year 2023 for early career investigators to develop independent research on well-being for people with frontotemporal degeneration, their families, and their caregivers. Applications are due November 11, 2022. Instructions are available on the organization’s website.

- **Hom Shrestha** identified himself as a doctoral student with mild cognitive impairment. He studies indigenous cultural perspectives on dementia and dementia care. He recommended prioritizing culturally competent care for these communities.

Concluding Remarks

Dr. Lamont noted that the Council’s next meeting will be held on January 20, 2023.

The meeting adjourned at 4:35 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.