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

Washington, DC and Virtual Meeting

April 29-30, 2024

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Adrienne Mims (Chair), Randall Bateman, Deke Cateau, Fawn Cothran, Roberta Cruz, Susan DeMarois, Keun Kim, Helen Bundy Medsger, John-Richard Pagan, Joanne Pike, Yakeel Quiroz, Rhonda Williams

- *Federal Members Present*: 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, National Institute on Aging [NIH/NIA]), Shari Ling (Centers for Medicare & Medicaid Services [CMS]), Erin Long (Administration for Community Living [ACL]), Lisa McGuire (Centers for Disease Control and Prevention [CDC]), Tisamarie Sherry (Department of Health and Human Services [HHS] Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Eric Weakly (Substance Abuse and Mental Health Services Administration [SAMHSA]), Joan Weiss (Health Resources and Services Administration [HRSA])

- *Quorum present?* Yes

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

General Proceedings

The Advisory Council on Alzheimer's Research, Care, and Services was convened for its second meeting of the year at 9:08 a.m. Eastern Standard Time on Day 1, and 9:22 a.m. Eastern Standard Time on Day 2 in Washington, D.C., and virtually. Dr. Adrienne Mimms, Advisory Council Chair, and Helen Medsger, Long-Term Services and Support (LTSS) Subcommittee Chair welcomed meeting participants and reviewed the meeting agenda on Days 1 and 2 respectively. The meeting was open to the public.

Federal Updates

Erin Long, *ACL*. Kari Benson is the new Deputy Assistant Secretary for Aging. Open ACL funding opportunities include the Alzheimer's Disease Program Initiative, the Center for Dementia Respite Innovation, Bridging Aging and Disabilities Project, and

Lifespan Respite Care Program. Recent National Alzheimer's and Dementia Resource Center webinars covered care navigation and social isolation and loneliness; the May topic is brain health and risk reduction. Recordings are available. Lifespan Respite hosted a February webinar on helping faith congregations become "dementia friendly" to support African-American family caregivers.

Arlene Bierman, *AHRQ*. AHRQ released a Roundtable Report on optimizing health and function. Over 90% of those with Alzheimer's disease and related dementias (ADRD) have multiple chronic conditions (MCC) and need comprehensive care plans. AHRQ is working on electronic care planning apps and resources to support person-centered care, including two eCare apps (one for clinicians and one for patients and caregivers) that will be available by year end, an MCC eCare implementation guide to be published in Spring 2024, and a national Person-Centered Care Planning for People with Multiple Chronic Conditions collaborative that will hold a summit in Spring 2025.

Helen Lamont*, ASPE*. HHS celebrated the 1-year anniversary of President Biden's Executive Order on *Increasing Access to High-Quality Care and Supporting Caregivers*. ASPE released an issue brief identifying gaps in data on the workforce delivering home and community-based services and providing recommendations to fill them. The brief, developed in partnership with the Department of Labor and other HHS agencies, will be covered in a May 21 webinar.

Lisa McGuire*, CDC*. The Alzheimer's Association and National Association of County and City Health Officials released a guide to help health departments integrate brain health messages. The Road Map for American Indian and Alaska Native People is being updated and will be released in November 2024. The BOLD Centers of Excellence released five new infographics on social determinants of health, an early detection of dementia toolkit for health systems, and a webinar series on successful dementia caregiving. The Health Matters Program and National Task Group on Intellectual Disabilities and Dementia Practices developed a family caregiver webinar series and publications focused on evaluating dementia in people with intellectual and developmental disabilities (IDD). The University of Washington has developed a free continuing medical education course, *Cognition in Primary Care*, available through *CDC Train*.

Shari Ling*, CMS*. The Alzheimer's National Registry for Treatment and Diagnostics is still open for studies that can address clinical and policy questions. Additional information from CMS forthcoming (July 2024). 2024 CMS quality conference included a session on the GUIDE Model. Dr. Lenise Cummings-Vaughn shared CMS and SAMHSA partnership to maintain a Center of Excellence for nursing home residents with serious mental illness or substance use disorders through training and consultation. In 2023, CMS began auditing medical records of nursing home residents diagnosed with schizophrenia to ensure appropriate diagnosis and medication usage. Dr. Pauline Karikari-Martin reviewed new national minimum staffing standards for safe and quality care in nursing homes, to be implemented over 3-5 years. Core requirements are a registered nurse onsite 24/7, minimum nurse staffing standards, and enhanced facility assessments. The landmark Medicaid Access Rule which strengthened home and community-based services was also reviewed.

***Sarah Fontaine**, DoD*. Appropriations for FY 2024 for the Peer Reviewed Alzheimer's Research Program (PRARP) are $15 million. Research funding opportunities related to Amyotrophic Lateral Sclerosis (ALS), Parkinson's, and Alzheimer's are available on the Congressionally Directed Medical Research Program website. Research has shown that veterans have about a 2-8 times greater risk of developing dementia than the general population. The three FY 2024 PRARP funding opportunities focus on clinical trials of interventions, reducing barriers to diagnosis, and identifying risk factors and risk reduction strategies. Letters of interest are due May 22 and applications are due June 20.

***Bruce Finke**, IHS*. The IHS Alzheimer's Grant Program site visits are underway and a second funding opportunity in 2024 for established programs is forecast. Ongoing Program partnerships include the Dental Clinic Early Dementia Detection Initiative with the IHS Division of Oral Health and the Geriatric Emergency Department Accreditation Initiative. The Community Health Representatives (CHR) Dementia Detection Initiative has launched, training CHRs in the use of cognitive screening tools in the home. The Indian Health Geriatric Scholars Pilot supports clinicians who develop community projects; a third cohort will be recruited this summer. The Geriatric Nurse Fellowship Pilot launched, training nurses in roles such as palliative care, cognitive screening, and falls prevention. IHS is promoting brain health through regional elder-focused health and wellness events. The first annual report to Congress of the Alzheimer's Grant Program is in review.

***Richard Hodes**, NIH*. The NIH 2023 Dementia Care and Caregiving Research Summit helped identify research priorities related to outcomes that matter, comprehensive care models, health information technology and disparities, identifying care partners, caregiver wellbeing, community-engaged research, workforce, and health care decision-making. New funding opportunities will support computational models associated with aging and ADRD, establish a national network of measures and methods for prevention trials, and attract early career Department of Veterans Affairs (VA) physicians and psychologists to ADRD research. A final report by NIH and National Institute of Neurological Disorders and Stroke (NINDS) identifying research priorities for preventing and treating ADRD is anticipated in early 2025. EUREKA Challenge for Early Prediction of ADRD prizes will be awarded in Fall 2024. The next NIH Summit is September 23-25, 2024; the theme is the path to precision medicine. NIA is also marking its 50th anniversary.

***Walter Koroshetz**, NINDS*. There are 23 NINDS ADRD funding opportunities currently open and planned, focusing on vascular risk factors for dementia, Frontotemporal Dementia (FTD), and Lewy Body Dementia (LBD). Recent research has pointed to changes in blood flow that occur before there are structural vascular changes. Other research relates to α-synuclein proteins in spinal fluid that can help diagnose FTD, LBD, or Parkinson's disease that can also affect people with Alzheimer's. TDP-43 is a proteinopathy found in ALS, a dementia called LATE, and FTD and Alzheimer's; work is being done on biomarkers for TDP-43.

***Eric Weakly**, SAMHSA*. SAMHSA helped release the National Strategy for Suicide Prevention, including many references to older adults, who have the highest suicide rates. Studies have indicated links between dementia and suicide. An Older Adults Suicide Prevention Policy Academy is being planned for Summer 2024. SAMHSA has also created a document for states on mental health and aging and programs that states can implement. May 2 was Older Adults Mental Health Awareness Day, with a 7th annual symposium co-sponsored by ACL, HRSA, and SAMHSA.

Crisis in Primary Care

***Adrienne Mims**, MD*

Dr. Mims provided a review of the 2021 National Academies of Sciences, Engineering, and Medicine (NASEM) Report, *Implementing High Quality Primary Care: Rebuilding the Foundations of Healthcare*, and *The Health of US Primary Care: 2024 Scorecard Report*. The NASEM report includes an evidence-based plan with actionable objectives and recommendations for implementing high-quality primary care in the United States. The Scorecard Report highlights five reasons why access to primary care is getting worse (and what needs to change): primary care workforce shortage, too few primary care residents with community-based training, underinvestment in primary care, technology burden, and insufficient primary care research. Dr. Mims charged meeting attendees with keeping in mind what system changes are needed to improve the quality of care for people living with dementia and their care partners.

Clinical Care Panel: Focus on the Clinical Care Post Diagnosis

Demographics Post Diagnosis

***Amy Kelley**, MD, MSHS, NIA*

People with ADRD have a higher prevalence of chronic, co-morbid conditions, impairment in activities of daily living (ADLs), and frequent hospitalizations and emergency department visits than people without ADRD. Care needs often extend 10 years or more. Seventy percent of care partners report stress in coordinating care and finding support, and their own health and wellbeing is often negatively impacted. Costs of informal care for people with ADRD also greatly exceed those of people without ADRD.

The NIA has supported several efforts to improve these outcomes. In 2018, the NIH commissioned a study to review existing literature on care and caregiving interventions. It found that most studies were of limited quality and recommended more robust evaluations of two types of interventions--collaborative care models and Resources for

Enhancing Alzheimer's Caregiver Health II. In July 2023, CMS announced a new voluntary collaborative care model, the GUIDE Model, focused on dementia care management and aimed at improving quality of life for people with ADRD, reducing caregiver strain, and enabling people to remain in their homes and communities. The Emergency Departments Leading the Transformation of Alzheimer's and Dementia Care Study was awarded in 2023 to improve care for people with ADRD and their caregivers visiting the emergency department. The IMPACT Collaboratory has established the Long-Term Care Data Cooperative, an integrated database of electronic health record data from more than 2,000 nursing homes in the United States.

Voice of the Caregiver of Person Living with Dementia (PLWD)

Roberta Cruz

Roberta Cruz shared her 9-year journey caring for her mother with ADRD while also raising two young children. She described the many challenges they faced as a family, and factors that helped them obtain good care. Her physician husband's knowledge of the medical system was a great advantage. Her family's cultural background emphasized treating medical professionals as an authority not to be questioned, so her husband's advocacy and knowledge were critical. They lived in communities with good medical care. However, navigating the process as a young mother and without a support network or any generational wealth was challenging. Small things like parking and getting to a physician's office within a large medical system can be tiring when caring for both an older parent and young children simultaneously. Ms. Cruz emphasized that there is too much to navigate for one caregiver alone. Over the course of her mother's illness, their family made several changes to care arrangements, including enrolling in concierge care, moving her mother into memory care, moving her back home, and utilizing hospice services. There was a constant need to weigh her mother's needs against the needs of her family.

"NO-CRISIS" Care: Toward Lifetime Health and Wellbeing in Dementia

***Soo Borson**, MD BOLD Center of Excellence on Early Detection of Dementia, Dementia Care Research and Consulting Clinical Care Panel: Care After Diagnosis*

ASPE identified 14 key components of dementia care in 2016. Uptake rates for these components are generally very low or unknown. As of 2023, only about 30% of Medicare annual wellness visits include cognitive screening. One study found that nearly half of dementia diagnoses happened during an unplanned hospital stay. Once a diagnosis is made, high continuity of care can reduce crises such as emergency department visits and hospitalizations. Primary care physicians (PCPs) have an important role to play in continuity of care, including participating in detection and diagnosis, educating patients and caregivers, and coordinating care, but PCPs often are not confident in ADRD diagnosis and care.

Dr. Borson has identified six domains of health in whole person care that have been incorporated into a medical teaching curriculum: cognitive health and function; emotional and behavioral health; physical health and function; care partner capacity/needs; health related social needs; and the care delivery framework. This is a teachable framework that sees the whole person and meets needs that arise. First, the clinician needs to detect where there is a problem. Next, a detailed assessment is conducted in the relevant domains, and finally, there is care management.

Typical Cases in Primary Care of Patients Living with Dementia

***Monica Parker**, MD, Goizueta Alzheimer's Disease Research Center, Emory University*

Dr. Parker presented three case studies of older women with ADRD, their co-morbid conditions, and their route to being diagnosed and treated. All three people had access to good health care but still experienced a circuitous route to getting the care they need. For people who have less access, such as non-English-speaking patients, it is even harder to access the care needed.

Care After Diagnosis: Specialty Memory Clinic

***Esther Oh**, MD, PhD Johns Hopkins Memory and Alzheimer's Treatment Center*

A 2016 study indicated that 80% of primary dementia care is provided by PCPs and roughly 3% each by geriatricians and neurologists. PCPs need more education on biomarker testing, the diagnostic process, treatments, and mild cognitive impairment. New Johns Hopkins patients often don't know or understand their diagnosis. Sensitive and impactful topics for patients and their caregivers to discuss include driving evaluations and advance care planning. Caregivers often must resign from their jobs to provide care due to limited adult day and in-home care options. Families need respite, care coordination, and direction on where to go for quality information and care. Advance care planning that focuses on "goals of care" is necessary and ideally happens before a crisis or hospitalization.

Facilitating Cognitive Assessment in Primary Care for the Timely Detection of Alzheimer's Disease

***Ian Neel**, MD, UC San Diego Health*

The new Cognitive Assessment and Care Plan (CACP) code pays for physicians' time to assess patients who are demonstrating signs of cognitive impairment and encourages the integration of cognitive assessment into clinical practice. To date, the code is underutilized, partly because of lack of awareness.

Billing for CACP services requires ten steps, performed by the physician and care team: (1) a physical exam and cognitive history; (2) documented decision-making of moderate-to-high complexity; (3) a functional assessment of ADLs/instrumental ADLs and decision-making capacity; (4) formal dementia staging; (5) medication review; (6) evaluation of behavioral and neuropsychiatric symptoms; (7) evaluation of home and driving safety; (8) caregiver identification and needs assessment; (9) advance care planning and palliative needs; and (10) development of a care plan. Telehealth visits may be used.

Integrating this process into existing workflows will take time. Dr. Neel emphasized the need for empathy and taking time to listen. These are difficult diagnoses to share. He recommended having written resources to provide to families and looking at education as an ongoing process that will occur over many visits.

Clinical Care Panel: Appropriate Care Across Health Care Settings

Integrating Primary and Specialty Care

Anna Chodos*, MD, University of California, San Francisco Dementia Care Aware*

Specialty care guidelines for PLWD are frequently lacking or vague. Dementia diagnoses often preclude patients from participation in clinical trials addressing other conditions, resulting in lack of data and guidelines on how to best treat PLWD and other conditions. Dementia can quickly worsen in the context of serious co-morbidities and people with chronic conditions need a lot of care coordination. PLWD may have challenges navigating treatment for other diseases and specialists may not consider whether they can self-manage their own care. Poor management of co-morbidities can contribute to more rapid cognitive decline. A personalized plan, coordination between clinicians and health care team members, advance care planning, and working with caregivers are essential. Dr. Chodos presented two case studies of older adults with co-morbid conditions, and the process of coordinating care and developing a care plan.

Hospital Care: American Geriatric Society CoCare Hospital Elder Life Program (AGS CoCare HELP)

Heidi Wierman*, MD MaineHealth*

Dementia is a risk factor for delirium, which often presents differently in people with ADRD as being tired or sleepy. People with ADRD and delirium can have accelerated cognitive decline. Proper prevention, recognition, and intervention for delirium can improve outcomes. The MaineHealth Medical System has successfully used the Hospital Elder Life Program (HELP), a delirium prevention program that uses volunteers to provide person-centered care. HELP has shown a 53% lower risk of delirium compared to controls and a reduction in falls, length of hospital stays, nursing home placement, and readmissions. HELP addresses precipitating factors for delirium. Targeted HELP interventions include maintaining cognition, early mobilization, nutrition and hydration maintenance (or improvement), employing relaxation/sleep protocols, and minimizing sensory impairment. Hospitals without the HELP program can prevent delirium by assisting patients with adequate movement, helping them order food, paying attention to hydration, avoiding waking patients for vitals and medications, providing daytime engagement, and knowing symptoms of delirium.

Geriatric Emergency Departments: Supporting Persons with Dementia and Care Partners Through Their Health Journey

Kevin Biese*, MD, MAT University of North Carolina at Chapel Hill*

PLWD are more likely to visit the emergency department, be hospitalized, and rehospitalized compared to those who do not. Safe and effective emergency department care strategies for PLWD are needed. Older PLWD are now taking amyloid monoclonal antibodies which have risk for intercranial bleeding and are not reliably detected by head CTs in most emergency departments.

Geriatric emergency departments are hubs within existing emergency department systems that can improve dementia care by identifying cognitive impairments, adapting care processes to reduce delirium risk, making referrals to support services, and addressing the patient’s chief complaint, geriatric syndromes and social determinants of health.

Building support for geriatric emergency departments requires aligning hospital incentives (e.g., decreased admissions and emergency department revisits, optimized hospital resources, and improved patient and staff satisfaction. The Geriatric Emergency Department Collaborative has developed an accreditation program that currently has 491 accredited sites.

Discussion

- Dr. Mims commented that some people go to the emergency department because they cannot get into primary care.
- Helen Bundy Medsger shared a negative experience with taking her sister with ADRD to the emergency department and having to wait an hour to see her. Dr. Biese concurred that this is a problem. Hospitals need to be aware that “caregivers are not visitors.”

Clinical Care Panel: Navigation of Care Through Advanced Disease

Care Ecosystem: Navigating Patients and Families Through Stages of Care

Kate Possin*, PhD, University of California, San Francisco*

Care Ecosystem is a telephone-based collaborative care scalable model begun in 2013. The model includes a Care Team Navigator (CTN), an unlicensed but trained care guide, as the primary point of care. CTNs consult with a team (pharmacist, nurse, and social worker) to provide personalized caregiver support and assistance with decision-making (medical, legal and financial), and managing medication and behavioral challenges.

Caregiver needs differ by dementia stage: Help is needed processing the diagnosis, navigating relationship changes, planning for care, and learning about resources (early stage); managing behavioral symptoms and other symptoms such as incontinence (moderate stage); pain management, caregiver respite and support, and hospice care (advanced stage).

Care Ecosystem was studied through a randomized clinical trial. Caregiver wellbeing and patient quality of life improved, emergency department visits, polypharmacy, and total Medicare claim costs were reduced. The monthly cost reduction was about $500 per month; cost savings were greatest among people with moderate to severe dementia. Costs of the Care Ecosystem Program vary by caseload and are highest at startup. The Care Ecosystem toolkit, care protocols, and CTN training program are free, and materials are available in Spanish and Chinese.

Integrated Memory Care Clinic

Carolyn Clevenger*, DNP, Emory University*

Integrated Memory Care (IMC) is a care model developed by Emory University, delivering primary care through a single site, led by geriatric nurses and physician supported. The model has expanded to 19 communities in metro Atlanta. Patients come to one team for most care (minor illnesses, hospital follow up, and care coordination). Dementia care includes full assessments, diagnosis, guidance and planning, and coordination with LTSS. Caregivers can receive one-on-one visits with practitioners, education classes, stage-based support groups, ad hoc dementia education, and family therapy. IMC outcomes compared to usual care show lower risks of hospitalization for any reason and of high-risk medication use.

A patient-family advisory council drives clinic processes and policies. Specialists, including palliative care specialists, are consulted in alignment with family care goals and to facilitate discussions on sensitive topics. IMC also connects families with community services and provides after-hours access to IMC dementia expert clinicians and same-day appointments.

Discussion

Advisory Council members shared reflections from the day's presentations:

- Adrienne Mims--The goal today was to understand what the clinical system is like for PLWD and their caregivers. There are best practices out there, but they are not widely disseminated.
- Keun Kim--Electronic medical records (EMRs) do not provide sufficient access for patients with limited English. The top EMR companies should make their tools available in other languages.
- Randall Bateman--The situation in the emergency department is not good for patients--it may be the worst place for people with ADRD. Acute delirium is a common reason for emergency department visits, and there is a lot of basic science and clinical research to be done on delirium.
- Shari Ling--How can CMS identify the registry data to share and how/when to do so?

- Joanne Pike--Reflected on the experience of administrators in the scenarios explored today. How can we incentivize and create change in the system based on quality and evidence? Especially in those places that are hard to serve and do not have robust infrastructure.
- Yakeel Quiroz--The team-based approach to care is important, along with psychosocial support. Also, we need to do better outreach to non-English-speaking communities.
- Deke Cateau--The health care system is very fragmented. Nursing homes operate even further outside this continuum but play an important role. We need better connections.
- Rhonda Williams--Emphasized the role of public health in convening and supporting efforts across the spectrum of care, including facilitating uptake of already available resources.
- Helen Bundy Medsger--Is interested in how to disseminate information on the programs shared today. How can we create partnerships to learn from these models? Adrienne Mims reminded attendees that Joanne Pike hosted a recent summit for payers to do just this.
- Roberta Cruz--How do we reach people who are not in an urban setting? And how can PCPs engage caregivers in the conversation?
- Fawn Cothran--How can we make caregiver resources accessible? Knowledge of the health care system and access to it involves privilege. How do we reach all caregivers?
- John-Richard Pagan—It is encouraging to hear about work such as CMS audits of schizophrenia medication use without a proper diagnosis. It is also frustrating to still hear dementia associated with old age. There are a lot of people who have dementia in their 30s and 40s.

Public Comments

- Subashri Garim, a Gerontology student at Georgia State University, shared concerns about low clinical trial participation of minorities in recent studies of new dementia drugs. Older Black adults are twice as likely to be diagnosed with dementia, and the medications may not work the same for everyone. The council should recommend better recruitment in underserved communities, which requires building community trust and addressing stigma.

- Cara Armstrong, an ambassador for the National Down Syndrome Society whose daughter has Down syndrome and who became a caregiver to her father with Alzheimer’s disease shared comments. The lifetime risk of Alzheimer’s disease is over 90% for people with Down syndrome. Individuals with Down syndrome need to be appropriately included in clinical trials and research, and provided access to new treatments and clinical care, and provide caregiver support.

Challenges and Supports Unique to Young Onset Persons Living with Dementia (PLWD) and Their Care Partners and Families

LTSS Challenges Unique to Younger Onset

***Susan Frick**, MSW, LSW Rush University*

Early symptoms of PLWD are often misattributed; seeking and getting an accurate diagnosis takes time and access to specialists is limited. Resources specific to young onset PLWD can be hard to find. Since 2004, the Rush Alzheimer’s Disease Center has run Without Warning, a support group for young onset PLWD and their family members. Frick shared their perspectives. Young onset PLWD may feel isolated, depressed, anxious, and have role, mood and personality changes. Loss of job, benefits, and autonomy are impactful to them. Balancing concerns about safety and autonomy of PLWD can be hard for families. Family members report feeling socially isolated and caregiving taking much of their time and resources. Caregivers must often leave their jobs to provide full-time care, or take on more work, which is difficult to balance with caregiving. Needed resources include adult day services, respite, home, residential, and palliative care, hospice, and legal and financial expertise.

The Voice of the Young Onset, Single, Veteran, LGBTQ+

Br. John-Richard Pagan

Brother John-Richard Pagan is a veteran, Latino, member of the LGBTQ+ community, and is living with LBD. As a young onset PLWD, his parents are his caregivers, which is something rarely discussed. His dementia symptoms started in his late 40s and prevented him from completing his PhD studies. His relationship with his boyfriend ended, and several people, including family members, did not believe his diagnosis was real. He could not relate to the older adults and their spouses that he met in a support group.

He receives a VA disability check but is no longer able to work and is not eligible for Social Security, Medicaid, or Medicare. He did not have time to obtain long-term care (LTC) insurance or save for retirement. He has struggled with feeling like a burden to his family and is concerned about what will happen to him if something happens to his parents, who are in their 80s. As a veteran, he can receive care in a VA facility, but does not feel comfortable receiving care there as a gay man.

Love, Loss and Resilience: A Caregiver Perspective on the Impact of a Young Onset Dementia Diagnosis

***Katie Brandt**, MM, Massachusetts General Hospital FTD Unit*

Katie Brandt shared her personal experience as a caregiver to her husband who was diagnosed with Behavioral Variant FTD (BvFTD) at the age of 29 and her father, who was diagnosed with early onset AD. Certain advantages helped her husband get an accurate diagnosis, including good insurance, paid time off of work, and an English-speaking spouse who was a strong advocate.

At 29 she was a caregiver for two men and had to leave her job, resulting in ineligibility for some financial aid. Their house was foreclosed, and she spent their retirement savings to get by. Costs for young onset PLWD is almost twice that of Alzheimer's. She experienced social isolation and was overwhelmed with responsibilities, including legal issues, medical appointments, educating herself about the diseases, insurance, and household management. During this, she was also a new mom. Although there is no cure yet for dementia, there is a cure for loneliness and isolation, and we can put in place programs to protect and help caregivers.

Young People of a Parent with Younger-Onset Dementia: How One Family's Story Inspired a Mission to Solve a Societal Problem

Diana Shulla Cose*, Lorenzo's House*

Lorenzo's House is an organization that empowers youth and their families living with young onset dementia. Their goal is to "shift the narrative" and build community. Their programs include: (1) Care Partner Connections, which matches peers to share support; (2) Light Clubs--virtual spaces to share stories and tips and learn mindfulness techniques; and (3) a Youth Summit--a worldwide virtual "camp" designed and led by young people who have a parent with young onset dementia.

The stigma that impacts young families living with dementia is damaging. Introducing innovative supports, increasing awareness, and connecting people provides them a lifeline.

Supporting People with Intellectual and Developmental Disabilities (IDD) as They Age: The Challenges and Opportunities

Amy Dewitt-Smith*, Neighbor Network of Northern Nevada*

In 2019, there were 7.39 million people with IDD in the United States, and only 19% were receiving state or LTSS. The majority are supported by family and other unpaid caregivers. Life expectancy for people with Down syndrome has increased to 60 years; 50% or more will develop dementia due to Alzheimer's, and this is the first generation that will likely survive their parents. Families need support planning for this reality. Caregiver training and support needs to be tailored to the IDD community and increase understanding that dementia will cause persons with IDD to lose skills, instead of focusing on habilitation--maintaining or acquiring skills.

Medicaid waivers often require habilitation; this funding model will need to adapt to an aging IDD population. Looking ahead, we can redefine success in LTSS for people with IDD, increasing programs that do not require habilitation and providing more in-home services.

Services and Supports for Young Onset: Gaps and Challenges

Frontotemporal Degeneration: Misdiagnosed and Misunderstood

Matthew F. Sharp*, MSS, Association for Frontotemporal Degeneration (AFTD)*

FTD, a group of brain disorders, affects about 60,000 people, and is often misdiagnosed. Symptoms include changes in behavior, personality, language, and motor function/movement, and can change over time. Two main variants of FTD are BvFTD (involving loss of social constraints, apathy, and empathy, withdrawal, and an inability to recognize self-impairment) and Primary Progressive Aphasia (involving loss of ability to understand language or speak). Other variants may involve motor symptoms and be misdiagnosed as Parkinson's disease or ALS. Most FTD cases are sporadic (no family history); about 40% are familial and a small subset are genetic. The financial impact of FTD is about twice that of Alzheimer's. Family income can decrease due to job loss and poor financial decisions made as part of FTD impairment. Families must navigate a complex care and services network. AFTD provides publications, small grants for people with FTD, support groups, and a helpline. For professionals, they offer diagnostic checklists, a newsletter, and webinar series.

Young Onset: Overview of Lewy Body Dementia, the Challenges, the Supports

Brandi Hackett*, LMSW, C-ASWCM, Lewy Body Dementia Association (LBDA)*

LBD is caused by Lewy body protein deposits in the brain and has two types: Parkinson's Disease Dementia and Dementia with Lewy Bodies. LBD is often misdiagnosed, affects 1.4 million people, and is very costly. Diagnosis barriers include limited clinical knowledge, lack of access to specialists, failure to report symptoms, and lack of reliable biomarkers. LBD can cause Parkinsonism, visual hallucinations, disrupted sleep, and cognitive fluctuations. Challenges for those with young onset LBD and their families include symptoms impacting more than cognition, ADLs affected early in the disease, altered perceptions, medication sensitivity, difficulty getting a diagnosis, residential facilities' lack of experience and training, and insufficient support networks. The LBDA provides education, volunteer "buddies" for caregivers, and support groups.

Unique Challenges of Those Living with Younger Onset AD or Other Dementia

Monica Moreno*, Alzheimer's Association*

About 200,000 PLWD are between ages 30 and 64; the average age of younger onset dementia diagnosis is 49. Unique challenges they face include job loss related medical and short-term and long-term disability coverage loss. Many young onset PLWD have financial obligations (mortgages, student loans, and families to support), and insufficient retirement savings. Downsizing and bankruptcy file is not uncommon. The 2-year waiting period after obtaining Social Security before eligibility for Medicare begins is a hardship for many. Young onset PLWD are often excluded from clinical trials. Adult children also face decisions about moving home to provide care at a time when they are beginning their careers. The Alzheimer's Association has an online support community and provides other education and support programs both in person and online.

Those with Young Onset Dementia in the Long-Term Care Setting

Deke Cateau*, A.G. Rhodes*

About 17% of nursing home residents and 6% of assisted living residents are under age 65, and these numbers are growing. Younger residents often feel out of place. Challenges for young onset PLWD in LTC include lack of age-appropriate activities and social connections, and ineligibility for financial resources.

Care costs are out of reach for many. Having young onset dementia should be an immediate qualifier for Medicare. The process for becoming Medicaid-eligible can devastate families financially. Possible ways to improve care for young onset PLWD include the creation of integrated LTC living models, Medicare coverage for all dementia, expansion of Medicare coverage and Older Americans Act services to include adult day and respite services, and development of programs suitable for younger people.

Discussion

- Helen Bundy Medsger asked what Advisory Council recommendations can make an impact. For example, tying the age of Medicare eligibility to the diagnosis.
- Keun Kim asked about the unique criteria that impact the LTC needs of young onset PLWD. Deke Cateau said that we simply do not know enough yet about these needs.
- Katie Brandt suggested that it may be more practical to educate the workforce on how to integrate people with younger onset ADRD into existing programs. For example, her dad "volunteered" at the local adult day, helping other participants. This helped him feel useful.

Dementia in Additional Populations

Rise in Homeless Adults 50+: Causes and Concerns

Margot Kushel*, MD, UCSF Center for Vulnerable Populations and UCSF Benioff Homelessness and Housing Initiative*

The proportion of single homeless adults over age 50 has increased from 11% (1990) to 48% (2023) and is projected to continue rising, driven by the affordable housing crisis. Nearly 60% of older renters struggle to pay rent. Dr. Kushel highlighted two research studies, the California Statewide Study of People Experiencing Homelessness and Health Outcomes of People Experiencing Homelessness in Older Middle Age (HOPE HOME) study which assesses participants every 6 months. Findings show that Black, Native American, and multiracial people are dramatically over-represented among the homeless and nearly half of older homeless adults first became homeless at age 50 or older. These adults differ from the younger homeless population and have been lower wage earners most of their lives and then face a crisis (e.g., job loss, divorce, illness, or death) without social support. About 20% became homeless after leaving an institution, often prison. Other findings include fair or poor self-rated health (53%); at least one (68%) or two or more (35%) chronic conditions; difficulty with one or more ADLs (43%) and mobility difficulty (32%). Mental health problems are prevalent and mortality rates are high (at least 33% of HOPE HOME participants died over a 10-year period. Among HOPE HOME participants, 26% had moderate to severe cognitive impairment and 35% moderate to severe executive function impairment. Many shelters are not equipped for disabilities. Dr. Kushel concluded with policy recommendations to improve access to affordable housing and targeted and equitable supports.

Aging in an Incarcerated Setting

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The United States incarcerates more people than any other country, and the prison population is aging. By 2030, 33% of those incarcerated will be over age 50. Those incarcerated have high rates of adverse childhood events, which accelerates aging and disease risk. Aging prisoners often experience profound health challenges (e.g., loss of mobility, vision, and hearing, serious illness, cognitive impairment, social isolation, and end-of-life care needs). Prisons need doctors and custodial staff with training in geriatric and palliative care and cognitive impairment, better programming for older adults, “normalized” spaces for end-of-life and memory care, and medical social work support. Dr. DiTomas described programs they have developed, including a memory care unit and a peer support program staffed by inmate volunteers who support people at the end of life.

State compassionate release program are underutilized. California recently added dementia as a criterion for release, but lack of post-release planning is a limiting factor. Policy recommendations include dementia training for law enforcement and criminal justice professionals, an obligation to provide humane care to incarcerated individuals, age-appropriate housing and supports, use of peer supports within prisons and at re-entry, more re-entry supports, and advocacy for compassionate release and medical parole.

Concluding Remarks

The next Advisory Council meeting is August 6, 2024, followed by one on October 21, 2024.

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.