

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

Washington, DC

**January 29, 2019**

## **WELCOME, CHARGE FOR THE MEETING, AND UPDATES**

### ***Laura Gitlin, Ph.D., Chair***

Dr. Gitlin opened the meeting at 9 a.m. At her request, members of the Advisory Council on Alzheimer's Research, Care, and Services introduced themselves by name, institution, and role on the Council. Debra Cherry, Bradley Hyman, Becky Kurtz, Susan Cooley, and Ellen Blackwell joined the meeting by telephone. Gavin Kennedy, Associate Deputy Assistant Secretary within the Office of the Assistant Secretary for Planning and Evaluation (ASPE), attended on behalf of Kara Townsend, Deputy ASPE. Dr. Helen Lamont introduced herself as the new Designated Federal Officer (DFO). Dr. Gitlin then presented highlights of the day's agenda, including a lunchtime meeting of non-federal Council members.

Dr. Gitlin made the following announcements:

- Five council members' tenures are expiring--her own and those of Gary Epstein-Lubow, Clinical Care Chair, and Angela Taylor, Research Subcommittee Chair. The Council is working closely with Dr. Lamont and ASPE to make a smooth transition. The aim is to identify replacements by the next Council meeting to provide time for meaningful mentorship of new members. ASPE will lead the selection process. Dr. Lamont said nominations should be out by late spring/early summer and final selections by late summer so new members are in place by the Council's October 2019 meeting.
- Allan Levey, Richard Hodes, and Dr. Hyman will make a presentation at a future Council meeting on the latest news about vaccines and other innovative approaches for the prevention and cure of Alzheimer's.
- The 2019 World Economic Forum conducted a session on dementia and made a call to address it worldwide. The Council will discuss the call in the future.

## **RECOMMENDATIONS AND NATIONAL PLAN UPDATE: TIMELINE AND FOCUS FOR 2019**

### ***Laura Gitlin, Chair, and Helen Lamont, DFO***

Dr. Lamont underscored the role that Council recommendations play in both the National Plan to Address Alzheimer's Disease and the work of federal agencies. She

provided a brief description of the Council's recommendation process. She said she has heard from federal Council members that the latest recommendations align with agency concerns.

### **Recommendation Timeline and the National Plan**

Dr. Lamont proposed that the Council keep the same timeline for its 2019 recommendations, but synchronize more directly to the timeline for the National Plan:

- Council subcommittees propose recommendations in spring 2019.
- Subcommittees meet to discuss proposed recommendations and vote on final versions in July 2019 (or earlier).
- Federal agencies incorporate Council recommendations into the National Plan due in October 2019.

Council members indicated that they agree with this approach.

### **Metrics for Measuring Council Progress**

Dr. Gitlin opened a discussion of how the Council can measure its progress as the 2025 deadline approaches for the achievement of National Alzheimer's Project Act (NAPA) goals. She suggested that a contractor could help the Council think through simple and available metrics.

Dr. Lamont said that measuring in 2019 what the Council has accomplished so far will allow members to think strategically and be more laser-focused about goals for 2025.

### **Questions & Comments**

- *Robert Egge* said that articulating and focusing on the Council's major goals for 2025 makes great sense. *Dr. Cherry* said that the more specific Council goals are, the stronger the strategy will be.
- *Dr. Lamont* suggested that each subcommittee focus on its major accomplishments and meaningful ways to measure progress.
- *Dr. Gitlin* suggested use of a driver diagram to compile federal agency measurement metrics. Dr. Gitlin, Dr. Lamont, and the Council's three subcommittee chairs could review the diagram, make recommendations, consult with a contractor, and make a presentation to the Council.
- *Dr. Lamont* said that federal Council members could suggest three measures for each important area of progress by the Council's April 2019 meeting.

### **Moonshots to Drive Progress Toward 2025**

Dr. Gitlin suggested that a small Council workgroup form to discuss potential moonshot goals that can drive progress toward the NAPA 2025 deadline. Moonshot examples include Medicare Advantage coding and dissemination avenues for effective

interventions. These moonshots could shape future Council recommendations. Dr. Gitlin called for volunteers, noting members could email her or Dr. Lamont to respond.

The workgroup would think broadly beyond the three Council subcommittee categories and could also include legislative ideas. These ideas could go to the subcommittees for discussion about recommendations. Dr. Lamont noted that workgroup ideas need not necessarily be constrained by what federal agencies can do under existing authority.

### **Questions & Comments**

- *Ms. Kurtz* suggested the workgroup include at least one representative from each Council subcommittee. She supported the concept of thinking strategically with big ideas. *Shari Ling* also volunteered for the workgroup.
- *Dr. Epstein-Lubow* also volunteered and said non-federal members may be able to think about 2019 recommendations that define value. He said the NAPA goal of a pharmacologic cure by 2025 could be recalibrated as an important moonshot.
- *Katie Brandt* and *Cynthia Huling Hummel* volunteered. *Ms. Brandt* noted the importance of having the voices of patients and families included.

## **CONGRESSIONAL UPDATE**

### ***Robert Egge***

**Council Comment to Congress** -- Non-federal Council members recently commented on the professional judgment budget for fiscal year (FY) 2020 and did so for the FY 2019 budget as well. Under the signature of Dr. Gitlin, the comments will be sent to National Institutes of Health (NIH) Director Francis Collins.

**Capitol Hill Briefings** -- Mr. Egge said there is enthusiasm in the new Congress for a briefing on Council recommendations. He said the timing is right to set a date. He explained that members of Congress typically send a key staffer to hear the recommendations, then carry that information back to legislators.

### **Hill Events Relevant to Council:**

- January 2018 -- Recognize, Assist, Include, Support, and Engage Family Caregivers Act (RAISE) signed into law.
- February 2018 -- Two-year extension of Independence at Home Demonstration at the Centers for Medicare & Medicaid Services (CMS).
- March 2018 and September 2018 -- FY 2018 and FY 2019 appropriations bills resolved in the last calendar year that together brought a significant research funding increase for Alzheimer's disease and related dementias (AD/ADRD).
- March 2018 -- Kevin and Avonte's Law signed by President Trump. Responds to items in the National Plan concerning first responder training on safety issues, wandering.
- December 2018 -- Building Our Largest Dementia Infrastructure for Alzheimer's Act passed. Among other items, the law authorizes \$20 million annually for

activities such as Alzheimer's Centers of Excellence, funding from the Centers for Disease Control and Prevention (CDC) for public health departments, and increasing data analysis and timely reporting. Congress must still appropriate funds for these activities.

- Funding has been consolidated for the Alzheimer's Disease Supportive Services Program and the Alzheimer's Disease Initiative Specialized Supportive Services to provide increased spending flexibility.

### **Questions & Comments**

- *Dr. Lamont* noted that the Administration for Community Living (ACL) received an FY 2019 appropriation to convene RAISE. ACL put out a call for nominees and is planning to hold the first meeting in late spring/early summer 2019.
- *Dr. Gitlin* asked Ms. Ling to find out what data is available on the Independence at Home Demonstration. Dr. Gitlin referred to work by the BrightFocus Foundation that spotlights the home as the future of support for people with dementia and their care partners.
- *Dr. Gitlin* said that she and Council subcommittee chairs will be meeting to discuss how to approach Capitol Hill. The chairs have already generated summaries of recommendations that will form an executive brief as part of that presentation.

## **QUALITY MEASURES FOR DEMENTIA**

### ***Gary Epstein-Lubow, M.D., and Lee Jennings, M.D.***

Drs. Epstein-Lubow and Jennings are long-time collaborators on a review of quality measures specific to dementia. Dr. Epstein-Lubow reviewed past Council recommendations and presentations on the subject. He then presented a crosswalk table comparing five quality measurement tools, including ASPE/RTI International's elements of best practice; the Alzheimer's Association's care practice recommendations; and tools from RAND Corporation, the Physician Quality Reporting System, and ACL.

Dr. Jennings noted that she and Dr. Epstein-Lubow have been updating the table as they prepare a manuscript for submission that summarizes quality measures and the organizations that develop them. She pointed out that there is not a widely accepted culture and practice that encourages the use of any of these measures. She wondered how groups of national influence such as the Council encourage use of these measures to change care delivery. Dr. Epstein-Lubow noted that no one set of measures works well in all care settings.

### **Questions & Comments**

Council members noted the following issues surrounding quality measures for dementia:

- Applying quality measures for best practices across care settings (medical and community based) and disease trajectories (early stages and early onset).

- Making measures easy to use by clinicians in medical, community, and home care settings.
- Incorporating the principles of patient-centered care into quality measures.
- Considering measures for other diseases, such as diabetes, when treating them in people with dementia.

The National Quality Forum has issued a report on care quality in various settings that is a useful resource.

*Dr. Gitlin* highlighted two focus areas:

- There is a potential need for new quality measures that take into account setting, disease stage, and both medical and community services.
- Some appropriate quality measures that do exist may not be in use.

She said that the Council could focus on one urgent category, such as the care plan, to develop quality measures for best practices.

Council members then launched into a discussion of the Council's 2018 Recommendation #4: *Determine a process for reaching consensus on national definitions of best practices for comprehensive care of AD/ADRD at all disease stages.*

The discussion included the following points:

- Families are caught off guard by a dementia diagnosis and do not know where to turn to develop a care plan. They do not know how to modify the plan as the disease progresses.
- Medicare has a billing code for cognitive assessment and care planning that is not being taken advantage of in broad practice. Families are often unready to take up care planning at the point of diagnosis and health care providers are not educated about the benefit.
- Early onset dementia patients are too young to qualify for Medicare. Caregivers in home and community-based settings are often not Medicare-certified providers.
- There are good models of dementia care management that do not get widely disseminated because they take place outside Medicare-billable settings.
- Care plans can help physicians keep track of dementia care taking place in other settings.
- A person-centered approach is important to capturing the patient's wishes at the beginning of the care process.
- Most care takes place at home. This must be taken into account in best practices.

*Dr. Gitlin* said effective care models are a possible topic for the next care summit. She said health care provider education on best practices should take place during medical training. She added that Recommendation #4 is a good candidate for a moonshot.

Dr. Epstein-Lubow said the Clinical Care Subcommittee will use the day's discussion to prepare 2019 recommendations for the Council's April 2019 meeting.

## FEDERAL WORKGROUP UPDATES

### Long-Term Services and Supports

#### ***Administration for Community Living (ACL)***

##### ***Erin Long***

ACL's latest activities include:

- **Alzheimer's Disease Programs Initiative**
  - 2019 States and Community Expansion Grants -- ACL has received applications for programs that will have a March 1 start date.
  - ACL is preparing a new upcoming funding opportunity for states and communities.
  - ACL has awarded grants in 36 states and Puerto Rico. Grants go to a mix of state and community organizations, hospitals, and universities. The agency is working to engage states that are not yet participating in its programs.
  - ACL released improvement scores for its Dementia Capability Assessment of states and communities that received grants in 2017. The analysis found an overall 22% improvement in the categories of identifying people with dementia, staff training, providing specialized services, and other dementia capability activities.
  
- **New Resources**
  - *Handbook for Helping People Living Alone With Dementia Who Have No Known Support* provides practical strategies for identifying people living alone, enhancing decision-making capacity, and understanding the basics of guardianship/conservatorship.
  - *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia* -- Includes strategies for building partnerships, resources for training and policies, and tip sheets.
  - *Disaster Planning Toolkit for People Living with Dementia* -- Includes resources for people with dementia, family members, and caregivers.
  - Measuring Outcomes to Evaluate Dementia Programs and Interventions: Strategies, Challenges, and Benefits webinar -- Recording and presentations are available online.
  - Updated website, ELDERCARE LOCATOR ([eldercare.acl.gov](http://eldercare.acl.gov)) -- Highlights include frequently asked questions from caregivers and resources on long-distance caregiving.
  - A \$70,000 grant to the National Ombudsman Resource Center will help address nursing home discharge and eviction and opioid use and pain management.

***Centers for Disease Control and Prevention (CDC)***

***Lisa McGuire, Ph.D.***

- **New Products Promoting CDC's Brain Health Initiative Road Map 2018-2023:**
  - Dr. McGuire listed a variety of products available at the new web page [CDC.gov/aging](https://www.cdc.gov/aging) to help organizations and public health officials make use of the road map's contents and implement its action items.

**Clinical Care**

***Health Resources and Services Administration (HRSA)***

***Joan Weiss, Ph.D.***

- **Funding Opportunities at HRSA:**
  - **Geriatrics Workforce Enhancement Program** -- Develops a health care workforce that maximizes patient and family engagement to improve health outcomes by integrating geriatrics and primary care. Grant announcement closes February 6, 2019. HRSA plans to make 47 awards of \$750,000 each over five years for a total of \$35-\$36 million. At least \$100,000 of each grant must be spent on educating the health care workforce.
  - **Geriatrics Academic Career Awards Program** -- Promotes the career development of individuals to be academic geriatric specialists. Opportunity closed January 16, 2019. HRSA plans to make 26 awards of \$75,000 each for four years for a total of about \$2 million each year.
  - **Alzheimer's Disease and Related Dementia Curriculum** -- Now available as continuing education for physicians, nurses, allied health professionals, health educators, and pharmacists. Fifteen continuing education units are available on HRSA's website.

***Centers for Disease Control and Prevention (CDC)***

***Lisa McGuire, Ph.D.***

- The CDC has released **Brain Health**, a new continuing education course developed in collaboration with the American College of Preventative Medicine. The course highlights risk factors and defines age-related cognitive decline and other dementias. The course is free and publicly available online.

***Department of Veterans Affairs (VA)***

***Marianne Shaughnessy, Ph.D.***

- Dr. Shaughnessy listed rural health dementia-related projects funded for FY 2019 and noted that the VA Office of Rural Health has developed a close partnership with the VA Office of Geriatrics and Extended Care to reach out to rural providers and veterans.
- Presented VA Geriatric Scholars projects and educational programs planned for FY 2019. These include training in geriatric medicine and rural interdisciplinary team training.
- Presented Resources for Enhancing All Caregivers Health (REACH) Updates, including REACH training incorporation into the Geriatric Scholars Program and

ongoing training through the University of Tennessee to extend REACH into Indian Country.

- Announced that later this year, VA will present to the Council an evaluation of the VA's "Hand-in-Hand" Dementia Training Program.
- Announced that VA dementia projections for FY 2019-FY 2033 are available online and cover dementia prevalence and incidence among veterans.

### **Centers for Medicare & Medicaid Services (CMS)**

#### **Shari Ling**

- Ms. Ling described a final CMS ruling effective January 1, 2019:
  - Permits providers to bill separately for virtual communications (tele-health).
  - Expands provider types in the Merit-Based Incentive Payment System.
  - Streamlines evaluation and management coding and documentation requirements.
- Other CMS initiatives include:
  - **Medicare Home Health Improvements** -- These include introduction of remote payment monitoring technology, a new focus on patient needs rather than volume of care, and categorization of remote patient monitoring by home health agencies as an allowable cost.
  - **Medicaid Dual Eligibility Guidance** -- This December 2018 State Medicaid Director Letter highlights opportunities to streamline care and better serve people who are dually eligible for Medicaid and Medicare.
  - **2018 Measures Under Consideration List** -- Released December 2018, these include an Annual Wellness Assessment: Preventative Care, Documentation of a Health Care Partner for Patients with Dementia or Mild Cognitive Impairment, and Cognitive Impairment Assessment Among Older Adults (75 Years and Older).
  - **Medicare Shared Savings Program Final Rule** -- Aims to allow better coordination among organizations that provide care to people with dementia and cognitive impairment.
  - **Updates to Value-Based Insurance Design Model for 2020** -- Updates how clinicians and health care systems are paid for care in a chronic care model. Focuses on better value care rather than the units of service delivered.
  - **Independence at Home Model** -- This report to Congress is available on the CMS Innovation website. The report concludes that model is promising, but with additional time and data could achieve the criteria set forth for all innovation center models.
  - **Nursing Home Oversight and Safety Improvements** -- Will provide more transparency for states and consumers to ensure facilities are adequately staffed.
  - **National Partnership to Improve Dementia Care** -- Reports a 38.9% decrease in use of anti-psychotics in long-stay nursing home residents.



- **Medicare Learning Network** -- The March 12, 2019, session will provide insight on a free, publicly available dementia care and psychotropic medication tracking tool.

## Research

### ***National Institute on Aging (NIA)***

#### ***Richard Hodes, M.D.***

- Dr. Hodes noted that the NIH AD/ADRD budget for FY 2018 is approximately \$1.8 billion. The budget for FY 2019 is an estimated \$2.3 billion.
- Reported that there are approximately 140 ongoing NIA AD/ADRD and related intervention and prevention trials. Categories include early stage, late stage, pharmacologic and non-pharmacologic, and care and caregiver interventions. Sixty-nine percent of these trials are non-pharmacologic.
- Presented breaking news about results from the Systolic Blood Pressure Intervention Trial, Memory and Cognition in Decreased Hypertension. The *Journal of the American Medical Association* will publish results showing that people with mild cognitive impairment and combined dementia showed a statistically significant reduction in these conditions with blood pressure interventions. NIH will continue to study how the control of hypertension caused these effects.
- Described a program under which researchers across NIH can request a grant supplement to include AD/ADRD-related activities in their research. NIH funded 300 such supplements in areas that include sleep improvement, integrating mind/body skills to improve pain outcomes, and brain-computer interface to enhance attention.
- **iCare-AD/ADRD Challenge** -- Contestants must submit technology applications that help patients and caregivers navigate the health care system. Submissions are due by June 30, 2019. Up to \$400,000 in cash prizes may be awarded to teams or individuals.

### ***National Institute of Neurological Disorders and Stroke (NINDS)***

#### ***Rod Corriveau, Ph.D.***

- **Alzheimer's Disease-Related Dementias Summit 2019** -- Dr. Corriveau urged those who want to attend to register promptly, as slots are filling up fast. Videocast will be available.
- **Upcoming FY 2019 ADRD Research Funding Opportunity Announcements:**
  - Post-Stroke Vascular Cognitive Impairment and Dementia in the U.S. including in Health Disparities Populations.
  - Development and Validation of Advanced Mammalian Models for ADRD.

## **PUBLIC COMMENTS**

### ***Diana Blackwelder, National Early Stage Advisor, Alzheimer's Association***

- The following actions are achievable and will yield the greatest return on investment:
  - Provide information about and assistance with leveraging technology that is already in the mainstream that would help those living with dementia remain independent longer, defer hiring assistance with financial and household responsibilities, and assist with daily cognitive therapy exercises.
  - Consider ways to include the costs of integrative and alternative treatments and therapies in covered services for those living with dementia.
  - Remove arbitrary age restrictions that prevent those living with early onset dementia from accessing the same services as those who qualify as senior citizens.

### ***Mary Hogan, Family Advocate***

- In addition to care interventions, focus on support systems and accommodations that help make life worth living for the person with dementia.
- Look at dementia as a human rights issue.
- Recognize the wide variation in the formal and informal care and support provided to people with dementia. Doctors do not have the time or expertise to create care plans. This creates a gap between how a person functions and how that person could function. We must expand beyond the medical model.

### ***Matt Janicki, Ph.D., National Task Group on Intellectual Disabilities and Dementia Practices***

- There is a dearth of diagnostic and post-diagnostic support for people affected by dementia, especially those with intellectual disabilities.
- Congress should amend the Older Americans Act, which is coming up for reauthorization, to allow state units on aging to designate special diagnostic centers for people with intellectual disabilities. This would encourage a critical mass of expertise among clinicians and create links between diagnosis and diagnostic supports. Dr. Janicki asked the Council to support this amendment and include links to post diagnostic support in its 2019 plan.

### ***Seth Keller, M.D., National Task Group on Intellectual Disabilities and Dementia Practices***

- Dr. Keller emphasized the following areas of concern:
  - When it comes to treating people with dementia, especially those with intellectual disabilities, medical practices are overburdened, operating as crisis management, and do not understand the patient population.
  - Even with research and information available, practitioners are not being trained and educated. They need assistance with developing a disease management model.

***Jadene Ransdell, Down Syndrome/Alzheimer's Advocate***

- Caregiving for people with intellectual disabilities and dementia poses distinct challenges.
- Dementia research has excluded or simply not included people with intellectual disabilities.
- The Council should recognize the importance of expanding specialized groups of support for families and caregivers of those with intellectual disabilities/dementia.

***Carolyn Rogers (Dr. Lamont read Ms. Rogers's comments)***

- Alzheimer's and vascular dementia often occur together. Exposure to ionizing radiation is known to produce cognitive deficits, Alzheimer's pathology, and vascular damage.
- It is time to take a look at the most common x-ray procedure--dental x-rays.
- A new study shows that leaky capillaries are an indicator of cognitive decline.
- Limiting exposure to dental x-rays may be a preventative measure against dementia.

***Matthew Sharp, Association for Frontotemporal Degeneration (AFTD)***

- AFTD has awarded its first Non-Pharmacologic Therapies and Tools Pilot Grant to Dr. Lauren Massimo, University of Pennsylvania School of Nursing. She will develop a mobile app as an intervention for apathy, then conduct a 3-month clinical trial to test its effectiveness. The opportunity for the 2019 grant is now posted.
- AFTD added a new type of grant to its Comstock Grant Program. This quality of life grant is targeted to people with dementia in the form of a \$500 Visa gift card to spend on products and services that affect quality of life.

## **AFTERNOON SESSIONS**

Ms. Taylor introduced the afternoon's subjects. Dr. Hodes introduced the State of the Science Initiative speakers.

## **STATE OF THE SCIENCE INITIATIVES**

### **Care Interventions for Individuals with Dementia and Their Caregivers**

***Melinda Kelley, Ph.D.***

NIA is conducting a rigorous, independent research review to determine which care/caregiving interventions are effective and ready for dissemination and implementation on a broad scale. NIA will also identify research gaps. The project is a collaborative effort.

NIA has engaged the Agency for Healthcare Research and Quality (AHRQ) Minnesota Evidence-Based Practice Center to conduct a systemic evidence-based review, which will take place February 2019-February 2020. The target date for the release of the draft AHRQ evidence report is March 2020 at the Care and Services Summit.

NIA has engaged the National Academies of Sciences, Engineering, and Medicine to create an expert committee to consider the evidence review provided by AHRQ, other relevant information, and develop recommendations regarding readiness of interventions for dissemination and specific research priorities. It is expected that the recommendations will inform next steps with care interventions, even in scientific areas where the evidence is not strong enough to justify broad implementation. The recommendations will be published and come back to NIA for next steps. The recommendations will influence NIA's communications about dementia care/caregiving, future research planning, and hopefully, relevant policies of other agencies nationwide.

Potential areas of focus include:

- AD/ADRD.
- Non-pharmacologic approaches.
- Outcomes for dementia patients and caregivers, including health, quality of life, and use of health care services.
- Paid and unpaid caregivers.
- Multiple diverse settings.

## **Behavioral and Social Sciences Related to AD/ADRD**

### ***Elena Fazio, Ph.D.***

Dr. Fazio described NIA's plan to conduct a decadal survey of behavioral and social science research on AD/ADRD with the aim of identifying lines of research with the greatest potential for impact over a 10-year period. NIA is a current sponsor, and other federal and non-federal sponsors are anticipated.

The survey will go beyond interventions and care/caregiving to focus on a broader range of AD/ADRD topics. Examples include cognitive and dementia epidemiology, disparities, and prevention.

Phase 1 ends in 2020 and includes website development, formation of a project committee, and two workshops. Nominations for committee membership were due February 6, 2019.

Phase 2 includes two more workshops and ends in spring 2020 with a consensus report.

### **Questions & Comments**

In response to Council members' questions, Drs. Kelley and Fazio provided the following information:

- A request will be made to NAM to seek health systems' input during the decadal survey.
- A report out on the decadal survey will be made at the 2020 dementia care summit.
- NIA will determine how to disseminate the report beyond agency websites.

## **NON-PHARMACOLOGICAL INTERVENTIONS -- THE GROWING ROLE OF TECHNOLOGY**

Dr. Levey introduced the sessions and speakers on the role of technology in interventions and outcome measures.

### **Technology to Advance Assessment and Interventions for Dementia**

#### ***Jeffrey Kaye, M.D.***

Dr. Kaye outlined challenges with the current assessment process for dementia patients, including the fact that sessions are subjective, episodic, clinic-based, and obtrusive. The heterogeneity of the data that results makes it difficult to detect meaningful change.

This paradigm could be changed to collect more comprehensive, holistic, and multi-domain data to give a full picture of the individual in his/her home with objective information that comes as continuously and unobtrusively as possible.

The Oregon Center for Aging and Technology's Collaborative Aging Research using Technology (CART) Home is as an example of how technologies can be incorporated into a home-like setting. The platform accommodates a variety of readily available technologies and standardized communications to gather data on sleep, cognition and behavior, social engagement, and many other areas. Data is gathered and transmitted via secure, standardized communications protocols. CART is supported by NIA and six other NIH institutes as well as the VA. The goal is to deploy the CART platform into tens of thousands of homes.

Example of how technologies can be used in interventions include:

- In-home monitoring to identify meaningful behavior changes during a loneliness intervention.
- Smartphones with preset walks and memory markers.
- Video chats that increase social interaction.
- Collecting quantitative information about the environment--noise levels, room temperature, ambient light--to examine their effects on dementia-associated behaviors.

## **Interventions for People with Dementia**

### **Using Tablet Devices for Management of Behavior Symptoms of Dementia**

#### ***Ipsit Vahia, M.D. [via telephone]***

Dr. Vahia described his study that examined whether iPads can be used to control agitation in dementia patients:

- Study conducted at the University of California San Diego Senior Behavioral Health Geriatric Psychology inpatient unit.
- Subjects were patients with a history of agitation that required psychotropic medication.
- Staff trained patients in iPad use. The menu only included apps that were free of cost.
- When patients became agitated, they were given iPads by research staff. iPads were used strictly as an intervention. The outcome measure was a subjective reduction in behavior. Results show promise that tablet use can help dementia patients manage agitation. The study sample was small (27 people) and will be replicated on a larger scale.

### **ARIES: Affordable Robotic Intelligence for Elderly Support**

#### ***Bertram Malle, Ph.D. [via telephone]***

The aim of this project is not an intervention to combat dementia, but to support individuals with the challenges of aging. Dementia is not the sole focus. The robotic technology is meant to supplement--not replace--professionals and family members.

The project uses Joy For All pet companions with the aim of making them more intelligent and keep their price under \$200. The intelligence to be added includes:

- Perception, memory, and nonverbal communication.
- The ability to track lost objects and guide a person to help the robot find the objects.
- Fall detection, medication reminders, social contact reminders, and data collection.

The enhanced companion pet will have infrared and acoustic sensors and software that allow it to learn objects and locations through encounters, respond to inquiries, and collaborate with the user through motions and sounds to find lost objects.

## **Interventions for Caregivers**

### **Tele-Savvy: A Fully Online Version of the Savvy Caregiver Program**

#### ***Ken Hepburn, Ph.D. [via telephone]***

The project is being run out of Emory University's Goizueta Alzheimer's Disease Research Center. The VA and Goizueta supported the pilot project. NIA is supporting the current randomized trial.

The Savvy Caregiver Program is a 6-week, in-person psychoeducational program for 6-12 caregivers to develop skills and knowledge for their role. Tele-Savvy is a virtual version of this program with seven weekly online group sessions of 75-90 minutes each.

These sessions are augmented with 36 daily 10-minute video lessons. Subjects include dementia 101, cognitive losses, behavioral issues, and behavior guidance.

Pilot results showed significant reduction in caregiver burden, caregiver depression, and an average frequency of behavioral and psychological symptoms of dementia. Results also showed an increase in caregiver mastery. The trial will expand on these findings

Dr. Hepburn noted that the trial is still recruiting and provided the eligibility criteria for participants.

## **The WeCareAdvisor**

### ***Laura Gitlin, Ph.D.***

The WeCareAdvisor (WCA) is a web-based tool to help caregivers address behavioral and psychological symptoms of dementia. It features a peer navigator to guide users, a Caregiver Survival Guide with hundreds of coping strategies, and daily inspirational messaging. WCA can also generate a treatment plan based on the DICE approach (describe, investigate, create, evaluate) tailored to address an individual's dementia-related behavior.

Results of a small randomized trial (57 caregivers) show a significant decline in caregiver distress and a significant improvement in caregiver confidence. More than 50% of pilot users said WCA was helpful, made care easier, and that they would recommend it.

The project team has a grant under review at NIA to test WCA on a cohort of more than 300 family caregivers.

## **Questions & Comments**

Presenters addressed the following questions from Council members:

- *What is the biggest impediment to progress in the area of technology's use?*
  - *Dr. Kaye* -- There is a combined set of expertise needed--engineering, computer science, analytics, user interface, and technology deployment--that is hard for any one researcher or group to have. That is why the CART initiative is a timely idea. Researchers have a ready-made platform. Another challenge is proprietary and closed-development technology.
- *What about privacy issues and people's willingness to be monitored?*
  - *Dr. Kaye* -- There has been some pushback over visualization of people in their homes and sharing data about personal activities. It depends on what you ask people to do. Many older people may not understand the technology until they experience it.

- *All presenters are from academic institutions. To what extent have you been able to collaborate with or feel you compete against the private sector?*
  - *Dr. Kaye* -- This research cannot and should not be done without engaging industry. Almost all of the algorithms and raw data from the wearables industry are not available to researchers except under very special agreements. This has created a problem for standardization.
  - *Dr. Gitlin* -- Industry partners need to be part of the conversation early on because their input can shape development. One question for researchers is: when is there enough evidence to support commercialization?

## **INTERVENTIONS FOR FURTHER EXPLORATION AND/OR WIDESPREAD DISSEMINATION**

### **The Unforgettables: People with Dementia and Their Family Caregivers Join in Making Music Together**

#### ***Mary Mittelman, Dr.P.H. [via telephone]***

Few pleasurable activities are available for people with dementia to do with their family members. Dr. Mittelman recognized the need to develop psychosocial interventions with evidence-based benefits. She started a chorus with the intention of studying the effects on caregivers. Family members in the early and middle stages of dementia were invited along. Psychologists warned Dr. Mittelman that people with dementia would not learn new songs.

The musical activity was geared to the level of the caregivers with the aim to demonstrate its effectiveness in providing social support. Dr. Mittelman also wanted to show the health care community that a drug-free intervention can improve the well-being of people with dementia.

At the end of her study, psychosocial measures showed that the people with dementia improved their quality of life and communication as much as, if not more, than the target caregiver population. People with dementia learned an average of 18 new songs for each concert.

Participants were so eager to continue the chorus that they have been contributing to costs since the pilot study ended in 2011. Due to popular demand, Dr. Mittelman started a second group.

### **Cognitive Rehabilitation for People Living with Dementia: A Practical Framework for Enablement**

#### ***Linda Clare, Ph.D. [via digital recording]***

Dr. Clare's team at the Center for Research in Aging and Cognitive Health in the United Kingdom conducted feasibility studies on whether cognitive rehabilitation could impact



specific areas of functioning, including remembering names and faces and reducing repetitive questioning. Positive results gave them confidence to conduct further studies.

A pilot study compared rehabilitation cognitive therapy (RCT), relaxation therapy, and treatment as usual. Only those in the RCT group improved their ratings of functioning and satisfaction.

Researchers conducted a larger goal-oriented cognitive rehabilitation (GREAT) trial at eight United Kingdom sites with 475 people in the early stages of AD, vascular, or mixed dementia and a family member study partner. Half received cognitive rehabilitation and half received treatments as usual. All participants identified goals for achieving everyday tasks.

Cognitive rehabilitation participants improved their functioning in relation to their specific goals. Their caregivers corroborated these perceptions. There were no significant changes among those who received treatments as usual.

The team then conducted a cognitive rehabilitation pilot trial for people with Parkinson's disease dementia and Lewy body dementia. The trial compared cognitive rehabilitation to relaxation therapy and treatments as usual. While cognitive rehabilitation participants improved their functioning, there were no significant changes in the other groups.

Cognitive rehabilitation is now recommended in United Kingdom guidelines that inform health practitioners about evidence-based interventions.

### **Testing a Dementia Care Intervention for Widespread Adoption: The COPE CT Study**

#### ***Richard Fortinsky, Ph.D. [via telephone]***

The Care of Persons with Dementia in their Environments/Connecticut (COPE CT) study identified 291 people with dementia and their caregivers. Occupational therapists worked with caregivers to identify three dementia-related challenges to be addressed. Patients were randomized to receive either the COPE CT occupational therapy interventions plus their usual home care or only their usual care.

- At the end of the study, according to caregivers, 75% of identified dementia-related challenges were reduced, 21% were eliminated, and 4% got worse.
- The COPE CT intervention had a statistically significant effect on caregiver perceived well-being. COPE CT caregivers also showed a trend toward increased confidence.

Next steps include a 12-month post-randomized data analysis to be completed by the end of February 2019 and a cost-benefit analysis of COPE CT.

## **CONCLUSION**

*Dr. Gitlin* thanked everyone for their attendance and announced that the next meeting will take place April 29, 2019.

*Dr. Gitlin* adjourned the meeting at 4:28 p.m.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at <http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings>.

## **PARTICIPANTS**

### **Advisory Council Members**

#### ***Present***

Arlene Biermann, M.D., Centers for Medicare & Medicaid Services  
Ellen Blackwell, Centers for Medicare & Medicaid Services *[via telephone]*  
Katherine Brandt, Massachusetts General Hospital  
Debra Cherry, Ph.D., Alzheimer's Greater Los Angeles *[via telephone]*  
Michelle Dionne-Vahalik, Texas Health and Human Services Commission  
Robert Egge, Alzheimer's Association  
Gary Epstein-Lubow, M.D., Brown University  
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]*  
Gavin Kennedy, Office of the Assistant Secretary for Planning and Evaluation, HHS  
Becky Kurtz, Atlanta Regional Commission, Area Agency on Aging *[via telephone]*  
Helen Lamont, Ph.D., Designated Federal Officer, Assistant Secretary for Planning and Evaluation, HHS  
Allan Levey, M.D., Emory University  
Shari Ling, Centers for Medicare & Medicaid Services  
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 *[via telephone]*  
Marianne Shaughnessy, U.S. Department of Veterans Affairs  
Angela Taylor, Lewy Body Dementia Association  
Sowande Tichawonna, Caregiver, Washington, DC  
Kara Townsend, Office of the Assistant Secretary for Planning and Evaluation, HHS *[via telephone]*  
Joan Weiss, Ph.D., Health Resources and Services Administration

#### ***Absent***

Billy Dunn, Food and Drug Administration  
Bruce Finke, Indian Health Service  
Anthony Pacifico, Ph.D., Department of Defense

### **Public**

#### ***Speakers***

Linda Clare, University of Exeter *[via digital recording]*  
Elena Fazio, National Institute on Aging/National Institutes of Health  
Rick Fortinsky, University of Connecticut School of Medicine  
Ken Hepburn, Goizueta Alzheimer's Disease Research Center Education Core  
Lee Jennings, University of Oklahoma Health Science Center

Jeffrey Kaye, Oregon Health and Science University  
Melinda Kelley, National Institute on Aging/National Institutes of Health  
Bertram Malle, Brown University  
Mary Mittelman, NYU School of Medicine  
Ipsit Vahia, McLean Hospital

***Attendees***

Dawn Beraud	Karin Hellsvik	Jadene Ransdell
Diana Blackwelder	Mary Hogan	Patrick Rochelle
Erin Cadwalader	Judit Illes	Emily Rosenoff
Fung Chow	Matthew Janicki	Andrew Ross
Alex Chiu	Seth Keller	Matthew Sharp
Rachel Conant	Yin-Yee Kong	Eric Sokol
Rod Corriveau	Ian Kremer	Carole Sztalryd-Woodle
Phil Cronin	Feng-Yen Li	Sarah Smith Tellock
Judy Dey	Eliezer Masliah	Salom Teshale
Patricia D'Antonio	Madelyn Morrison	Laura Thornhill
Kate Gordon	William Morton	George Vradenburg
Kristi Guillory	Iara Oliveira	Courtney Wallin
John Haaga	Douglas Pace	Marion Weisse
John Hall	Jennifer Pollack	C. Grace Whiting