

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

Washington, DC

July 30, 2018

WELCOME AND CHARGE FOR MEETING

Laura Gitlin, Ph.D., Johns Hopkins University, Chair

Rohini Khillan, Office of the Assistant Secretary for Planning and Evaluation

Dr. Gitlin opened the meeting at 9:03 a.m. noting that this was a particularly important day because it reflects the culmination of much work and many phone calls. Today, members will tackle critical issues and initiatives. She invited participants to introduce themselves and state the subcommittee they had joined. Erin Long, Becky Kurtz, and Ellen Blackwell joined the meeting by telephone.

Ms. Khillan announced that the 2018 National Plan has been completed and is going into departmental clearance. This time, only federal items have been added. Everyone will get a copy when the update is released, perhaps in mid-August.

Philanthropist Bill Gates has announced a number of Alzheimer's disease initiatives. In May, he sent a letter to the Council expressing his interest and intent to work on ways to improve data-sharing and scientific collaboration on future treatments. On July 17, he announced Diagnostic Accelerator, a project of the Alzheimer's Drug Discovery Foundation, which aims to advance bold ideas for earlier and improved diagnosis of Alzheimer's disease. Partners include Leonard Lauder, the Dolby family, and the Charles and Helen Schwab Foundation. We would like to have him address the Council at a future meeting.

Comments and Questions

- ***Richard Hodes***, suggested convening an extensive meeting on data-sharing and transparency to kick things off.

DISRUPT DEMENTIA

Sarah Lock, AARP

In June 2018, AARP launched the Disrupt Dementia campaign to commemorate its 60th anniversary; the Brain Health Fund has invested \$60 million. AARP has never before picked a particular disease issue to address, but now they believe they have to address the question of hope for the future. Currently, more than 6 million people in the United States suffer from dementia, and that number will only increase.

One of AARP's goals is to develop new drugs by 2030, for which the United Health Group and Quest Diagnostics are collaborating with AARP. People want to stay sharp as they age and they want to choose how they live as they age. AARP can address this by educating consumers. AARP has divided this issue into the categories of risk reduction (shrink the time of disability), cure, and care. To address all three areas, AARP, in collaboration with the British charity Age United Kingdom, established the Global Council on Brain Health, which has distilled the science of how to reduce the risk for cognitive decline into a one-page document for lay people. Regardless of our age, we can reduce the chance of age-related diseases and optimize our chance of maintaining cognitive health. AARP focuses on five pillars of brain health: exercise, manage stress, learn new things, eat a healthy diet, and be social. Two other platforms AARP uses to educate members are Staying Sharp, a website that provides science-based tools to assess, maintain, and improve brain health; and the Brain Health and Wellness channel, a section of the AARP website that features the latest news and research on brain health and conditions. In addition, *AARP Magazine* is the most widely circulated in the world. If a person is not cognitively intact, they must rely on caregivers. Therefore, AARP offers many resources for caregivers on its website, <https://www.aarp.org/caregiving/>.

The work addressed by the National Institutes of Health (NIH) Summit is critically important to disseminating information on currently available best practices. It takes too long to implement the best practices that we have now.

Comments and Questions

- **Laura Gitlin** applauded AARP for changing the order of risk, cure, and care. We have to work on all three fronts at the same time. Although \$60 million has been allotted to dementia care and prevention, especially to cure, what about the facets? **Ms. Lock** agreed that they have spent millions on risk reduction and especially education and outreach. AARP is talking about equal contributions, but the \$60 million is probably dwarfed by the accumulation of the other contributions. **Ms. Lock** thought the AARP partnership with the Alzheimer's Association and others had been very successful and she anticipates this growing stronger.
- **Laura Gitlin:** There's an incredible gap between having evidence and circulating it to the people who need it. What's new in care is that we have evidence-based programs, but, they are not being implemented. They have to be embedded in practice. Is AARP working on this? **Ms. Lock** agreed that working with primary care is critical, as is getting tools into the hands of nurse practitioners and other health care workers. Physicians' attitudes that nothing can be done is counterproductive. We must change the framework about what is possible. We must change hopelessness to hope and then provide health care workers with concrete tools. We need to empower health care providers, and the health care

policy community needs to work on this to change physicians' attitudes (e.g., who pays for long-term care and who pays for acute care?).

- **Gary Epstein-Lubow.** This is a lead into a number of recommendations. AARP is already setting an example.

NON-FEDERAL MEMBER UPDATES

Georgia Memory Net

Allan Levey, M.D.

In the State of Georgia, 385,000 patients are self-reported. In response, the state has initiated the Georgia Memory Net to improve diagnosis and care. The goal is for all citizens of the state to be within 90 miles of a Memory Assessment Clinic. The state encourages annual wellness visits, during which time the Mini-Cog assessment tool is administered. The goal is to train primary care physicians to use tools to diagnose memory loss. These clinics connect patients with local services for continued care. They hope these memory clinics will save \$2 billion in preventable hospital admissions. This model provides a consistent platform to manage care and uses resources in Georgia to connect those services with the people in need.

Comments and Questions

- **Gary Epstein-Lubow** asked what brought about cohesion among all the players. **Dr. Levey** attributed it to leadership in the state government, which embraced the need. People in the clinics helped educate legislators over a 1-2 year period and then launched five sites across the state as a pilot. **Dr. Gitlin** thought this could be a potential model. **Dr. Levey** said they had learned from other states, took the best practices, and added to them. He views it as a national model.

Hebrew SeniorLife

Gary Epstein-Lubow, M.D.

Hebrew SeniorLife's role embraces both health care and housing for seniors via the Institute for Aging Research, in partnership with Harvard University. It offers a center for care, research, education, and policy, beginning with evidence-based practices for care and services and emphasizing continuity of care. To be part of this, the senior living community needs an operating clinic program. Program goals include care and services, research and innovation, education, and policy development and advocacy. Hebrew SeniorLife is trying to meet the expectations presented at the Care and Services Summit and address the gap between the cost of service delivery and reimbursement received.

Research Centers of Excellence Program

Angela Taylor

The Lewy Body Dementia (LBD) Association launched a Research Centers of Excellence (RCOE) Program in coordination with the Mayo Clinic, Rochester, Minnesota, to increase access to high-quality clinical care over the course of LBD, build a clinical trials-ready network, increase access to support for people living with LBD and their caregivers, increase knowledge of LBD among medical and allied professionals (outreach to the community includes the lay public as well as health officials), and create infrastructure and resources to advance LBD research. This initiative has interested some 20 companies. RCOE now has 24 sites at leading academic institutions throughout the United States. The next LBD conference will be held in June 2019.

Dementia Cal MediConnect Project

Debra Cherry, Ph.D.

California is working to improve detection and care management, partnerships between health systems and family/friend caregivers, and partnerships with dementia-specific community-based organizations. MediConnect seeks to improve health plans' system of care through advocacy, care management, Dementia Care Specialist training and support, family/friend caregiver education and respite, support services through referrals to local Alzheimer's organizations, and technical assistance to health plans and government entities to create system-wide change. Advocacy resulted in California's ten plans having added a trigger question for Cognitive Impairment in Health Risk Assessment. Six of these have adopted a validated screening tool and three integrated results into their electronic health records, which makes referral easier. Five have a protocol to refer members for a diagnostic evaluation if the screen is positive. Another focus is caregiver identification, assessment, and involvement. The system addresses risks, quality of care, and prevalence. It is a promising practice and is now being replicated in Texas.

Alzheimer's: A Call to Serve!

Cynthia Huling Hummel

Ms. Hummel is now an itinerant pastor, having had to give up her permanent position because of memory difficulties. She now advocates for people living with dementia to provide respite care and raise awareness. Last year she published *Unmasking Alzheimer's--the Memories Behind the Masks*, a collection of photographs of the 30 masks she created, along with her reflections on the challenges and hopes of living well with an Alzheimer's disease diagnosis. She also contributed chapters to a book about Alzheimer's. These are a few of the opportunities for which she is thankful. People who work on the various aspects of dementia need to find ways to engage the faith-based community. This is a condition that will be cured with faith, hope, and love.

Comments and Questions

- **Katherine Brandt** thanked Ms. Hummel for contributing her perspectives.

Alzheimer's Association

Robert Egge

The Alzheimer's Association convened two conferences: the Alzheimer's Impact Movement (AIM) Advocacy Forum (its 30th annual meeting) held in Washington, D.C., and attended by 1,200 people; and the Alzheimer's Association International Conference for 2018 (AAIC>18), held in Chicago and attended by more than 5,000 (the largest gathering of Alzheimer's and dementia researchers in the world). The outreach for each was productive. AIM honored Senators Susan Collins and Catherine Cortez Masto with the AIM Humanitarian of the Year Award, and featured remarks by Dr. Francis Collins. The Senate Aging Committee Hearing will feature advocate and caregiver Marcia Gay Harden. AAIC>18 presented 100 sessions and 550 podium presentations covering the spectrum of dementia research. Highlights included presentations on aberrant network activity in Alzheimer's, neuroimaging and biomarkers, the relationship between general anesthesia and decline, and results from important trials.

Texas Health and Human Services

Michelle Dionne-Vahalik

Alzheimer's disease and related dementias (AD/ADRD) initiatives in Texas focus on training and include training for licensed and non-licensed caregivers. They have three major dementia care training academies, including the 2-day OASIS Training Academy. Texas uses Person-Centered Thinking Training; Music & Memory; Reminiscence Activity Project; and TRAIN, a national Learning Management Network affiliated with the Centers for Disease Control and Prevention (CDC). Texas has also established Centers of Excellence and intergenerational programming, which includes HOSA-Future Health Professionals, in which they use *A Snapshot on Aging and Dementia* as part of the high school curriculum. They offer Advanced Person-Centered Behavior Training for Residents with Dementia as well as Handfeeding Techniques for Nursing Facility Residents' Train-the-Trainer Program. Lastly, they convened a symposium on geriatrics.

Comments and Questions

- **Sowande Tichawonna** asked whether the students expressing interest had relatives with dementia. **Ms. Dionne-Vahalik** said that there was interest from both personally affected students and those unaffected. One of the biggest motivators for students is the Music & Memory program, which helps the person with dementia connect with loved ones.
- **Laura Gitlin** was impressed by the amount of programming throughout the State of Texas.

Massachusetts General Hospital Frontotemporal Dementia Unit

Katherine Brandt

The Massachusetts General Hospital (MGH) Frontotemporal Dementia (FTD) Unit has several initiatives to serve this atypical patient population. Caregivers in existing memory care residential programs generally have limited experience and understanding of the unique care needs of this population. The care of this younger population must include connections with community-based agencies. MGH has a prototype for informal partnership between medical centers and community agencies. It offers clinical support (e.g., monthly calls between the FTD Unit nurse and the residence's nurse practitioner), educational opportunities (e.g., on-site staff workshops), community engagement (e.g., residence staff attendance at and support of MGH FTD Unit community events), and opportunities for scale-up.

Comments and Questions

- Responding to ***Dr. Epstein-Lubow, Ms. Brandt*** clarified that the intent of the monthly calls was to prevent crisis calls and to clarify medication to prevent emergencies.

Drexel University

Laura Gitlin, Ph.D.

Dr. Gitlin represents the research community. Working with colleagues--whether from a biological or social/psychological perspective--is a successful approach. In partnership with the University of Michigan, she has been involved with the Adult Day Service Plus Program, for which the National Institute on Aging (NIA) funded support for caregivers. WeCareAdviser is an online program that operationalizes the advice approach to provide strategies for solving challenges in the home. It provides a sense of purpose through activities that are disease-stage appropriate. Other countries have picked up and are using information provided by United States researchers, and yet, we can't seem to implement practices for which we have evidence of success. Effectiveness has been shown with the Community Outreach and Patient Empowerment project and there is a structure for program rollout. Tools and strategies continue to be developed. This year Dr. Gitlin and Dr. Nancy Hodgson published *Better Living with Dementia: Implications for Individuals, Families, Communities, and Societies*, which highlights evidence-based best practices for improving the lives of patients with dementia. The goal is to change the culture of despair, so the conversation now is about what we know we can do. Drexel continues to offer free, online courses, which more than 70,000 people have accessed.

FEDERAL WORKGROUP UPDATES

Administration for Community Living

Erin Long [via telephone]

The Administration for Community Living (ACL) has offered the following webinars this year:

- Finding the Balance--Enhancing Self-Efficacy in Persons Living with Dementia (814 people trained).
- Disaster Preparedness for Community-Dwelling Older Adults with Dementia and Caregivers: Key Design Elements and Lessons Learned from a Health System Pilot (554 people trained).
- Addressing Health Disparities in People Living with and at Risk for Dementia (will be presented July 31).
- First Responder Training and Programs to Support People with Dementia (will be presented August 7).

The 2018 Alzheimer's disease grant program applications are under review and ACL hopes to award Alzheimer's Disease Programs Initiative grants given to states and communities in September. ACL has received applications for Alzheimer's Call Centers, which will also be awarded and launched in September.

Centers for Disease Control and Prevention

Lisa McGuire, Ph.D.

CDC has established its Data for Action program, which is updated annually, in 29 states and the District of Columbia. CDC has published state-specific infographics on subjective cognitive decline (SCD) and offers access to a data portal that provides information on cognition, caregiving, etc., free of charge, including the recent publication on SCD, *Know Someone with Memory Loss?*

The Healthy Brain Initiative is a state and local partnership to address dementia in the 2018-2023 Road Map. This was developed with the Alzheimer's Association and is the second in a series of road maps to advance cognitive health as an integral component of public health.

The goals of Healthy People 2020 include: (1) continuing to increase the proportion of adults 65 and older with diagnosed AD/ADRD, and their caregivers, who are aware of the diagnosis; and (2) reducing the proportion of preventable hospitalizations among this population.

Objectives for Healthy People 2030 are now under discussion, and ACL, NIA, and CDC are co-leading a workgroup to develop objectives. Objectives will include increasing the proportion of people 65 and older with SCD who have discussed their confusion or memory loss with a health care professional.

CDC's recent efforts to raise awareness include online publications such as Alzheimer's as the disease of the week in June, which shares key facts, prevention tips, and a quiz; Emergency Preparedness for Older Adults, which focuses on cognitive impairment; and Dance Your Way to Better Brain Health, which emphasizes the importance of exercise.

Centers for Medicare & Medicaid Services

Terri Postma, M.D. [for Shari Ling, M.D.]

There are several dementia-related programs within the Centers for Medicare & Medicaid Services (CMS):

- The National Partnership to Improve Dementia Care in Nursing Homes: CMS is tracking its progress using the percentage of long-stay nursing home residents who receive an antipsychotic medication as an indicator. They have found an overall decrease of more than 35% for all ten regions.
- Comprehensive Primary Care Plus (CPC+), a model to improve quality, access, and care, has just under 3,000 practices participating. They released their final report and, in addition, released two infographics summarizing progress in the first year with CPC+ Medicare Payments Calendar Year highlights. Results showed that health practices engaged in substantial, challenging transformation and improved how they delivered care, reducing Medicare beneficiaries' hospitalizations and emergency department visits. However, savings to Medicare were not sufficient to cover the total care management fee payments.

People living with dementia have both short and long-term care and use more standardized items. In April, CMS released guidance to Medicare Advantage Organizations for additional services to beneficiaries with multiple chronic conditions and the social factors outside the reach of traditional medicine that can contribute to them. These include:

- Changes for the 2019 Medicare payment policy to remove some admissions documentation requirements (simplifying paperwork); the proposed Patient-Driven Payment Model would replace the Resource Utilization Group system.
- Changes in the 2019 Medicare physician fee.
- Expansion of Medicare Supplemental Benefits (i.e., home and community-based services such as wheelchair ramps, transportation to doctors' offices, and home-delivered meals).
- Advancement of virtual care by paying clinicians for virtual check-ins.
- Pay for rural health clinics and federally-recognized health centers.
- Pay for clinicians when they review and evaluate photos.
- Expansion of the definition of "primarily health related".

In July, CMS issued a proposed rule outlining 2019 Medicare payment updates and quality reporting changes for home health agencies. The proposed rule can be

downloaded from the *Federal Register*. They will accept comments until August 31, 2018. Additional guidance on the CHRONIC Care Act of 2017 will be released.

U.S. Department of Veterans Affairs

Marianne Shaughnessy

The U.S. Department of Veterans Affairs (VA) Geriatric Scholars Program is a workforce development program that integrates geriatrics into primary care practices. It includes a longitudinal multi-modal continuing education program for health care professions. The focus is on rural VA clinics with outreach to Indian Health Service (IHS) clinics. Several sites have practices specific to dementia.

Webinars that support the Geriatric Scholars toolkit include Dementia and Rehabilitation, Overview of Dementia, Pain Assessment and Management with Dementia, Ethics in Dementia, and Modifiable Risk Factors for Dementia.

The VA Geriatric Scholars Rural Interdisciplinary Team Training in care of older veterans offers onsite training for rural community-based outpatient clinic staff on teamwork in care of older adults and recognition of geriatric syndromes and functional impairments including dementia.

For IHS, the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program into Indian Country has been extended for another year (through January 2019). A brochure and website have been developed and the program aims to reach 50 troubled communities by February.

Comments and Questions

- ***Marianne Shaughnessy*** responded to ***Dr. Gitlin***'s question: The REACH program has not yet influenced many family caregivers, but the program will get to them.

National Institute on Aging

Richard Hodes, M.D.

The Bypass Budget requires NIH to prepare for Congress the budget needed to maximize progress toward goals defined in the National Plan. The Bypass Budget is the annual professional judgment budget for additional federal funds needed to accomplish various goals. The recently released 2020 budget includes funds to treat or prevent AD/ADRD by 2025 (\$477.7 million).

The process involves input from constituents to define milestones, but added funds are needed to enact those milestones. Two AD/ADRD summits have been convened since the last Bypass Budget. In addition, the National Academy of Medicine and the Agency for Healthcare Research and Quality (AHRQ) convened an expert panel to identify areas where further research is needed.

The 13 NIH Institutes and Centers with dementia-related programs have a number of AD/ADRD programs, including developing new tools to obtain a clearer picture of the complex underlying mechanisms of AD/ADRD. NIH is promoting use of Common Alzheimer's Disease Research Ontology (CADRO) as a framework for big data management. CADRO provides a framework for the International Alzheimer's Disease Research Portfolio, which enables implementation tracking.

A critical need is to increase the size of the research community; 39% of investigators last year had never received an AD/ADRD research grant before. Another mechanism is the Eureka Prize, for which NIH has awarded \$42.2 million to fund 38 exceptionally innovative research projects that could have an extraordinarily significant impact on many areas of science.

The next AD/ADRD Technological Innovation Summit will be held March 14-15, 2019, and the AD/ADRD Care/Services Summit will be held March 24-25, 2020

Comments and Questions

- **Robert Egge:** In the past, when Congress has provided funding, you have been able to bring things forward. What do you foresee for this year? **Dr. Hodes:** People at NIA are confident that funding will be increased because that would allow accomplishment of a particular goal. It is a matter of constant targeting.
- **Laura Gitlin:** If moneys are allotted to particular categories, how do translational research and clinical intervention overlap with care? It is all risk prevention, care, and cure. **Dr. Hodes:** The project has to be an additive for the structure of the Bypass Budget, but there is much overlap. Acceleration of research feeds into a Bypass Budget. When NIA and NIH saw a recommendation coming, they accelerated the focus on that even before formal release of the recommendations. That propelled investigations into other already-funded research.
- **Laura Gitlin:** The two infographics show two different numbers of dementia-afflicted persons (i.e., 6 million vs. 5.5 million) and the two use different terminology. **Dr. McGuire:** CDC is actually using 5.7 million, but the number is growing, so they said nearly "6 million." **Ms. Khillan:** They are also talking about more than Alzheimer's when they include AD/ADRD. This may have to be worked out.

HEALTHY BRAIN INITIATIVE ROADMAP TO ADDRESS DEMENTIA: 2018-2023

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map ***Lisa McGuire, Ph.D., CDC***

Alzheimer's prevalence and costs are expected to increase steadily from 5.5 million people and a cost of \$277 billion in 2018 to 13.8 million and \$1.14 trillion in 2050. Yet, the public health perspective has not received enough attention. In 2005, CDC and the Alzheimer's Association partnered to form the Healthy Brain Initiative to advance cognitive health as a central part of public health practice and to harmonize the approach.

Over the years, the partnership has produced road maps for state and local public health leaders of practical and expert-guided actions with flexible agendas grounded in public health approaches. Surveillance has increased significantly (e.g., in maps of the United States, 2015-2017, one indicated the prevalence of SCD and another indicated the number of caregivers).

Growth in the implementation of road map actions has also steadily increased. Approximately 84% of action occurs at the state level, but action also occurs at local, Tribal, and other levels. A 148-member Leadership Committee was formed to update the current road map and identify leading public health issues for 2018-2023. The Committee obtains subject matter, practitioner, researcher, and stakeholder expertise on top issues and proposes and reviews actions for the next road map, which will be released via a phased rollout beginning in October. They are now developing an implementation guide. The Leadership Committee was divided into five workgroups and subsequently made the following decisions:

- Focus on state and local public health agencies in collaboration with partners on aging, health care, academia, and other sectors.
- Keep the public health framework.
- Reduce actions but elevate impact by emphasizing policies, systems, and environments.
- Integrate dementia caregiving and generate evidence for action.

In this framework, essential services of public health are to ensure that people are trained in cognitive care (i.e., ensure a competent workforce), monitor and evaluate to understand whether interventions are making a difference, educate and empower the nation, develop policies, and mobilize partnerships. This requires collaborating and leveraging resources, maintaining and sustaining impact moving forward, collaborating across multiple sectors, and promoting health equity.

Core topic areas are: risk identification and risk reduction, early detection and diagnosis, quality of care, dementia caregiving, education and training for professionals, and data and evidence for action. Priority actions that drive the discussion among health professionals include:

- Integrating the best available evidence into messaging.
- Educating the public about the importance of brain health and recognizing the important role caregivers play.
- Improving access to the best interventions.
- Promoting the use of effective interventions and best practices and supporting better informed decisions by educating policy makers.
- Ensuring a competent workforce that knows how to use the available information and integrate it into people's lives.
- Providing continuing education for health care professionals and continuing to train health care providers.
- Implementing the Behavioral Risk Factor Surveillance System optional module for cognitive decline in 2019 or 2020.
- Using data gleaned through available surveillance strategies.
- Convincing states to implement the cognitive decline model over 2 years (because it is a costly model to implement).

In addition, CDC is adding a version of the road map for Indian Country, which has been modified to be more applicable to various groups. Now, people in public health and the aging network can raise awareness and educate members and constituents of national organizations. Public health professionals can also get state and local stakeholders to review the road map, prioritize and implement actions, evaluate, and share their successes. People in the aging network can share the road map with public health, establish shared goals, and partner to implement. Other partners can promote the road map, inform policy makers, integrate the map into existing community benefits and other plans, collaborate on implementation, and conduct applied research and translation.

In summary, the new *Healthy Brain Initiative Road Map* will help partners chart a course for dementia care in the future and will prioritize applied research and translation to help advance the field.

Comments and Questions

- **Laura Gitlin** thought that the effort to have a competent workforce has to be integrated into the existing educational framework. **Dr. McGuire** agreed. CDC is working with the Health Resources and Services Administration (HRSA) and partnering with the Alzheimer's Association to attract and work with public health students to integrate training and provide new training for current health professionals.
- **Michelle Dionne-Vahalik** noted that the approach is already being used by health professionals.

Building Our Largest Dementia Infrastructure for the Alzheimer's Act
Robert Egge, Alzheimer's Association

The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, sponsored by bipartisan House and Senate members, directs CDC to establish Alzheimer's Centers of Excellence. These centers are increasing the education of public health officials, health care professionals, and the public on Alzheimer's, and are implementing strategies to improve early detection and diagnosis, reduce risk, and prevent avoidable hospitalizations. The BOLD Act also awards cooperative agreements to public health departments to help them implement effective Alzheimer's interventions and strategic action items identified in the Public Health Road Map. It increases data collection, analysis, and timely reporting by helping stakeholders track public health response progress and identify opportunities for public health interventions via data-collection tools such as the Behavioral Risk Factor Surveillance System.

ASSESSING THE PREPAREDNESS OF THE U.S. HEALTHCARE SYSTEM
INFRASTRUCTURE FOR AN ALZHEIMER'S TREATMENT

Jodi L. Liu, RAND Corporation

Soeren Mattke, M.D., D.Sc., RAND Corporation

We focus on Alzheimer's treatment now because, while AD/ADRD affects more than 5 million Americans, there is currently no treatment. Nevertheless, we maintain guarded optimism for Alzheimer's disease-modifying therapies that are in development. The treatment paradigm has shifted to early stage disease (13.9 million Americans are estimated to have mild cognitive impairment [MCI]). Our objective is to quantify the potential mismatch between supply and demand for the delivery of a future Alzheimer's treatment.

The disease-progression model assumes that a disease-modifying therapy for early-stage Alzheimer's will be available by 2020. It is expected to involve therapy delivered by intravenous infusion every 4 weeks for a year and that the treatment will reduce relative risk of progression from MCI to AD/ADRD by 50%. Dementia specialists should include neurologists, geriatricians, and geriatric psychiatrists.

Uptake rates for the treatment are based on expert input. With treatment first available in 2020, the investigators expect wait lists to persist until 2034.

Specialist shortage is the most urgent issue. However, this binding constraint is unlikely to be resolved. To improve productivity, more specific secondary screening tests for MCI would reduce the number of false positives and enable prioritization based on risk. Task shifting must occur during the evaluation process and we must expedite development and deployment of screening tools.

Qualifying providers from other specialties to evaluate MCI due to Alzheimer's would relieve some of the workforce shortage. Physicians in larger specialties (e.g., internal medicine or general psychiatry) could become mid-level providers of dementia care.

Moreover, we could use telemedicine to facilitate access to dementia care specialists by primary care providers.

The range of diagnostic options could be expanded. Expanding capacity for PET scans is technically feasible, but probably inefficient. Currently, access to amyloid PET is limited by geographic gaps in cyclotrons that manufacture tracers. Use of CSF assays is a possible solution: samples can be obtained in most clinics and sent to central labs, which would make it less expensive per test. Home infusions could play an important role. Expected prevalence implies the need to triple existing infusion chair capacity. Home infusion delivery could increase capacity in the short run without fixed infrastructure. This will be covered for patients in traditional Medicare starting in 2020 and is already covered by many Medicare Advantage plans. The nature of this treatment could allow short duration home infusion for cognitively intact patients.

Implications for the research agenda are:

- Developing better screening tools that would reduce the large numbers of patients entering the care pathway would probably have a high return on investment.
- Demonstration projects for scalable delivery models that better leverage specialists' time are needed, which would also help regional access issues.
- Capacity constraints on diagnostic testing and infusion delivery are likely to be addressed with current efforts, assuming adequate reimbursement.

In summary:

1. Disease-modifying Alzheimer's therapy would be a breakthrough.
2. Simulation suggests that the United States health care system is ill-prepared to deliver a therapy to a large number of cases.
3. Increasing capacity to deliver such a therapy would involve payment policy, regulatory requirements, workforce considerations, and capacity planning.

Comments and Questions

- **Robert Egge** asked whether the assumptions about therapy were robust. **Dr. Mattke**: Efficacy of treatment does not matter for the model. That is, how many people will get sick does not affect the rate of disease progression, but it does affect the wait time.
- **Laura Gitlin**: That is an important tool for us. Can you build on this model thinking about treatment differently? People experience significant changes in their ability to carry out daily activities (e.g., becoming hampered by anger, depression, and withdrawal from activities). Could you run this model with other types of treatments? Although it complicates the situation, it is important for us to

think about that. Treatment cannot be just one thing; it must be multifaceted. **Dr. Mattke:** This is just the tip of the iceberg--this just gets patients into initial treatment. **Ms. Killan:** This also cuts across disciplines and is an area for this Council to take on.

- **Gary Epstein-Lubow:** Where do infrastructures exist to manage these populations? **Ms. Taylor:** Are we considering pure Alzheimer's disease only or mixed pathology? And, how do you define amyloid-positive? **Dr. Postma:** This all points to the need for clinical trials.

PUBLIC INPUT

John Dwyer, Global Alzheimer's Platform Foundation

Current Alzheimer's disease trial centers have inadequate capacity to enroll and execute clinical trials. Even if qualified participants can be recruited, few sites can accommodate these participants. Therefore, to successfully execute trials in the Alzheimer's pipeline, changes to the current system are critical. In response to NAPA's recommendations, the Global Alzheimer's Platform (GAP) Foundation is working on decreasing the cost of clinical trials networks. GAP-Net is poised to increase site capacity by increasing the total number of sites, shortening the duration of Alzheimer's clinical trials, collaborating on infrastructure investment, and facilitating site optimization activities. In addition, GAP is incubating novel pre-screening technologies intended to reduce the rate of screen failure, thereby creating additional site capacity. While we at GAP believe these tactics will make a significant contribution to reducing the shortage, larger and more systemic strategic programs must be considered to close the gap between pending Alzheimer's disease clinical trial demands and the supply of clinical trial sites in North America.

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

Dr. Janicki and Dr. Seth Keller are co-chairs of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), an affiliate of the American Academy of Developmental Medicine and Dentistry, which is associated with the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago. Dr. Janicki wants to raise the issue of the need to enhance supports to families and others who are the primary caregivers for adults with intellectual disabilities and dementia resulting from Alzheimer's disease and related causes. Articles have been published about the declining reservoir of caregivers for the aging population and the need to shore up supports for caregivers nationally. One difference for AD/ABD-related dementia is the difference in care given. The main caregivers are the parents and often siblings of the afflicted person. The NTG recommends increased supports for caregivers, paid or unpaid, of adults with intellectual disability and dementia; increased research on community-living settings related to people with intellectual disabilities; acknowledgment of the influence of cultural values and practice diversity in caregiving; increased screening for dementia;

raised public and professional awareness; and leveraged integration of the nation's aging networks and disability networks. There is great need for contextual diagnosis and informing parents of that diagnosis. Other issues include housing assistance, research into family caregiving, cultural differences, and age groups.

Sarah Sozansky, Association for Frontotemporal Degeneration

Ms. Sozansky's father, a well-known attorney, was diagnosed with FTD in 2008, but did not die until 2016. FTD is a devastating illness that thousands of patients and caregivers are dealing with each year. But, they have nowhere to turn for guidance and support. Ms. Sozansky asked that the Council continue to improve upon and expand the resources that are included in the National Plan. Specifically, that they take into consideration the needs of younger caregivers and patients, the financial impact of FTD, and the need for better long-term support service options when updating the National Plan. It is imperative that families have unrestricted access to the necessary resources that can assist them.

Theresa Goodwin Morrison, parent of an adult with Down syndrome regression [read by Ms. Khillan]

Ms. Morrison addressed Down syndrome regression and the frequent misdiagnosis of AD/DRD for very young people with Down syndrome. She gave the example of her son who has Down syndrome. He was doing well until his regression when he became angry and aggressive and stopped going to school, his job, and social activities. She finally found an online caregiver support group sponsored by NTG and eventually found the Alzheimer's Society. But, these resources should have been more readily available.

Ms. Morrison asked the Council, along with NTG and other organizations, to help doctors understand the difference between Down syndrome regression and Alzheimer's. A medical checklist should be available to doctors, especially neurologists and psychiatrists, and others who work with people with intellectual disabilities, especially people with Down syndrome.

Paula Gann, parent of an adult with Down syndrome [read by Ms. Khillan]

Ms. Gann's 46-year-old daughter has Down syndrome and has been enrolled in a study on Alzheimer's disease and Down syndrome searching for biomarkers. She manifests symptoms of MCI, and her condition has not progressed. Ms. Gann asked that the Council not forget people with Down syndrome and Alzheimer's disease, the aging parents caring for their failing children, and the brothers and sisters who must manage their siblings while caring for aging parents.

Ashley Helsing, National Down Syndrome Society [read by Ms. Khillan]

Last November, the National Down Syndrome Society (NDSS) and their partners released *Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers*. They want caregivers to know that NDSS supports them and they want to provide resources about Alzheimer's disease. This guidebook was written to empower caregivers and families with knowledge and guidance about the connection between Down syndrome and Alzheimer's disease. It also includes how to evaluate changes that

may be observed with aging and how to adapt and thrive within an ever-changing role when a diagnosis has been made. Ms. Helsing encouraged Council members to download the book from the NDSS website.

2018 RECOMMENDATIONS: PRESENTATION AND DISCUSSION

Rohini Khillan

Ms. Khillan reported that the recommendations had been sent to the U.S. Department of Health and Human Services (HHS) Secretary in June. Non-federal members had identified issues and representatives of the three subcommittees had worked on the Driver Diagram to clarify time frames and how to measure success. Everything will be combined into one Driver Diagram. On July 20, the subcommittee chairs met and each chair presented their subcommittee's recommendations, which were combined and edited and then presented to the group for further discussion.

Each subcommittee will now present their recommendations.

Clinical Care Subcommittee Recommendations

Gary Epstein-Lubow, M.D.

The subcommittee reviewed last year's recommendations from which they generated a list of some 20 ideas for new recommendations. These were consolidated into five themes, with a single recommendation crafted for each:

Recommendation 1. Advance the themes and results of the 2017 National Research Summit on Care, Service, and Supports for people living with dementia and their caregivers.

The research findings should be incorporated into federal agencies' recommendations and should address gaps in knowledge and practice. Federal and non-government organizations should allocate funding. ASPE should integrate the 12 themes from the Care Summit into the goals and strategies of the National Plan.

Discussion

- ***Laura Gitlin:*** We will be coming back to the Advisory Council to discuss a format, so part 1b may not be necessary.

Recommendation 2. Educate the public about early detection and diagnosis of AD/ABRD.

Education about early detection is important because people living with cognitive symptoms are better able to participate. This is less prescriptive about education itself. Increased education of the public, promotion of educational materials, encouraging opportunities for locals (e.g., ACL's No Wrong Door) entitles people to advance. Other

examples include CDC's Healthy Brain Initiative, ACL's Brain Health, HRSA training material, and NIA's What Is Brain Health Initiative. The U.S. Preventive Services Task Force is an independent group of national experts in prevention and evidence-based medicine that works to improve the health of all Americans by making evidence-based recommendations about clinical preventive services such as screenings, counseling services, or clinical preventive services.

Recommendation 3. Enhance current and future workforce.

This expands prior years' recommendations and includes new training, disaster preparedness, acute care, behavioral health, and continuing education on training with evidence-based guidelines.

Discussion

- **Joan Weiss, Ph.D.:** Recommendations 2 and 3 are similar in treating AD/ADRD from a public health perspective. **Dr. McGuire:** Recommendation 2 relates to the broad sphere of public health and Recommendation 3 adds managing co-morbidities in the context of AD/ADRD.
- **Laura Gitlin:** This represents a real gap of great need. This could be simplified and condensed. **Dr. Weiss:** Recommendation 2 (at the end of the bolded paragraph) should be used as the standard definition for all the recommendations. If needed, we could refer the reader to additional web-based recommendations.

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 new recommendation is important to define comprehensive care so everyone is working toward the same target. We could identify a workgroup that considers factors such as elements of care and services based on level of function, health disparities, and cultural competencies to advance best practices and the development and evaluation of technologies to link persons living with AD/ADRD and family members to care providers. This group could also consider risks related to quality of life (e.g., financial risks).

Discussion

- **Cynthia Huling Hummel:** All people involved in treatment and care must come together to define best practices. Privacy concerns are one of the complicated issues of technology in enhancing and delivering care. A federally authorized workgroup could be a way to address this. Some people do not want their cognitive health reflected in electronic records. **Dr. Gitlin:** It should be here but needs wordsmithing. **Dr. Epstein-Lubow** will work on it and circulate a draft to members. The Advisory Council should identify a process. **Ms. Khillan:** The

Council has to decide how detailed it wants to be. **Dr. Gitlin:** These are items to consider. Then the Advisory Council will decide the best way to proceed.

Recommendation 5. Encourage further development, evaluation, and use of health care models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.

This recommendation is new. It relies on a definition of value-based care (a health care delivery model in which caregivers are paid based on patient outcomes). It links to measures recently launched by CMS.

Discussion

- **Robert Egge:** We are at the point of moving on to the next action now that we have some information.

Long-Term Services and Supports Subcommittee Recommendations **Debra Cherry, Ph.D.**

The most effective impact of NAPA is research funding. The Long-Term Services and Supports (LTSS) Subcommittee had clear and aspirational goals that focused on particular persons and agencies. LTSS has diffuse accountability. They identified five themes and, from these, developed recommendations with the intent of building more effective integration between clinical care and home care-based services. This would rely on improved family/friend caregiver identification, assessment, support, and engagement by health care systems. The goal is to provide high quality, person and family-centered LTSS, including home care service programs, and to address behavioral symptoms across the spectrum.

Recommendation 1. Decrease disparities in access to home and community-based LTSS for people.

We must meet the needs of an increasingly disparate population. Congress should increase funding by 2025 for ACL's Alzheimer's Program Initiative, the Older Americans Act, and the National Family Caregiver Support Program. The Office of Minority Health should prioritize dementia and dementia-support programs. All divisions in HHS should tailor their programs to address dementia.

Discussion

- **Ms. Khillan:** The recommendation should add "for whom disparities should be decreased."

Recommendation 2. Build more effective integration between clinical care and home and community-based LTSS.

CMS should issue informational bulletins on dementia as should the Office of the National Coordinator for Health Information Technology. AHRQ and CMS should use existing measurement strategies to establish baselines for satisfaction, at the same time addressing Health Insurance Portability and Accountability Act issues.

Discussion

- **Terri Postma** thought the subcommittee should list the caregivers for interoperability. She will send her suggested edits.

Recommendation 3. Address behavioral symptoms across the full range of care settings.

This implies increasing the number of grant programs for caregivers and others.

Discussion

- **Michelle Dionne-Vahalik:** Use the same definition of caregiver as the Care Summit did.

Research Subcommittee Recommendations

Angela Taylor

Research themes include a robust biomedical and holistic strategy, sufficient resources, and minimization of “silos.”

Recommendation 1. The 2018 National Plan should continue to provide a robust, comprehensive, collaborative, and transformative scientific road map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD.

Recommendation 2. The top priority remains the urgent need for Congress to fund research for all three subcommittees.

Recommendation 3. Emphasis should be given to the standardization of terminology about cognitive impairment and dementia by all agencies involved in the National Plan to reduce ambiguity over confusing and overlapping terms and to reduce stigma-associated mistreatment.

Discussion

- **Gary Epstein-Lubow:** Does “dementia” include, for example, FTD? **Ms. Taylor** suggested defining that in a footnote.

Recommendation 4. Maintain global efforts to support research, care, and continuation of collaboration between public and private entities.

Recommendation 5. Enhance recruitment efforts to identify those at risk of developing AD/ADRD. This should require documentation of recruitment goals.

Discussion

- **Joan Weiss:** The workforce should be educated to include persons in clinical research.

Recommendation 6. Federal agencies should develop a strategy and infrastructure to increase open sharing of, access to, and utilization of research data.

This strategy should accelerate the pace of scientific discovery and should be established as a standard practice. International expertise could be leveraged at meetings.

Recommendation 7. All federal and non-government agencies funding AD/ADRD research--along with the Patient-Centered Outcomes Research Institute, academia, and industry--should establish the engagement of the AD/ADRD community as a standard practice.

Discussion

- **Cynthia Huling Hummel** thanked the Council for including persons living with dementia. It is important to keep this discussion person centered.

VOTE ON 2018 RECOMMENDATIONS

Laura Gitlin, Ph.D.

Rohini Khillan

All non-federal members voted in favor of all Recommendations.

In the past, the order of Recommendations has been research, clinical, and long-term, but the Council can decide that.

The 2018 Recommendations are ready except for inclusion of definitions and reference links as well as minor wordsmithing. Recipients include the HHS Secretary, members of Congress, and anyone on the NAPA listserv (approximately 500 people).

DISCUSSION OF DISSEMINATION AND NEXT STEPS

Laura Gitlin, Ph.D.

Discussion

- **Debra Cherry:** Every person gets money to send one person to these meetings.
- **Rohini Khillan** asserted, that money cannot be repurposed.
- **Debra Cherry:** We have two audiences: agencies and caregivers.
- **Laura Gitlin:** What particular organizations do we want to target? Do we want to modify the appearance? Should we request action plans? Should we include an executive summary? **Dr. Gitlin** asked for a small working group to determine and develop messages that should be sent along with the Recommendations. **Dr. Epstein-Lubow** volunteered to align the recommendations within the Driver Diagram. Others willing to volunteer should contact Dr. Gitlin.
- **Katherine Brandt:** Is it appropriate to ask an elected official to issue a press release? **Dr. Gitlin** thought this presented an opportunity. **Ms. Dionne-Vahalik** suggested targeting the Senate Committee on Aging for a briefing and disseminating the document to State Boards of Nursing. **Dr. Weiss** said the Deputy Secretary for Health was interested and that he would take it to various senators. We need to compile such ideas for a dissemination strategy.
- **Laura Gitlin** will convene a subcommittee meeting in mid-August to finalize the format and other details and prepare a draft of the document. By then we will have the edited version of the Recommendations so Ms. Khillan can send it to members.

CONCLUDING REMARKS

Dr. Gitlin adjourned the Council meeting at 3:25 PM.

The next meeting will be in October 2018.

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 and Medicaid Services [*via telephone*]
Katherine Brandt, Massachusetts General Hospital
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
Laura Gitlin, Ph.D., Drexel University, *Chair*
Richard Hodes, M.D., National Institute on Aging
Cynthia Huling Hummel, a person living with Alzheimer's disease, Elmira, NY
Bradley Hyman, M.D., Alzheimer's Disease Research Center
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 [*via telephone*]
Allan Levey, M.D., Emory University
Erin Long, Administration for Community Living, Administration on Aging [*via telephone*]
Lisa McGuire, Ph.D., Centers for Disease Control and Prevention
Terri Postma, M.D., Centers for Medicare and Medicaid [*for Sheri Ling, M.D.*]
Marianne Shaughnessy, U.S. Department of Veterans Affairs
William Spector, Ph.D., Agency for Healthcare Research and Quality
Tina Tah, Indian Health Service [*for Bruce Finke, M.D.*]
Angela Taylor, Lewy Body Dementia Association
Sowande Tichawonna, caregiver, Washington, DC
Joan Weiss, Ph.D., Health Resources and Services Administration

Absent

Billy Dunn, Food and Drug Administration
Deborah Olster, Ph.D., National Science Foundation
Anthony Pacifico, Ph.D., Agency for Healthcare Research and Quality

Public

Speakers

Jodi L. Liu, RAND Corporation

Sarah Lock, AARP

Soeren Mattke, M.D., D.Sc., RAND Corporation

Attendees

Joe Balintfy

Andrew Beil

Dawn Beraud

Martin Blanco

Erin Cadwalader

Rachel Conant

Rod Corriveau

Martin Blanco

Phil Cronin

Morgan Daven

Marleah Denkenberger

John Dwyer

Molly French

Katie Gordon

Mary Hogan

Anisha Imhoff-Kerr

Matthew Janicki

Melinda Kelley

Christopher Laxton

Feng-Yen Li

Katie Maslow

Eliezer Masliah

William Marton

Melissa McGowan

Douglas Pace

Jennifer Pollack

Katherine Scott

Michael Simmons

Sarah Smith

Eric Sokol

Sarah Sozansky

Eleane Swift

Courtney Wallin