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

Washington, DC

October 19, 2018

WELCOME, CHARGE FOR THE MEETING, AND UPDATES

Laura Gitlin, Ph.D., Chair, & Rohini Khillan

Dr. Gitlin opened the meeting at 9:10 a.m., noting that the Council could look forward to a fascinating and jam-packed agenda. She invited Council members to introduce themselves by stating who they represent and the Council subcommittees on which they serve. Gavin Kennedy, Acting Associate Deputy Assistant Secretary within the Office of the Assistant Secretary for Planning and Evaluation (ASPE) attended on behalf of Kara Townsend, Deputy ASPE. Katie Brandt, Susan Cooley, and Brad Hyman joined the meeting by telephone. Dr. Gitlin reflected that Council members wear many different hats, more so than ever before. This reflects the issues they face in moving forward with dementia research and care.

National Plan Update

Ms. Khillan announced that the 2018 National Plan has been released in final form. A link to the plan (which has an accompanying video) was sent via email to the Council listserv. The format returns to that of previous plans and is organized by goals, strategies, and actions. Due to Federal Government timing, recommendations are not included in the current update. It makes more sense that they influence next year's plan and the research planning currently taking place throughout the Federal Government. In future meetings, federal Council members can address those recommendations. The plan is indexed by year on the National Alzheimer's Project Act (NAPA) website. Viewers can click on a strategy and see how it has changed over time.

Impact of Care Summit

Dr. Gitlin said manuscripts are in development or have gone to press as a result of the first research summit on care and services. She encouraged panelists and speakers from the summit to move forward with presentation of their papers.

A meeting took place between the Alzheimer's Association and the National Institute on Aging (NIA) to discuss the groups' research priorities. The meeting helped the Alzheimer's Association determine how to leverage its research funds in terms of care and services.

2018 Recommendations

Ms. Khillan announced that the Council's 2018 final recommendations had just been posted on the NAPA website. She is compiling the three Driver Diagrams from the subcommittees into a single Driver Diagram, which should be completed within about a week.

Dr. Gitlin described a call to discuss how non-federal members can impact the dissemination of the recommendations. She said that Mr. Egge has agreed to co-chair an all-volunteer non-federal workgroup committed to disseminating the recommendations so they have an impact on the local, state, and national levels. Mr. Egge said that Capitol Hill is one main target. He noted that the current Congress has been busy as it approaches the elections and closeout of its current session. The summary and recommendations will be presented to the new Congress after it is seated in January as a way to introduce members to the issues of Alzheimer's and related dementia (AD/ADRD).

Actions by the Council

Planning for the 2020 Care Summit--ASPE and NIA have just begun working together on a plan to ensure the summit covers both science and stakeholder issues.

Identifying an approach/workgroup to outline best practices for comprehensive dementia care--Dr. Gitlin noted that one of the Council recommendations is to identify a workgroup/approach to evaluate existing quality indicators and best practices for comprehensive dementia care. She reported that she, Dr. Lubow, and Dr. Finke have volunteered for this effort. Others who want to volunteer can let her know by email. A workgroup will be organized by the end of the year and will report back to the Council in January.

Nomenclature--Angela Taylor noted that the Council has made recommendations on nomenclature for the last 2 years. The effort is needed because there is overlapping and confusing terminology across and within stakeholder groups. She said it is time to review the terminology to see what opportunities exist to improve them.

Toward that end, Ms. Taylor has formed a workgroup of researchers across the spectrum of dementia chaired by a former chair of the Council, Dr. Ronald Petersen of the Mayo Clinic. After two meetings, the workgroup has developed a preliminary strategy. Ms. Taylor and Dr. Petersen will chair a session on dementia nomenclature at the 2019 Alzheimer's Disease-Related Dementias (ADRD) Summit. She directed Council members to their meeting packets for a more in-depth overview of the nomenclature issue.

Ms. Taylor asked that the workgroup be formally charged to take on the nomenclature issue on behalf of the Council. Ms. Taylor presented the Council with an informal list of deliverables, including summit preparation and a process to formalize recommendations with the input of stakeholders and the public. She aims to complete a framework and strategy by March 2019 and eventually publish formalized recommendations.

Questions & Comments

- *Becky Kurtz* asked whether *Ms. Taylor's* group has seen the evidence-based work on aging and elder justice by the FrameWorks Institute. She suggested it would be a good resource for the workgroup. *Ms. Taylor* said she is aware of the Institute's work and it can inform the workgroup activities. *Dr. Gitlin* said the methodology used involved multiple stakeholders and is changing the stigma of language among health care providers.
- *Dr. Lubow* suggested that the workgroup should have at least one member with dementia. *Ms. Taylor* agreed.
- *Dr. Gitlin* moved to charge the workgroup on dementia terminology. The motion passed unanimously. She noted that the workgroup can get input from stakeholders at the ADRD Summits.

LTSS SUBCOMMITTEE AGENDA: ADDRESSING BARRIERS TO ACCESSING QUALITY HCBS FOR PEOPLE LIVING WITH AD/ADRD

Debra Cherry, Long-Term Services and Supports Subcommittee Chair

Dr. Cherry remarked that 2018 has seen a new high in funding for AD/ADRD. This is due in part to the work and recommendations of the Council. Members should feel good about that.

Even if an effective treatment is found for AD/ADRD in the next few years, decades will remain in which increasing numbers of people will be living with these conditions and families will struggle to care for them. That is where long-term services and supports (LTSS) come in. The Council is challenged to improve supports and increase access to them, which is the focus of the subcommittee's recommendations for this year:

Recommendation 1: Improve access to LTSS including nursing home care and home and community-based services (HCBS) among persons at-risk for and living with AD/ADRD and their caregivers.

The number and diversity of people living with AD/ADRD is growing, with the greatest burden for care falling upon family. Dr. Cherry said the subcommittee defines "family" broadly to include friends and communities. The subcommittee is hoping that federal and state programs, national organizations, and community groups will improve quality of and access to HCBS for the increasingly heterogeneous United States population.

Recommendation 2: Build more effective integration between clinical care and HCBS across the disease trajectory.

Many people who get an AD/ADRD diagnosis are left to cope on their own. The subcommittee wants everybody who gets diagnosed to get disease education, identification of an appropriate caregiver, a full assessment, and other supports needed to face this devastating disease. Recommendation 2 is an attempt to address what is missing.

Recommendation 3: Identify and address behavioral symptoms across the disease trajectory and in all care settings.

One reason people with AD/ADRD do not get quality LTSS is because they exhibit behavioral symptoms that are difficult to manage.

Dr. Cherry explained that each of the three following panels would speak to one of these recommendations. She challenged the Council to listen actively and called on federal, state, and community organizations to think how they can improve quality and access to HCBS services for heterogeneous populations, address behavioral symptoms, and improve integration of health care and community support.

SESSION 1: WHEN DEMENTIA IS DIFFERENT: MEETING THE LTSS NEEDS OF A HETEROGENEOUS POPULATION

Introduction: Katherine Brandt, NAPA Council Member (via telephone)

Panel Discussion:

Moderator: Cynthia Huling Hummel, NAPA Council Member

- Diana Blackwelder, National ES Advisor, Alzheimer's Association
- Mary Hogan, Family Advocate
- John Collinge, Caregiver
- Veronica Cool, CEO and Hispanic Strategist, Cool & Associates, LLC

Questions & Comments: Cynthia Huling Hummel, Moderator

Ms. Brandt presented the four goals of the panel discussion:

1. Heterogeneity is Here: Defining Our Differences--Ms. Brandt noted that dementia-related diseases affect people at many stages of life with varied cultural, lifestyle, and socioeconomic backgrounds.
2. Knowledge is Power: Learning the Needs of Our Entire Community--Understanding the unique needs of each individual within the community leads to an understanding of the needs of the entire community.
3. Stronger Together: Inclusion for Everyone--Inclusion of one segment of the population promotes access for all patients and caregivers.
4. Awareness to Action: Steps for Inclusion and Improvement Now--Developing an awareness of issues induces action.

Ms. Brandt related the story of her husband, Mike, who was diagnosed with frontotemporal dementia (FTD) at age 29. Her family faced the challenges of finding appropriate treatment at every stage of Mike's disease. Ms. Brandt said she is determined that FTD will not have the final word in her family's story. She noted that while there is not yet a cure for these devastating diseases, there is a cure for the isolation and loneliness that comes with a diagnosis. That cure is bringing together the entire community.

Ms. Brandt introduced the four panelists and session moderator Cynthia Huling Hummel.

By way of introducing herself, Ms. Huling Hummel described experiencing memory problems in 2003 when she was only 49 years old. She did not receive the diagnosis of amnestic mild cognitive impairment most likely due to Alzheimer's for 8 years. One of the obstacles to getting a timely diagnosis was that she did not fit the stereotype of someone in the early stages of Alzheimer's.

Ms. Huling Hummel said she agreed to moderate the panel to raise awareness of the challenges being faced when Alzheimer's looks different. She also wants to raise awareness that people living with a memory disorder are capable. They want to advocate for what they need and educate the medical community and others what it is like to live with a dementia diagnosis.

Ms. Huling Hummel described her family's genetic disposition to dementia disorders. She said she is fueled by family, friends, faith, hope, and love to do as much as she can for as long as she can to advocate for those with a dementia diagnosis.

Diana Blackwelder

Ms. Blackwelder described her experience with being diagnosed with younger onset Alzheimer's after a successful career as an information technology (IT) software systems integration and security engineer. She is 57 and single with no children and lives alone with her two pet cats. She is independent and wants to live as full a life as possible with shared, rich experiences. It has been a year since her diagnosis, but she has been living with the symptoms of Alzheimer's for several years. She spent a year debating whether to seek a diagnosis and another 2 years getting one. Her primary care physician (PCP) dismissed Alzheimer's as a diagnosis. Specialist appointments required months of waiting, misdiagnoses, and treatments that failed. She said she wanted to stick her head in the sand and wondered how many people do just that.

She said the geriatrician who gave her the diagnosis was compassionate and took the time to explain the next steps, but she was sent home with that list and expected to do it all alone. No one followed up with her. During a hospital stay, the lead resident informed her she could not possibly have Alzheimer's because she spoke coherently with him each day. There were no special procedures in the hospital for dementia patients to minimize noise, commotion, and other disturbances. It was up to her to communicate with all providers that she has Alzheimer's.

Ms. Blackwelder found that many counselors and support groups have a minimum age requirement of 65. The one resource she found for an early-stage patient with no fulltime caregiver is a 4-hour round trip from her home in the Washington, DC area. She found a private early-stage support group, but it was full. Helping facilitate the independence of people like her should be a priority because it alleviates the demands on caregivers. The medical establishment and community service providers need to have greater awareness of early-stage and younger onset Alzheimer's. This awareness will lead to standardized procedures to address patients at varying disease stages and levels of independence.

Mary Hogan

Ms. Hogan began her presentation with photos of people she has met over the last 7 years who have died due to complications of Alzheimer's disease. These people were born with Down syndrome in the 1950s and 1960s when families were encouraged to place their loved ones in an institutional setting. Their families fought to have them included in schools and communities. Now the fight is for inclusion in care for end-of-life issues, including dementia. People with Down syndrome and other intellectual disabilities (IDs) are living longer lives, into their sixties and seventies. People with Down syndrome are more susceptible to developing dementia at an earlier age than the general population due to their extra copy of chromosome 21. Most people with Down syndrome live with their families, and those families live in dread of a dementia diagnosis.

People with Down syndrome and other IDs often have complex health issues, poorer health outcomes, and health care disparities that are more evident with the progression of dementia. It is more difficult for them to report and their families to notice subtle changes in longstanding abilities. Physicians need to be retrained on the subject of aging and IDs so they can make a differential diagnosis rather than rushing to a conclusion.

Ms. Hogan presented a slide of people with Down syndrome who are also living with an Alzheimer's diagnosis, some in their 20s and 30s. She said she believes younger people are being misdiagnosed. When a person receives a diagnosis, family members are usually left to their own devices to problem solve. Social media helps families find each other for support. Once an Alzheimer's diagnosis is made, all behaviors are often attributed to the disease rather than co-occurring conditions. The greatest fear is that the family will not have access to a knowledgeable workforce that can act on their family members' behalf and support them as people. Other challenges include lack of respite care and the fact that Medicare funding makes it difficult to move to another state because funding does not follow. The goal is to make this not only a dementia-friendly world but a dementia-inclusive world.

The message from families is: Person-centered care needs to be truly person centered. We lack caring in health care. Our society needs to reflect on how we treat those who are most vulnerable and how we can make them included in our dementia care.

John Collinge

Mr. Collinge told the Council that he was there to honor his wife, Zandra, for whom he is a caregiver, and help others avoid the bumbling, stumbling, and groping that they both went through. Zandra is 14 years into visible signs of FTD. She was an accomplished senior foreign service officer and the first African American woman hired as a Secret Service special agent. She struggled to master Korean for an assignment in the late 1990s, but did not consult a neurologist until 2009, when symptoms were undeniable. The diagnosis was permanent, irreversible memory loss. She received an early onset Alzheimer's diagnosis in 2014. Thankfully, Zandra had taken out a superb long-term care policy. Mr. Collinge shared what he has learned through his journey:

- We still do not know much about dementia--why it occurs and how to treat it. Much more research is needed.
- There are plenty of brain booster solutions out there but they are silver bullets and silver bullets do not work in real life.
- Everyone needs long-term care insurance. It needs to be made available and affordable.
- If you or a family member seem to be slipping into sustained memory loss, see a neurologist. Press the neurologist to be thorough and candid about what the diagnosis means for the patient and family.
- As a caregiver, be honest with yourself about what you are seeing and feeling. Watch for burnout and depression. Tell your friends to be blunt if they see you wearing down and needing help.
- No caregiver can do it alone. Look to support groups, professionals, and other resources.
- Accept that the day will come when you have done all you can and you must give up caregiving. That is a gift of love.

Veronica Cool

Ms. Cool noted that she is not involved in government, research, or medicine, so her comments come completely from an end user's perspective. She launched her company 5 years ago after working with nonprofits as one of the few Latinas in corporate banking. She recognized the need for a bridge between the Hispanic segment and mainstream culture.

Ms. Cool related how her own family attributed her father's Alzheimer's-related memory loss to "old age." He passed at 91 from Alzheimer's-related complications. She saw how cultural and language barriers add to the typical struggles to get dementia care and resources. Hispanics are 34% more likely to be undiagnosed and one-and-a-half times as likely to have dementia. The culture and language gap is huge. Ms. Cool said she participated in the panel to draw attention to this gap. The Roadmap is glorious, but there is nothing about Hispanics and other cultures. Resources are not coming to the community. Support is not in the neighborhood coming from a culturally sympathetic place.

Ms. Cool urged the dementia community to think about cultural diversity in policy, grant writing, and staff. Eighty percent of Latinos use social media to network for resources. Even educated, articulate people have trouble getting services. Add the layers of cultural and language barriers and people have no idea that resources are available. Those resources need to be tailored to the community.

Questions & Comments

- *Ms. Huling Hummel* asked *Ms. Blackwelder* to describe a common misperception about a person with AD/ADRD who lives alone. *Ms. Blackwelder* replied that people see the situation as unsafe. She said people also misperceive that all those with AD/ADRD belong in a nursing home, not living alone, and should not drive. She said the secret is using mitigation measures and adjusting them as the disease progresses.
- *Ms. Huling Hummel* asked *Ms. Hogan* for suggestions to improve health outcomes for those with Down syndrome and other IDs. *Ms. Hogan* said health care disparities must be shrunk over time. Steps include training physicians with culturally-related information about IDs, acknowledgement of ageism in the dementia and disabilities fields, and distribution of tools available from the National Task Force Group on Intellectual Disabilities and Dementia Practices and other dementia-related groups. People need a support network at diagnosis and after. She called on the Council to pull together these resources into a toolbox for physicians.
- *Ms. Huling Hummel* asked *Mr. Collinge* what kind of supports would have helped him. He replied that he thought he could go it alone, which was a mistake. After friends pushed him to seek support, he reached out to the employee support group at his job. They directed him to a support group oriented toward elder care, not dementia issues. A year later, he connected with Iona Senior Services in Washington, DC. He signed up for an AD/ADRD support group, then a partner-caregiver support group. His wife also entered the arts and wellness program until she went into long-term care.
- *Ms. Huling Hummel* asked *Ms. Cool* how to better connect services with the Latino community. *Ms. Cool* suggested:
    1. Language access--Allocate resources to translate materials into Spanish. Make sure those who do the translations speak medical Spanish.
    2. Culturally-competent care--Recognize that Latinos often do not question doctors.
    3. Sensitivity--Latinos are currently vilified in the media, which discourages them from trusting sources they are not familiar with. Information must be grassroots and hands-on.
- *Mr. Tichawonna* said his parents also did not question doctors when his mother was diagnosed with dementia. He said he cannot overemphasize the importance of educating the first line of health care providers. There has to be a standard that physicians can use to approach the subject with patients. He added that this has been an ongoing issue during his 4 years on the Council.
- *Ms. Cool* commented that cultural and diversity goes beyond ethnicity. It includes religion, geographical location, and rural vs. urban lifestyles. All these layers

impact how we absorb information. A 30-minute online course is insufficient. *Ms. Hogan* added that photos of diverse populations in a publication do not equate to cultural competency. The information itself must be culturally rich. *Ms. Khillan* noted that cultural diversity is part of the nomenclature issue as well. *Mr. Spector* said the reluctance to question the doctor is also part of his rural culture. He added that the doctors themselves live in that culture, which impacts the way they interact with patients. *Ms. Hogan* pointed out that age is also a cultural factor. Older patients can be reluctant to question doctors. They fear the doctor will judge them and punish them if they express a concern.

- *Dr. Gitlin* said she was struck by how these discussion themes resonate with the October care summit's focus on the need for research on nomenclature, stigma, and adaptation processes for people living with dementia. *Dr. Cherry* said she was also struck by how the panel's themes need to inform the next care summit. Diagnosis requires a whole summit by itself and the Council needs to revisit the subject next year when discussing recommendations. This includes metrics for reducing the burden of getting a diagnosis.
- On the subject of workforce preparation, *Dr. Gitlin* said the emphasis should be on medical school curriculum to educate physicians, nurses, nurse practitioners, physical therapists, etc., rather than continuing education after the fact. Education has to change at the ground level and as soon as possible. She suggested the Council may want to have professional groups give presentations about competencies and accreditation requirements. She also suggested the Council invite the FrameWorks Institute to present on nomenclature.

Ms. Brandt thanked panel members for not only highlighting the heterogeneity of the disease but conveying what is the same--the need for dignity and respect and the opportunity for love, connection, and inclusion.

Dr. Allan Levey (via telephone) and *Ellen Blackwell* joined the meeting.

Dr. Gitlin introduced the panel on Managing Behavioral Symptoms of AD/ADRD, noting it will help the Council navigate their understanding of key critical features of AD/ADRD. There is research moving forward on how behaviors can inform diagnosis, yet they remain undertreated and misunderstood. Behaviors are also part of quality indicators that have to be understood and addressed. *Dr. Cherry* introduced panelist *Dr. Helen Kales*.

SESSION 2: MANAGING BEHAVIORAL SYMPTOMS OF AD/ADRD

Introduction: Michelle Dionne-Vahalik, NAPA Council Member

Panel Discussion:

Moderator: Laura Gitlin, NAPA Council Chair

- Helen Kales, M.D., University of Michigan, Ann Arbor
- Ellen McCreedy, Ph.D., Brown University

Questions & Comments: Michelle Dionne-Vahalik, Moderator

Dr. Kales

Currently 5 million people with dementia and their 15 million family members navigate all the spheres of dementia--medical, legal, functional, financial, and social--without resources, personalization, or training.

The behavioral and psychological symptoms of dementia (BPSD) are a big part of what people deal with on a daily basis. One-hundred percent of people with dementia will experience some type of behavioral change, and there are many symptoms that do not fall neatly into psychiatric categories. In one study, when caregivers were asked what the most problematic behaviors are, they named things like asking the same question over and over.

These changes in behavior are associated with outcomes such as greater functional impairment, worsened quality of life, potentially preventable hospitalizations, earlier nursing home placement, increased caregiver burden, and reduced caregiver income. BPSD add an estimated $10,000/year to care costs. Symptoms can also bring on severe dementia more rapidly and may even accelerate mortality. These outcomes create an imperative to improve dementia care for BPSD.

Dr. Kale presented three problems associated with dementia care for BPSD:

1. Inability to access relevant resources precisely when needed. There are fewer than 1,800 geriatric psychiatrists in the United States and very few PCPs with extensive dementia care training. Resources are available, but it can be hard for caregivers to find them when they need them. These shortages affect caregivers (burnout, depression, lost income), the person with dementia (health function, limited social engagement and activities), and dyads (lack of understanding, poor communication, expecting too much for the dementia stage).
2. Lack of personalized and precise dementia care. The lack of cultural sensitivity discussed earlier is part of the problem. Most day-to-day care focuses on behavior. Much of real-world management is centered on medicating or sedating people with dementia. This occurs without sufficient assessment.
3. Lack of training among caregivers and providers on how to use proven nonpharmacological strategies to manage behavioral symptoms. Medications--

many in use since the 1950s--are not very effective and usually do not treat the underlying problem. Medications can produce serious side effects including death. Limiting the use of one medication (antipsychotics) can drive up the use of others (anticonvulsants) that are less effective but have the same potential level of risk. Behavioral and environmental strategies are more effective, if chosen appropriately (precision medicine). Although antipsychotic use has declined, 55%-58% of people with dementia are still medicated with some psychotropic agent. Meanwhile, use of anticonvulsants has increased.

Dr. Kales co-developed a conceptual model to illustrate how neurodegeneration associated with dementia increases a person's vulnerability to stressors, which leads to BPSD. Many of the stressors, however, are modifiable. These include patient factors such as acute medical problems and unmet needs, caregiver factors such as stress and lack of education about dementia, and environmental factors such as safety issues and lack of activity and structure. Medication does not treat any of these factors. A paradigm shift is needed in how behavior is treated.

Non-pharmacologic treatment ("ecobiopsychosocial" interventions) has not often been translated into real-world care. This is due to lack of scalable training programs, lack of guidelines, the amount of time required, and the fact that there are so many interventions (acupuncture, music therapy) that it is hard to know what works.

The Program for Positive Aging convened a 2011 meeting of national experts across disciplines to consider how to solve these problems. The outgrowth is the DICE (Describe, Investigate, Create, Evaluate) Approach:

- *Describe* the challenging behavior in detail. Consider psychiatric medication only if there is a concern for harm/risk.
- *Investigate*--Search for clues by exploring the person with dementia, caregivers, and environment for triggers and possible causes of behaviors. Consider psychiatric medication if the behavior is not allowing a full investigation (e.g., fear of aggression, preventing blood draw or urine sample).
- *Create* a prescription in collaboration with the team to prevent and manage behaviors. Integrate pharmacologic and nonpharmacologic strategies without knee-jerk prescribing. Consider medication as a first line if there is serious depression, psychosis, or aggression with risk.
- *Evaluate* the prescription's effectiveness. Modify or restart as needed.

DICE training has been piloted in 1-day workshops that include both family and professional caregivers. Both groups significantly improve their knowledge. The most helpful aspects include workshop materials such as case studies and role playing, use of a simple framework, coverage of medication issues, and handouts to take home.

The DICE website will roll out December 1, 2018, to provide online solutions to the three big problems:

- *#1 Lack of access to relevant resources precisely when needed*--The website will allow families and professionals to access workshop modules in video format and practice what they learn in simulation videos. WeCareAdvisor is also available as an online resource, including a comprehensive Caregiver Survival Guide with professionally vetted information and links to additional resources. The website also includes supportive/motivational messaging for caregivers.
- *#2 Current dementia care is not personalized or precise*--The website includes an online personalized peer navigator that leads in applying the DICE Approach to figure out individual reasons for functional and behavioral changes.
- *#3 Lack of training for caregivers on nonpharmacologic strategies*--An algorithm using information from the DICE Approach provides an individualized "prescription" for the caregiver and person with dementia.

A randomized controlled 1-month trial of the WeCareAdvisor compared with a wait-list control showed significant reduction of distress in family caregivers. Caregivers also gave positive feedback on the tool.

Ms. Dionne-Vahalik introduced Dr. McCreedy, who made her presentation via telephone. Dr. McCreedy is the study director of Music & Memory: A Pragmatic Trial for Nursing Home Residents with Alzheimer's disease (METRIcAL). A cluster-randomized controlled trial of the Music & Memory program is set to begin in January 2019.

Under the program, staff identifies the music that nursing home residents with dementia preferred when they were between the ages of 16-26. Thousands of nursing homes are certified in Music & Memory. As a nonpharmaceutical alternative to manage agitated behaviors, the program's potential benefits include improvement of sleep/alertness, appetite stimulation, and quality of life. Rigorous evaluation is needed to establish efficacy and effective implementation.

The mechanism for music's effect on behavior is not completely understood. Groundbreaking neuroscience suggests musical memories are encoded in regions of the brain relatively unaffected by AD/ADRD. These familiar musical memories theoretically reduce agitated behaviors by addressing boredom, sensory deprivation, and/or loneliness.

Dr. McCreedy's team compared administrative data in nursing homes certified in the Music & Memory program to similar nursing homes that were not certified. Those with the program showed greater increases in antipsychotic discontinuation among residents and reductions in agitated behaviors. Limitations on the preliminary evidence are as follows: large variation in how the program is implemented; selection (nursing homes that get certified in the program are likely high performing); and a statistically significant but relatively small effect on behaviors, which may be due to staff underreporting behaviors that are commonplace in a nursing home setting.

METRIcAL just completed the 6-month Music & Memory pilot (R21) in four nursing homes with the aim of standardizing protocol and testing measurement strategy. A 4-

year pragmatic, cluster-randomized trial (R33) will involve 81 nursing homes and address the limitations of previous research with standardized protocol and measuring variation, randomized nursing home selection, and direct observation of residents when using and not using music. She pointed out an exciting feature of iPod that allows collection of metadata to measure when music use begins and ends and what songs are played.

The pilot involved four nursing homes, one from each corporation that will be participating in the trial. Forty-seven residents with moderate or severe dementia received the Music & Memory program over the 6-month period. Thirty-four residents had data available pre-music and post-music. Results show a 16% overall reduction in agitated behavior using the program. Direct observation tools were the Agitation Behavior Mapping Instrument and the Lawton's Modified Behavior Stream. Dr. McCreedy noted that no causal results are implied by this data.

Several barriers were identified during the pilot that likely apply to other pragmatic trials of nonpharmaceutical interventions. These include measurement challenges, providing opportunities for nursing staff to "own" nonpharmaceutical interventions by witnessing their value, and the obstacle of low-quality nursing homes without consistent high-speed Wi-Fi for downloading preferred music. Dr. McCreedy emphasized that interventions must have low-tech adaptations or the most vulnerable dementia patients will be left out.

Questions & Comments

- *Ms. Dionne-Vahalik* related that 4 years ago, Texas was ranked 51st in the nation by the Centers for Medicare & Medicaid Services (CMS) for antipsychotic usage in long-term care facilities. This triggered a search for the root cause and the realization that another approach to intervention was needed--a step that lead to Music & Memory. Today, Texas has more than 600 certified Music & Memory facilities among the state's 1,200 facilities. The CMS ranking is now 17th and, for the first time, the state is below the national norm for antipsychotic usage in long-term care facilities. Music & Memory has touched more than 10,000 people who live in long-term care facilities. Data analytics show decreases in problem behaviors and increases in quality of life. The METRIcAL research is needed because it is hard to promote an alternative intervention.
- *Ms. Dionne-Vahalik* asked *Dr. Hodes* if NIA is planning to do any work on music intervention. He replied that NIA is participating in the National Institutes of Health (NIH)-wide efforts, focused on the basic neuroscience of the relationship between music and the brain as well as more pragmatic applications. Ms. Blackwell noted that CMS uses Civil Money Penalty Funds to pay for grants to improve dementia care in nursing homes through nonpharmacological approaches. *Ms. Dionne-Vahalik* noted that most of the work done in Texas was through Civil Money Penalty funding.
- *Ms. Dionne-Vahalik* posed a general question about how information can be distributed broadly so people know about the music intervention. *Dr. Kales* said research must be elevated to the same level of pharmacological research or the

industry will dismiss nonpharmacological interventions as fluff because studies do not look at the same outcomes. *Dr. Gitlin* agreed that pragmatic trials are important. They show how interventions work in a real-world context so there is less of a translation problem. Technology such as online resources are important to bring the interventions from the developer to distribute them broadly. She added that measurement must consider the outcomes important to the end user. One such outcome is how long the impact of the intervention lasts. Is an immediate effect enough? *Dr. McCreedy* noted that nursing staff is asking for a "dose"--they want a script for music intervention. *Ms. Long* from the Administration for Community Living (ACL) awards grants through the agency's home and community-based program for thinking outside the box about low-cost innovative ways to benefit the community. *Ms. Dionne-Vahalik* noted that Texas is sharing information through its HCBS and programs for individuals with IDs.

- *Mr. Egge* raised the issue of getting information to PCPs. They often learn based on problems patients bring to the doctor's office. The DICE work is exciting because of the potential for patients to bring that work to their doctors. Dr. Kales added that physicians can actually help generate adequate treatment plans.

PUBLIC COMMENTS

Matthew Sharp, Association for Frontotemporal Degeneration
Mr. Sharp thanked the Council for how inclusive it has been on the subject of dementia. Accessing quality care remains a huge challenge for people living with FTD, their families, and their care partners. Mr. Sharp said he is glad to see the LTSS subcommittee give attention to the subject. At the root of the quality care problem is the fact that FTD is a rare disease that most health care professionals never encounter. This is compounded by the disease's unique presentations. Most of the time, FTD does not look like dementia, especially for providers who serve people in their 70s and 80s and who equate dementia with memory loss. A person in her fifties who just bought a new car looks successful. The fact that she used her children's college savings is usually hidden, and usually not considered a sign of dementia even when discovered. It takes someone with special experience to recognize personality and behavior changes as symptoms of a neurological disease. The answer is to have discussions and presentations such as those presented this morning.

Mary Anne Sterling, Sterling Health IT Consulting
Ms. Sterling's comments were read by Ms. Khillan.

Ms. Sterling updated the Council on her family's journey with dementia. She and her husband have three out of four parents impacted by it. With so much experience, she and her husband were convinced that they could find caregiving support for her mother-in-law. In fact, the only support they could access is 10 hours of respite per week from a U.S. Department of Veterans Affairs (VA) caregiver. It took 2 years to put that resource in place, which is disgraceful. Low-income seniors with Alzheimer's and their caregivers are falling through the cracks. Medicare does not cover anything related to Alzheimer's.

The only resource is navigating the complicated Medicaid eligibility process and placing loved ones in long-term care. This involves long wait lists for an eligible bed and nursing homes with a revolving door of staff who are not trained in dementia care. We need a sea of change in Alzheimer's care and a road map for HCBS to get us there. This is an epidemic and the response from the VA, CMS, and all federal agencies needs to reflect that.

Dr. Gitlin noted that phone attendees left for the afternoon.

SESSION 3: INTEGRATING CLINICAL CARE WITH HOME AND COMMUNITY-BASED CARE

Panel Discussion Moderator: Becky Kurtz, NAPA Council Member

- Tim Engelhardt, Director, CMS Office of Medicare and Medicaid Coordination
- Debra Cherry, NAPA Council Member
- Kathy Vesley-Massey, CEO, VAAA Cares
- Marisa Scala-Foley, Director, Aging and Disability Business Institute, n4a

Ms. Kurtz

Earlier in the day, recommendations being developed in the LTSS subcommittee were discussed, with the second recommendation aimed at building more effective integration between clinical care and community-based LTSS supports across the disease trajectory. That is also what this panel will focus on, including models for what is happening now and what to look forward to in the future. This is a hopeful conversation. There is a lot going on in this space and a lot more to do.

Improving health is only about 10% clinical care. Health behaviors, social and economic factors, genes and biology, and physical environment make up the rest. Although the United States spends an extraordinary amount on health care--17% of the gross domestic product, the highest amount among Organization for Economic Cooperation and Development countries--it does not spend as much as other industrialized countries on the social services that help make people healthy. Although the programs started at the same time, many, many more dollars are spent for Medicare than for social services under the Older Americans Act.

Mr. Engelhardt

Integrating clinical care with HCBS is important to holistic, person-centered approaches to care. Even though clinical care is only 10% of the picture, preventative and primary care are important to keeping people healthy as they age. Integration does not mean medicalizing HBCS nor "de-medicalizing" the physician's office.

Nineteen percent of the 12 million people simultaneously enrolled in Medicare and Medicaid are living with dementia. For the dually enrolled, Medicare is the primary payer. Dual eligibility correlates with poorer health outcomes despite the fact that CMS and the states pay out $300 billion/year. This is because this population lives with a full range of social risk factors, many associated with poverty and a high rate of disease burden.

There are other factors as well, including the financial misalignment between Medicare and Medicaid. That means investments or disinvestments in one program may result in savings or costs to the other. One example is state investments to improve care to Medicaid recipients resulting in savings that accrue to Medicare from lower acute care costs. Integrated care holds the promise of realigning these incentives.

The current approaches to integrated care are:

- Programs of All-Inclusive Care for the Elderly, a managed care benefit featuring a comprehensive medical and social service delivery system using an interdisciplinary team approach in an adult day health center.
- Dual-Eligible Special Needs Programs, which enroll individuals entitled to both Medicare and Medicaid in plans specifically designed to provide targeted care and limit enrollment to special needs individuals.
- The CMS Financial Alignment Initiative tests models that integrate service delivery and financing of both Medicare and Medicaid through federal-state demonstrations to better serve the population. The goals are to reduce expenditures while preserving quality of care and increasing access to quality and seamlessly integrated services for the dually eligible population. California's financial alignment initiative--Cal MediConnect--supports beneficiaries with a dementia diagnosis through health risk assessments and care plans, involvement of caregivers, and availability of dementia care specialists.

Debra Cherry

Dr. Cherry gave more details about the Dementia Cal MediConnect Project. She commented that all Council members want to see more home-based community care delivered when people can use it to avoid hospitals and nursing home placement. California has 1.1 million "duals" (Medicare/Medicaid eligible). Over 200,000 have AD/ADRD. One-tenth of the duals are in the demonstration. She listed the organizations providing funding for the initiative and the organizational structure with partners. These include three offices of the Alzheimer's Association, the Institute for Health and Aging, and the duals' 10 health plans.

The three-way contracts among CMS, the state, and health plans require that a trained dementia care specialist be in place in each health plan. Guidance is also provided on identifying a caregiver and includes an information brochure on dementia created by CMS and distributed to all the health plans. There is follow-up with health plans on their selection and training of dementia care specialists and how the plan handles dementia treatment.

The three project goals are:

- Better detection and documentation of patients with dementia.

- Better identification, assessment, support, and engagement of family/friend caregivers.
- Better partnerships with community-based organizations (CBOs).

Actions to put the project in place included:

- Advocacy with CMS, the state, and health plans.
- Case manager training and support.
- Extensive technical assistance to health plans.
- Support services for patients and caregivers.

Dr. Cherry described indicators of a dementia-capable system in terms of the project's three goals:

1. Better detection: Include a cognitive impairment question on the health assessment. Train care managers to conduct a validated screen for cognitive impairment and document it in the e-medical record. Have a protocol in place if the screening is positive.
2. Better support of family/friend caregivers: Place their names in the medical record, Conduct a validated assessment of their needs. Arrange for disease education and support. Engage caregivers (and patients when appropriate) in the care plan.
3. Better partnership with CBOs: Adopt a proactive referral tool to connect families to LTSS.

After 4 years, nearly 500 care managers and 109 dementia specialists have been trained. Tools provided to care managers include those for screening, evidence-based care management, and direct referral to local AD/ADRD organizations. Families are asked if they want to be contacted, then their information is provided to the support organization.

When the program was evaluated, all care manager training outcomes changed significantly from the baseline to 6 months. This included involving the caregiver in planning and referrals to HCBS. Changes also occurred in 10 health plan systems. Every health risk assessment used by these plans has at least one trigger question for cognitive impairment. Dr. Cherry highlighted numerous improvements in caregiver involvement and referrals to HCBS. She concluded with a video documenting one family's positive experience with Cal MediConnect and acknowledged the Cal MediConnect project team.

Kathy Vesley-Massey

Ms. Vesley-Massey described VAAACares, a statewide collaboration of the Virginia Network of Area Agencies on Aging (AAAs). She called it a one-stop shop from health care providers and systems to accessing community-based services. AAAs are Aging and Disability Resource Centers serving people 18 and older. They serve as the hub for care transitions, chronic care management, and behavioral health integration across Virginia.

VAAACares' evidence-based care transitions intervention model is a 30-90-day intervention targeted to patients with one or more acute hospital stays. The intervention becomes part of the discharge process. One reason for the model's success is that it works extensively in the home. The social needs of patients and caregivers are prioritized.

Two-year performance analysis shows the program saw 900-1,000 patients a month and was able to reduce the 30-day hospital readmission rate from 23.4% to about 9% for chronically ill patients. Evidence-based confidence scoring shows that patients score their confidence level when they leave the hospital at about 5. Intervention moves the scale to about 8. This is important because the more confident a patient or caregiver is, the less likely there will be a readmission.

The "secret sauce" of the program's success includes:

- Doing assessments and medication tracking, having a medication plan in place when the patient goes home, and facilitating the patient in keeping appointments with PCPs.
- Taking as much training into the home as possible. AAAs have been going into the home for 40 years and know how to talk to people about their real needs.
- Customizing the intervention, including based on the payer plans. People with AD/ADRD are included in the program as long as they have an active caregiver.

Ms. Vesley-Massey concluded with the real-life success story of a couple, the Millers. They overcame Mr. Miller's denial of his condition and Mrs. Miller's lack of knowledge about how to cope with a support system including respite care, telehealth medical monitoring equipment, an AD/ADRD support group for Mrs. Miller, and a care plan that worked for the couple.

Marisa Scala-Foley

Ms. Scala-Foley directs the Aging and Disability Business with a mission of building and strengthening partnerships between CBOs and the health care system. The aim is to provide older adults and people with disabilities the support they need to remain in their homes and communities as long as possible. Ms. Scala-Foley presented a list of the Business Institute's funders and partners.

She discussed new opportunities under the Medicare Advantage program as a result of the 2018 Creating High Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act. Among other provisions, the act expands Medicare Advantage supplemental benefits to include the flexibility to offer some types of LTSS.

Changes for 2019 include:

- Benefits may now be targeted to groups of beneficiaries who share a common condition. These targeted benefits must be medically related to that condition.
- Supplemental benefits must be “primarily health related.” The term is now defined more broadly to include benefits that prevent or treat an injury, compensate for physical impairments, ameliorate the functional/psychological impacts of injuries or health conditions, or reduce avoidable emergency or health care use.
- Benefits must be recommended by a licensed professional as part of a care plan.
- Some examples of benefits include adult day care services, respite care, transportation, and support for caregivers.

Changes for 2020 include:

- Expansion of supplemental benefits even further to allow those for which there is a reasonable expectation that they will improve or maintain the health or overall function of a chronically ill enrollee. Benefits may not be limited to being primarily health related.
- The HHS Secretary may waive uniformity requirements for supplemental benefits to chronically ill enrollees.

The door is open for CBOs to be paid for some of their services, particularly under the Medicare program. In order to do so, Ms. Scala-Foley advised organizations to:

- Define the value they bring to health plans, physicians’ offices, health systems, and accountable care organizations. How do CBO services align with what keeps payers up at night? One example is ensuring that patients make it to post-hospital and follow-up doctor visits.
- Focus on results in terms of services provided to older adults and persons with disabilities. An example is the impact an organization can have on a plan’s star ratings.
- Leverage experience in the Medicaid space, particularly familiarity with how CBOs can impact the quality of life of their members. If the CBO has current contracts with the Medicaid or duals plan, that is a great opportunity to approach the Medicare Advantage plans under the same company.
- Do not underestimate the value of retention and how CBOs can contribute to patient satisfaction.

Ms. Scala-Foley concluded with a list of resources for further information.

Questions & Comments

Ms. Kurtz began the Questions & Comments session with a list of additional resources:

- A *Health Affairs* blog from earlier this year on health care and CBOs with some examples of integration.

- A front-page article in the current issue of *Aging Today* from the American Society on Aging that includes an evaluation of the work described by *Dr. Cherry*. Also included is an example of using technology to determine the value proposition and return on investment that CBOs can bring to partners and payers.
- A book titled, The American Healthcare Paradox: Why Spending More is Getting Us Less.
- OECD.org, which offers a picture of how much social and health care spending is done in the United States compared to other countries.

Ms. Kurtz asked *Ms. Blackwell* to provide updates about what guidance to expect from CMS on the CHRONIC Care Act. Ms. Blackwell mentioned some additional benefits of the Act, including memory fitness and nonopioid pain management. She noted that CMS issues a Call Letter every April and that the Agency will work closely with colleagues to make sure the 2019 guidance aligns across Medicaid and Medicare.

Ms. Kurtz opened the floor to questions from all Council members.

- *Ms. Huling Hummel* asked *Ms. Vesley-Massey* what services are available for those in the early stages of AD/ADRD who live alone. *Ms. Vesley-Massey* said the first step would be a visit from an options counselor to assess needs. The next step is putting a plan in place for care as the AD/ADRD progresses. She clarified for *Mr. Kurtz* that services are not limited to those with a caregiver. As an agency on aging, VAAACares will talk to anyone. Although no services are offered specifically for dementia, her organization works hand-in-hand with the Alzheimer's Association.
- *Dr. Cherry* commented that, in looking at the list of evidence-based health promotion programs, they seem to omit many of the evidence-based caregiver programs, like Savvy Caregiver or Powerful Tools for Caregivers. Savvy Caregiver seems to reduce caregiver depression and anxiety and improve tolerance for challenging behaviors. *Ms. Kurtz* said the AAA in her area does provide powerful tools for caregivers. AAAs try to reflect the needs in their area. *Ms. Velsey-Massey* noted that VAAACares works with the Rosalynn Carter Institute for Caregiving. VAAACares now guarantees services statewide.
- *Dr. Gitlin* said the information presented by the panel represents the potential for dramatic changes, particularly in supplemental benefits. It represents a different paradigm of care that is not understood by providers. She asked *Dr. Cherry* how she views future funding and if supplemental benefits will help. *Dr. Cherry* said her organization will continue to thrive because of its range of revenue sources. She is hoping to have some support from Medicare Advantage. Partners need to be educated about what is available, and then you can take the step of getting paid for the work that you do. *Ms. Scala-Foley* said the Business Institute has already conducted webinars to educate CBOs on changes to the supplemental benefits. The Institute plans to do more, including one-on-one consultations and small group work. There also needs to be joint work between CBOs and health plans to determine what programs meet a person's holistic needs.

WRAP-UP

Debra Cherry

Dr. Cherry said she was struck by common themes that emerged from all three panels:

Persistence of Issues--Change is iterative. We move forward and we slip back. There were three types of change Dr. Cherry noticed that could have special impact for the people in the room.

1. Workforce and caregiver training: The workforce must be capable of dealing with the increasing heterogeneity of the population.
2. Person and family-centered care: The broad family (including friends and community) needs to be included in care planning over the course of this disease.
3. The importance of social determinants of health care: This includes poverty, literacy level, and lack of family caregiver support. How can you deal with dementia when you face overriding issues of food and housing?

Dr. Cherry listed actions needed to tackle these themes in the context of the Council's 2018 recommendations:

- Increase the funding for HCBS and nursing home care.
- Determine how to target existing research and services programs to a diverse population. For example, if you're building a grant, you need to look at what is effective for diverse populations.
- Scale evidence-based nonpharmacologic approaches to serve diverse populations.
- Create more information bulletins to help push providers for better quality of care.
- Address health IT issues about getting a person's diagnosis into his/her electronic record and the privacy issues surrounding information necessary for referrals.

FEDERAL WORKGROUP UPDATES

Research Federal Workgroup Update

National Institute on Aging
Richard Hodes, M.D.

- This year, the budget for NIH has been appropriated on time at the beginning of the fiscal year (FY), so research can proceed. In a bipartisan, bicameral effort, NIH has been appropriated $39 billion, a $2 billion increase over last year and $9 billion over 4 years. The budget earmarks:
  - $40 million increase for the universal flu vaccine

    - $29 million increase for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative
    - $86 million increase for All of US
    - $3.1 billion increase for NIA
    - $425 million increase for AD/ADRD research
    - $84 million increase for other NIA research
- Milestones from the 2017 National Research Summit on Dementia Care and Services have been incorporated into overarching AD/ADRD research milestones that will translate into initiatives in care and services as well as basic research. These milestones informed the FY2020 AD/ADRD Bypass Budget. Planning for the next care summit is already underway.
- Dr. Hodes provided a list of initiatives to be funded in 2018-2019 focused on the themes of care and services, including disparities, access to care, impacts on families and communities, health care systems research, and behavioral and social networks.
- The second AD/ADRD Care/Services Summit will take place March 24-25, 2020, in Bethesda, MD.
- The Agency for Healthcare and Research Quality has chosen the researchers who will conduct an evidence review of care interventions for individuals with dementia and their caregivers. Dr. Hodes presented the National Academies of Sciences, Engineering, and Medicine committee that will provide input on questions and study design.
- NIH's first eureka prize competition is called Improving Care for People with AD/ADRD Using Technology (iCare-Ad/ADRD) Challenge. The goal is to provide software apps that will improve dementia care coordination and/or care navigation. Up to $400,000 in cash prizes may be awarded. Submissions will be accepted until June 30, 2019.
- A representative from the VA briefed the Council on ongoing collaborations between NIA and the VA, including Collaborative Aging (in Place) Research using Technology and the International Alzheimer's and Related Dementias Research Portfolio (IADRP), to identify and close key knowledge gaps. Other planned collaborations include an interagency workshop on deployment-related traumatic brain injury as a risk factor for dementia, an effort to increase veteran participation in NIA-funded clinical research, and a development program to match young VA clinicians with NIH-funded mentors.
- Dr. Hodes noted the upcoming ADRD Summit 2019 to be held March 14-15 in Bethesda, MD.

LTSS Federal Workgroup Update

Administration for Community Living/Administration on Aging
Erin Long

- At the end of September, ACL awarded 19 new grants under its 2018 Alzheimer's Disease Programs Initiative for states and communities. Grants totaled $16.9 million to cover a broad range of activities, including helping states develop dementia-capable systems. New for 2018, 50% of total grant awards go to direct services, including substantial training and behavioral symptom management. Additional grants went to the Alzheimer's Association for its national call center ($1.2 million) and its program for Strengthening the Financial Literacy and Preparedness of Family Caregivers.

- The Administration on Aging's National Family Caregiver Support Program (NFCSP) received a $30 million funding increase in 2018 for a total of $180 million. The highest priority of service requirement is diagnosis of AD/ADRD. Sixty-two percent of persons served are caregivers of people with a medical diagnosis of AD/ADRD. NFCSP offers dementia-specific, evidence-based caregiver training.
- Ms. Long listed ACL's latest webinars on improving health care, first responder (law enforcement) training, and health disparities.
- In August 2018, 296 Tribal grantees, Tribal stakeholders, and federal partners attended the Title VI National Conference. Workshop topics included Alzheimer's in Indian Country, supporting those living with dementia, and dementia assistance for elders.
- Ms. Long presented a sampling of ACL's Long-Term Care Ombudsman Programs, including emergency preparedness, nursing home eviction and discharge, and sexual abuse in nursing homes.

Indian Health Service
Bruce Finke

- The Native Elders National Indian Council on Aging Biennial Meeting held in September 2018 presented two panels related to Alzheimer's, which reflects the growing interest and awareness of the disease in the Native American community.

Centers for Disease Control and Prevention
Lisa McGuire

- The Centers for Disease Control and Prevention (CDC) released a paper demonstrating some of the projections for AD/ADRD, including a tripling of the number of people with the disease between 2014 and 2060. The paper also identifies racial and ethnic disparities.
- CDC released a Morbidity and Mortality Weekly Report (MMWR) based on CDC grand rounds in collaboration with the Alzheimer's Association, AARP, and others. The MMWR emphasized supporting older adults in being healthy and independent as long as possible.
- CDC published a paper on the economic value of informal caregiving, financial and health barriers, and caregiving-related difficulties.
- CDC distributed to NAPA members print copies of the Healthy Brain Initiative Road Map, 2018-2023. The publication identifies 25 action items for state and local public health departments that are applicable to other organizations as well. CDC will post topic-specific maps based on road map contents, including early diagnosis, caregiving, and risk reduction/risk identification. These and other related documents will be rolled out in coming months. The road map for Indian Country may be available by NAPA's January meeting.

- As part of its data series, CDC has an infographic based on its behavioral risk factor surveillance system, which sponsors the caregiving module. The infographic's map of the United States shows the states that have administered that module. Still to come are state-specific infographics for those that have administered the module,
- Ms. McGuire highlighted Memory Sunday to take place this year on June 10. Sponsored in conjunction with The Balm in Gilead faith-based organization, Memory Sunday reaches 246 primarily African American congregations to raise awareness about Alzheimer's and the importance of caregiving.

Clinical Services Federal Update

Centers for Medicare & Medicaid Services

Ellen Blackwell

- The official measure of the National Partnership to Improve Dementia Care in Nursing Homes is the percentage of long-stay nursing home residents who are receiving an antipsychotic medication (excluding those with certain conditions). The goal for nursing homes with high rates of use is to decrease antipsychotic medication use by 15% by the end of 2019.
- The updated *Hand in Hand: A Training Series for Nursing Homes* is now available online as self-paced training or an instructor-led course.
- Beginning in 2019, CMS is expanding the definition of "primarily health related" for Medicare Supplemental Benefits. As a result, nearly 270 Medicare Advantage plans will provide an estimated 1.5 million enrollees new types of supplemental benefits in 2019.
- The Patients Over Paperwork is an agency-wide process to streamline regulations and operations to reduce unnecessary burdens, increase efficiencies, and improve the customer experience. Ms. Blackwell urged interested parties to sign up for newsletter updates and find up-to-date information on the CMS website.
- The CMS Quality Conference is scheduled for January 29-31, 2019, in Baltimore, MD. The focus is on current topics in health care quality.

Department of Veterans Affairs

Marianne Shaughnessy, Ph.D., CRNP

- The VA Geriatric Scholars Program is the primary method by which the department is preparing the VA workforce to meet the needs of older veterans. The program is jointly funded by the Office of Rural Health (ORH) and Office of Geriatrics/Extended Care. There are 12 Geriatric Research, Education and Clinical Centers (GRECC). GRECC Connect presents webinars for VA staff focused on cognitive impairment and dementia.
- VA is enhancing the curriculum of its REACH-VA Caregiver Support Intervention program to include REACH into Indian Country. The program has exceeded its goals of a trained and certified Tribal Coach in at least 50 tribal communities. There are now 56 coaches.

- The VA ORH operates an initiative called Advanced Care Planning via Group Visits in which veterans are made more comfortable with the subject of advanced care planning because of their shared experiences.
- The ORH Veterans Rural Health Resource Center in Salt Lake City provides a Dementia Caregiver Video Series on its website.
- The Caring for Older Adults and Caregivers at Home program assists veterans with moderate to severe dementia who are living at home with a caregiver. The program provides support to keep the veteran at home as long as possible.
- The VA has a large Vietnam era cohort that is aging into the system. Many returned from Vietnam with emotional, psychological, and physical injuries for which help was not available or for which they did not seek help. Many of them self-medicated for extended periods of time. Many of them have traumas that have never been addressed and now have behavioral issues. The Behavioral Recovery Outreach (BRO) Team Training works to transition veterans from the nursing home environment to less restrictive environments in the community. BRO works with caregivers and family through a staged transition with support for managing behaviors.

Progress on the AD/ADRD Prioritized Research Milestones

National Institute of Neurological Disorders and Stroke
Roderick Corriveau, Ph.D.

Dr. Corriveau explained that additional AD/ADRD research funds from NIA are used by the National Institute of Neurological Disorders and Stroke (NINDS) for new milestone-responsive AD/ADRD research programs (FY17, $26.6 million) and increased investment in investigator-initiated AD/ADRD research (FY17, $19.6 million).

Dr. Corriveau presented AD/ADRD research initiatives and programs that respond to planning milestones:

Multiple Etiology Dementias, Health Disparities

- Detects--Consortium to develop paradigms to increase detection of cognitive impairment including dementia.
- Health disparities and AD funding opportunity announcement to encourage health disparities research.
- Vascular cognitive impairment dementia (VCID) and Stroke in a Bi-Racial National Cohort (REGARDS longitudinal study).
- Recruitment and retention strategy for clinical research planning efforts.
- Scholarship program for ADRD Summit 2019 to fund trainees’ attendance. They will benefit from a pre-meeting with researchers before the summit and a debriefing after.

Lewy Body Dementia (LBD)

- Supporting biomarker discovery studies for LBD.

- Leveraging existing LBD data and biospecimens for a meta-analysis to move the field forward.
- Pathway and target identification for LBD and AD/ADRD program.
- Structural biology of alpha-synuclein in LBD.

FTD

- Multi-center, interdisciplinary Tau “Center Without Walls.”
- FTD Sequencing Consortium.
- Structural Biology of Tau and TDP-43 in FTD.

Vascular Dementias

- National consortium to bridge the gap between academic biomarkers and biomarkers that are applied.
- Several initiatives on basic science of VCID.

NINDS is also interested in communicating with the public. The director is comfortable including in his message that high blood pressure is a risk factor for brain health and that preventing stroke by treating high blood pressure can protect brain health and possibly prevent cognitive impairment and dementia.

NINDS collaborates with nongovernmental organizations (NGOs) and through trans-NIH activities. NINDS met on June 22, 2018, with seven AD/ADRD-related NGOs to provide research updates and discuss opportunities for potential collaboration. Dr. Corriveau presented several trans-NIH AD/ADRD collaborations on research and workshops. He highlighted the IADRP, a database supported by public and private organizations worldwide.

A milestone resulted from a special session at the ADRD Summit 2016 that calls for development of consistent nomenclature in dementia research and care. Additionally, NINDS has a new AD/ADRD web page on current research.

National Strategy for Recruitment and Participation in Alzheimer’s Disease Clinical Research

National Institute on Aging
Marie Bernard, M.D.

Over 200 Alzheimer’s and related clinical trials are currently underway and seeking 100,000-plus participants. Studies are competing for volunteers and sometimes do not reach their targets. Broad representation and appropriate numbers of volunteers are needed for precision medicine. Recruitment challenges include invasive and time-consuming procedures, strict eligibility criteria, and lack of awareness among PCPs. NIA’s analysis of inclusion in AD/ADRD trials found that representation of non-white populations is variable.

Dr. Bernard announced NIA's National Strategy for Recruitment and Participation in Alzheimer's and Related Dementia Research. The goal is to engage broad segments of the public in dementia research, focus on underrepresented communities, and assist studies in enrolling and retaining people to better understand and eventually cure these disorders. Four areas of focus are:

1. Increase awareness and engagement by identifying diverse audiences and developing and disseminating culturally and linguistically appropriate content.
2. Build and improve infrastructure. Strategic priorities include improving existing registry infrastructure, use of ITs, supporting study site capacity building, and improving the effectiveness of screening.
3. Engage local communities and support participants through strategies such as developing community partnerships, promoting health and science literacy with a focus on cognitive health, and expanding trial design to encourage participation of more diverse communities.
4. Develop an applied science of recruitment. The means developing baseline measures and evaluating the effectiveness of recruitment strategies.

Dr. Bernard outlined how government agencies, advocacy and community organizations, the research community, and people with dementia and their families and caregivers can play a role in better recruitment. She noted that NIH's inclusion policy goes into effect January 2019. Although it may cost more for outreach to diverse communities, researchers are responsible for asking for the resources they need in their applications.

NIA has released a funding opportunity for Examining Diversity, Recruitment, and Retention in Aging Research that encourages building collaborative teams and community infrastructure. NIA designated October 23 as #ResearchDiversity day.

CONCLUSION

In summarizing the day's activities, Dr. Gitlin said the presentations represent game changing progress in science, public awareness, and funding levels. She then announced that it was Ms. Khillan's last day with the Council after 4 years. She will move to a position with AARP. Dr. Gitlin thanked Ms. Khillan and praised her extremely high level of conceptual understanding of the field.

Ms. Khillan thanked the Council for the learning experience and the dedication and engagement of all those involved with the Council. She said she has heard many personally moving stories in her time with the Council. She introduced her successor, Helen Lamont.

Dr. Gitlin adjourned the Council meeting at 4:30 p.m.

The next meeting will be in January 28, 2019.

Minutes submitted by Rohini Khillan (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.

PARTICIPANTS

Advisory Council Members

Present
Ellen Blackwell, Centers for Medicare & Medicaid Services
Katherine Brandt, Massachusetts General Hospital [*via telephone]*
Debra Cherry, Ph.D., Alzheimer's Greater Los Angeles
Michelle Dionne-Vahalik, Texas Health and Human Services Commission
Robert Egge, Alzheimer's Association
Gary Epstein-Lubow, M.D., Brown University
Bruce Finke, Indian Health Servicer
Laura Gitlin, Ph.D., Drexel University, *Chair*
Richard Hodes, M.D., National Institute on Aging/National Institutes of Health
Cynthia Huling Hummel, a person living with Alzheimer's disease, Elmira, NY
Bradley Hyman, M.D., Alzheimer's Disease Research Center [*via telephone]*
Rohini Khillan, Office of the Assistant Secretary for Planning and Evaluation, HHS
Gavin Kennedy, Office of the Assistant Secretary for Planning and Evaluation, HHS [for Kara Townsend]
Becky Kurtz, Atlanta Regional Commission, Area Agency on Aging
Erin Long, Administration for Community Living/Administration on Aging
Lisa McGuire, Ph.D., Centers for Disease Control and Prevention
Deborah Olster, Ph.D., National Science Foundation
Anthony Pacifico, Ph.D., Department of Defense
Marianne Shaughnessy, U.S. Department of Veterans Affairs
William Spector, Ph.D., Agency for Healthcare Research and Quality
Angela Taylor, Lewy Body Dementia Association
Sowande Tichawonna, Caregiver, Washington, DC
Joan Weiss, Ph.D., Health Resources and Services Administration

Absent
Allan Levey, M.D., Emory University
Shari Ling, Centers for Medicare & Medicaid Services
Billy Dunn, Food and Drug Administration
Kara Townsend, Office of the Assistant Secretary for Planning and Evaluation, HHS

Public

Speakers
Diana Blackwelder, National Early Stage Advisor, Alzheimer's Association
Mary Hogan, Family Advocate
John Collinge, Caregiver
Veronica Cool, CEO, Cool Associates
Helen Kales, University of Michigan, Ann Arbor [via telephone]

Ellen McCreedy, Brown University [via telephone]
Tim Engelhardt, CMS Office of Medicare and Medicaid Coordination
Kathy Vesley-Massey, CEO, Bay Aging
Marisa Scala-Foley, National Association of Area Agencies of Aging (n4a)
Rod Corriveau, National Institute of Neurological Disorders and Stroke/National Institutes of Health
Marie Bernard, National Institute on Aging/National Institutes of Health

Attendees

Amiee Aloi
Erin Cadwalader
Rachel Conant
Mary French
Jordan Gladman
Kristi Guillory
J. Taylor Harden
Mary Hogan
Judit Illes
Matthew Janicki
Ian Kremer
Katie Maslow
Madelyn Morrison
Mary Naugle
Jennifer Pollack
Jadene Ransdell
Marisa Scala-Foley
Matthew Sharp
Eric Sokol
Sarah Tellock
Laura Thornhill