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

Washington, DC

July 28, 2017

WELCOME AND CHARGE

Ronald Petersen, Ph.D., M.D. (Mayo Clinic)
Dr. Petersen opened the summer meeting of the National Alzheimer's Project Act (NAPA) Advisory Council at 9:05 a.m. He then welcomed the Secretary of the U.S. Department of Health and Human Services (HHS), Dr. Thomas E. Price.

Secretary's Remarks

Thomas Price, M.D., HHS Secretary
Dr. Price welcomed the meeting participants, then thanked Dr. Petersen, the other Advisory Council members, and the HHS staff. He considers it a privilege to be the HHS Secretary, and an honor to head a department with people trying to help improve the lives, health, and well-being of Americans. Serving on the NAPA Advisory Council requires a significant investment of time and energy, and everyone at HHS appreciates the members' work. Therefore, he wanted to thank the members for their commitment to improving our ability to treat and prevent Alzheimer's disease. He was especially thankful for the leadership of Dr. Petersen, who has been on the Council since its inception in 2011. It is inspiring to think of the progress that has been made, and it would not be possible without Dr. Petersen and his colleagues.

In 2016, the Advisory Council recommended a research summit for caregivers, which will become a reality this October. It is a testament to the efforts of the Council, and it shows what happens when people work together. HHS and Congress receive the National Plan each year, and they look forward to seeing what the council recommends. Much of this work would not be possible without the Council. With the aging population, the stakes could not be higher. How we as a society respond to Alzheimer's disease will contribute to defining who we are as a nation. If we are to find new ways to treat and prevent Alzheimer's disease, we must work together. For their efforts in that direction, he thanked the Council. He especially thanked them for their work, dedication, commitment, and for showing a positive way forward.

Welcome and Charge, continued

Dr. Petersen thanked Dr. Price for his remarks. He then welcomed the participants to the Advisory Council meeting. This was the 24th such meeting, and it was to start with a symposium on where we are, the gaps that exist, and a charge for going forward. Dr.

Petersen then asked everyone to give their name, institutional affiliation, and role on the council.

Ms. Kara Townsend, the new Deputy Assistant for Disability, Aging and Long-Term Care Policy within the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE), said that she was honored to be present. She has seen a lot of the great work the Council has done on the National Plan for Alzheimer's Disease Research, Care, and Services. She was previously on the staff of the Senate Committee on Health, Education, Labor, and Pensions. She looked forward to working with the council.

AREAS FOR BIOMEDICAL RESEARCH

Implications of a Biologically Based Definition of Alzheimer's Disease

Clifford R. Jack, Jr., M.D., Mayo Clinic

Alzheimer's disease has erroneously come to be equated with dementia. This confusion creates problems, in that about 20% of diagnosed Alzheimer's is something else, some "non-Alzheimer's clinical syndromes" are actually due to Alzheimer's, and up to 40% of those with Alzheimer's are asymptomatic. The solution to this situation lies in biomarkers, of which there are currently three: measures of amyloid plaques in the brain, measures of pathologic tau, and measures of neurodegeneration. These can be found via PET scans, and neurodegenerative brain atrophy can be identified using MRI scans. These measures allow investigators to make biologically based diagnoses, which are important in research, particularly in clinical trials. Should a patient with a different kind of dementia than Alzheimer's disease enter such a trial, she would be treated for a disease she does not have and possibly skew the results.

A model of the dynamic biomarkers of Alzheimer's indicates that the biomarkers are abnormal prior to the onset of symptoms. This is significant in that the disease could take up to 30 years to manifest. If the goal is to identify treatments to prevent onset of symptoms, a biologically based definition is essential. To reach that point, there is a need for specificity of biomarkers in order to treat those with Alzheimer's. This will require clinical trials that inform clinical practice. Further, these biomarkers will need to have a degree of sensitivity. In using biomarkers, the prevalence of diagnosed Alzheimer's will be higher. However, the number of patients who are overcounted is smaller than the number of those who are undercounted. This will be the subject of much research over the next few years.

The Many Challenges of Alzheimer's Disease

Eliezer Masliah, M.D., National Institute on Aging (NIA)

NIA estimates that 5.3 million Americans aged 65 and over are living with Alzheimer's, a number that is projected to triple by 2050. Worldwide, the estimate is 46.8 million cases of dementia, to reach 131.5 million by 2050. There have been challenges to these

projections, such as the Framingham Heart Study finding of a reduced incidence of dementia from the late 1970s. This reduction reflected the education levels of the study population, as higher education also correlates with reduced incidence of dementia.

The cost of caring for dementia is serious, currently about $200 billion annually. Half of that amount is the value of unpaid care provided by family members. The greatest health care cost burden for patients with dementia is in their last 5 years of life. The impact is greater for women, especially single women, for whom the out-of-pocket cost is double that of married women. A cost of care comparison shows that dementia, at about $300,000 per year, is roughly double that of cancer and other diseases. A breakdown by age group shows that the greatest risk is for individuals who are 85 and older. These data will help forecast pre-clinical and clinical Alzheimer's disease, with potential impact on prevention interventions. The data also show the need to determine lifetime risks of Alzheimer's based on biomarker screening.

Comments and Questions

- ***Ronald Petersen*** noted the analogy of how we define cancer, where individuals with positive biopsies or biomarkers are told they have the disease even if they are asymptomatic. ***Dr. Jack*** said that the tests he described are expensive or invasive, pointing to a need for less-expensive tests and information on patients' age, genetic history, and possible blood biomarkers. Such tests would allow clinicians to screen the general population, sending those at risk for more detailed screening. This approach would be comparable to cardiovascular screening. ***Dr. Masliah*** agreed, adding that NIA is funding research for blood markers that can be combined with genetic markers.

- ***Gary Epstein-Lubow*** said that the Alzheimer's Association issued a special report on this topic. The science is progressing in the direction of identifying a blood marker and refining diagnostics. The four essential elements are prevention, early detection, more sophisticated diagnostics, and treatment. Having a treatment and the capacity to identify patients when they are pre-symptomatic will have significant implications for the work in this field and for public health.

- ***Richard Hodes*** agreed that there is a need for precision of diagnosis. However, the public has concerns that Alzheimer's is receiving attention to the exclusion of other types of dementia. This is not the case. The National Institutes of Health (NIH) is looking at all dementia. ***Dr. Jack*** agreed. The imprecision of definitions is a barrier to treatment and a cause of confusion due to the conflation of Alzheimer's with dementia. Public education is the answer. ***Dr. Petersen*** added that the council covers both Alzheimer's disease and related dementias (ADRD).

- ***Shari Ling*** said that it is important to think about the clinical utility of what the data mean. At the end, it is about how a clinician would use the information from the tests to make decisions with the patient and family about treatment and care.

AREAS FOR CLINICAL CARE RESEARCH

Increasing Opportunities for Choice and Control for Persons with Dementia

Suzanne Crisp, Public Partnership
Self-direction honors personal choices and preferences, and encourages independence. Individuals with dementia and Alzheimer's are challenging and present difficulties such personality changes, communication problems, and limited decision-making abilities. At the same time, caregivers are stressed, and they must learn how to provide care. Representatives can help. They can enter the situation when a person is apprehensive and concerned. Representatives must be close to the individual, and must know and base decisions on the person's values and preference. About 40% of elderly people have a designated representative.

Self-direction is right for many individuals with dementia. It allows greater access to services in rural areas, creates new opportunities for caregiver employment, is flexible enough to address changing preferences, facilitates access to services on nights and weekends, and allows individuals greater engagement in community activities. The costs are equal to or less than traditional personal care services. Caregivers tend to like the arrangement as well. Survey data show that 1.1 million people self-direct across all disability groups. Challenges include lack of interest by some case managers, labor-intensive enrollment, employment considerations, and concerns about misuse of program funds.

Self-direction is not right for everyone, but those with cognitive limits should have the option, as they are the experts when it comes to their own lives, and some will be quite active. Certain supports are necessary, but research shows that about 80% of the budgets are spent, indicating wise participant choices. Budgets can cover safety items, like reminding devices and wandering devices. Twenty-four percent of those receiving Medicaid/Medicare home health services have moderate to severe cognitive impairment. The program appears to be cost-effective, though cost studies are not definitive.

Managing Chronic Conditions in People Living with Dementia

Deirdre Johnston, M.D., Johns Hopkins University School of Medicine
The crux of managing dementia is identifying the comorbid conditions that send the patients to the hospital: prevention that results in better quality care. Dementia has a progression that looks different from one person to the next. The capacity to self-manage varies, but it is lost over time. Early intervention and caregiver education help individuals plan ahead and make their preferences clear. Dr. Johnston often hears that caregivers do not want to take away the patient's independence and therefore hesitate to take on some tasks.

The average person with dementia has four comorbid chronic conditions. Fragmented care is the norm, and clinical guidelines focus on single disorders instead of the full group. Therefore, they often see multiple providers for multiple chronic conditions, each of which may have its own treatment protocol that includes one or more medication. Participants in a recent study of individuals with dementia took an average of 8.23 medications, while their caregivers, who skew older, took an average of 5.07 medications.

Cognitive impairment is underdiagnosed, in part because it is hard to convey the diagnosis to patients and families. Physicians may fail to diagnose or document dementia due to time, cost, stigma, and futility. There are many cost implications of unmanaged chronic disease in dementia. The impact of dementia on coexisting chronic conditions include loss of ability to self-manage, lower continuity of care and higher use of emergency facilities, and unneeded testing and hospitalization. Everyone with dementia needs a flag on their electronic records so that the ER staff, primary care physician, and others are all aware of the need to communicate with each other. Screening and diagnosis allow treatment and management of dementia, education and support of the caregiver; and management of comorbid conditions. Public education is key in moving toward better quality care.

AREAS FOR LONG-TERM SERVICES AND SUPPORT RESEARCH

CommunityRx for Community-Residing People with Dementia and Their Caregivers

Stacy Lindau, M.D., CommuityRx

An estimated 10,000 individuals with dementia reside in the CommunityRx coverage area. The program received Centers for Medicare & Medicaid Services (CMS) funding to develop a sustainable business model to support this work. The CommunityRx goal is to promote better health, better health care, and lower costs, as well as support the future workforce and provide a sustainable business model. MapCorps employs local youth to generate data for just under 20,000 locations, with the goal of identifying resources. The data are public, and have been used by health care providers to connect people to resources. CommunityRX connects electronic medical records and the identified community resources through use of an algorithm linking 37 conditions. The result is 113,000 patients using 7,000 community resources. These patients reflect those who seek services, rather than the general public.

The program tracks the number of referrals by health condition, including dementia. A supplement allows caregivers to provide input as to whether the participants are getting what they need. Travel issues and geographic disparities are issues to address and CommunityRx is studying geospatial resources, which show the needs for activities and services. The program is also identifying the areas with the greatest need for support. This work is most closely related to the NAPA goal of expanding services and supports

for people with dementia and their families. Attendant needs include intensive caring for caregivers, proactive transparency, and sustainability.

Dementia Caregiving in the United States

C. Grace Whiting, J.D., National Alliance for Caregiving

Ms. Whiting's report was secondary data analysis from a biannual AARP report on dementia care. About 22% of the 44 million American family caregivers care for someone with dementia. The typical dementia caregiver is a middle-aged woman, often without medical training. Two promising models of care are Partners in Dementia Care, a phone-based intervention program that coordinates care and support services, and REACH VA, a randomized controlled trial (RCT) that provides education, support, and skill-building to family caregivers.

The first study finding is that, with dementia, the person receiving care is often older than those with other conditions who receive care. In addition, the caregivers tend to be older, and the caregiving affects their health. The recommendation is to find a way to train caregivers and to analyze the needs of those needing care. Second, with health care shifting to the home, there should be additional research on understanding the caregiver and home care providers, also examining options for training. A comprehensive dementia caregiver assessment would help identify why the caregivers provide the care, and identify resources that can help them. Caregivers often work outside the home, often full-time, speaking to a need to identify and evaluate low-cost or no-cost workplace accommodations to allow caregivers to continue with their careers.

Caregivers want to be part of the circle of care, so there needs to be research on how to simplify that and make it happen. In addition, many caregivers want to see the recipients' medical charts but are often unable to do so, speaking to the need for research on shared decision-making. Respite care has been proven to help but is under-utilized; researchers should examine ways to promote this resource. Finally, many caregivers want access to LTSS, which is another area for expansion.

Living Alone with Dementia: Prevalence, Challenges, and Strategies for Service Providers

Erin Long, M.S.W., Administration for Community Living (ACL)

More than 30% of people with dementia lived alone in 2011. Living alone increases vulnerability, and the progressive decline may go unnoticed until an emergency occurs. Service providers try to identify these people and get into their homes to assess their risk. The need is to support safety while respecting the individuals' autonomy. Involvement of family and friends can help, as can an expanded network of support and coordination of paid providers. ACL's Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) program targets four gaps identified by the NAPA Advisory Council. These include providing effective support services to persons with dementia who are living alone, providing effective care and services to such persons and their caregivers, improving the quality and effectiveness of such programs, and

delivering behavioral symptom management training and assistance to family caregivers.

The program is for community-based organizations only, and there are matching requirements. Of the 32 active grants, 25 focus on approaches for those living alone. Ms. Long gave some examples of innovative approaches, as well as program highlights. A Texas program helps identify persons with dementia and connect them with screening, services, and dementia-specific case management. Maine has a pilot of community support that operates through Meals on Wheels to identify people with dementia. The program has found that 75% of the cases are complex--the participants may have unmet needs, comorbid conditions, or lack connection to a health system. Dementia specialists with small caseloads and a very coordinated approach get them the right services. The California Care Circle Approach has a live-alone algorithm that is spreading across the state. It supports a wide range of needs for those seeking services, including a resource guide and coordination among friends, neighbors, and others who help. The National Alzheimer's and Dementia Resource Center website (http://www.nadrc.acl.gov) includes a wide range of resources, including a guide for professionals, a webinar, and an issue brief.

Comments and Questions

- ***Gary Epstein-Lubow*** asked what should be the focus when thinking of high-value care and attention to cost. Who should identify the caregiver, should there be legal attention for power of attorney, etc.? ***Dr. Johnston*** added that a diagnosis requires a good medical history and elimination of other causes, which falls to the primary care physician. This is time-consuming, and there needs to be a better way to put together the history. Caregivers are often self-declared, usually the person who comes to an appointment with the patient, which is important to note. Patients may not come forward with their issues due to fear of burdening family members, and this needs to be addressed. It is possible to train non-experts in preventing non-medical problems from becoming medical problems, as long as there is a backup of clinicians. There may be a need for a new category of worker.

- ***Margaret Kabat*** observed that there is still a strong tension when it comes to the caregiver representing the care recipient, as their interests and needs often differ. ***Ms. Crisp*** replied that this goes to the maternalistic model of the caregiver knowing best. It speaks to the need to identify the care recipient's preferences and to teach the representative the proper role. Case managers can help make sure that happens.

- ***Angela Taylor*** asked how the prevalence of mixed dementia plays into the diagnostic scenario and the implications for clinical trials. ***Dr. Jack*** replied that while there are biomarkers for Alzheimer's disease, there is a gap in identifying biomarkers for other conditions contributing to dementia. For example, small strokes can be microscopic and hard to detect.

- ***Mary Worstell*** asked about the disparate impact of Alzheimer's disease on women, and whether the observation of the different biomarkers between women and men might change the numbers. She added that while the public now sees cancer and heart disease as manageable, dementia is greatly feared, more than many cancers. There is not yet a message that one can live well with Alzheimer's disease, and this affects the dynamics of family and others. ***Dr. Masliah*** replied that while there is slightly more Alzheimer's in women than in men, possibly related to longevity or estrogen, the growth seems to be similar in men and women. As for communication, that is difficult. There are inherited forms of Alzheimer's disease with a genetic component, and sometimes people do not want to know if they have the gene. However, that will have consequences for their children. A message that this is important for the family and community can help.

- ***Ron Petersen*** said that if people are identified when they are clinically normal, it can lead to lifestyle changes that might delay or mitigate the onset. This is a challenge to communicate, however. ***Harry Johns*** noted that science does not have us to that point yet, and there will be a lot of work needed in order to have these conversations with the public, especially as the field moves closer to the cardiovascular model. The Alzheimer's Association is working on these things already in terms of consumer surveys and related activities.

THE NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE (NASEM) REPORT: PREVENTING COGNITIVE DECLINE AND DEMENTIA: A WAY FORWARD

Interventions to Prevent or Slow Cognitive Decline, Mild Cognitive Impairment (MCI), and Dementia in Individuals without Dementia

Mary Butler, Ph.D., M.B.A., NASEM
Howard Fink, M.D., M.P.H., NASEM

None of the interventions in this study are FDA-approved to prevent or slow cognitive decline in patients with or without dementia. The objective was to review evidence on the efficacy and harms of interventions to prevent or delay cognitive decline, MCI, and dementia in individuals without dementia. The findings are as follows:

- *Cognitive training improves cognitive tests in the domain trained*. There was insufficient evidence for individuals with MCI. Those with normal cognition improved in the specific domain. There was no evidence that commercial "brain training" had an effect.

- *Aerobic and resistance exercise showed mixed benefits*. There was no or insufficient evidence for individuals with MCI, while there was a pattern of results indicating effectiveness for individuals with normal cognition.

- *There were mixed benefits and no difference for multimodal interventions compared to controls on cognitive tests*.

- *The other nonpharmacological treatments evaluated showed little to no benefit in preventing or delaying cognitive decline, MCI, or dementia, those treatments included the following*:
    - Diet;
    - Nutraceuticals; and
    - Vitamins, although B12 and folic acid provided slight memory improvement for individuals with normal cognition.

- *Estrogen and progestin therapy increase the risk for dementia and MCI*. For individuals with normal cognition, both estrogen alone and estrogen with progestin increase the risk of dementia. A high dose of raloxifene reduces risk of MCI but not dementia. No hormone treatments improve cognitive tests, and there were important harms noted for all hormone treatments.

- *Other pharmacological treatments evaluated have little to no benefit in preventing or delaying cognitive decline, MCI, or dementia in individuals without dementia*. These treatments include the following:
    - Dementia medications;
    - Anti-hypertensives, though there is some evidence that individuals who do not have cognitive impairment but do have hypertension may reduce their risk of impairment by taking anti-hypertensive medications;
    - Diabetes medications;
    - Lipid-lowering medications; and
    - Nonsteroidal Anti-Inflammatory Drugs and Acetylsalicylic acids.

Many of the trials in the review were not designed to assess cognitive outcomes, and most were too short to show meaningful cognitive change in cognitively normal participants. Another issue was high attrition. The cognitive outcomes were heterogeneous between trials, and there were reporting issues as well. Studies often did not report incidents of MCI and dementia, there was little reporting of subgroup data, and adverse events were poorly reported.

Preventing Cognitive Decline and Dementia: A Way Forward

Story Landis, Ph.D., NASEM

NASEM has released the assessment of this report, which was conducted by the Committee on Preventing Dementia and Cognitive Impairment. The Committee's task was to examine the evidence for delaying or slowing Alzheimer's and Related Cognitive Diseases (ARCD) and preventing, delaying, or slowing MCI and Clinical Alzheimer's-

type Dementia (CATD). The interventions were to be supported by sufficient evidence and incorporated into public health strategies and areas for future research. The study design was novel, first informing the design of an Agency for Healthcare Research and Quality (AHRQ) systematic review, then drawing from the AHRQ systematic review and other evidence sources. The Committee reviewed additional sources because AHRQ only looked at RCT data. The supplemental sources of evidence included public testimony, cohort studies, neurobiology studies, and knowledge of benefits, harms, and costs.

The conclusion was that there was evidence to justify a public health information campaign to encourage adoption of three specific interventions that are supported by evidence that is encouraging, though inconclusive. All have minimal risk of harm, and two are beneficial for other conditions. The three interventions are cognitive training, blood pressure management for those with hypertension, and increased physical activity.

- *Cognitive training*: Despite the limitations of the Advanced Cognitive Training for Independent and Vital Elderly study, moderate evidence from RCTs show that cognitive training can make a positive difference in delaying or slowing ARCD, especially in activities of daily living. There is no evidence that commercial brain training works; however, nor is there evidence that cognitive training prevents, delays, or slows MCI or CATD.
- *Blood pressure management*: The panel struggled most with this conclusion. RCT data do not offer strong support that blood pressure management in patients with hypertension slows or delays ARCD. Nor do the data indicate that blood pressure management prevents, delays, or slows MCI and CATD. However, the “Hill criteria” suggest that data from non-RCT studies indicate that effects of blood pressure management on incidents of CATD in hypertensives are consistent with a causal relationship.
- *Increased physical activity*: The Committee felt that the benefits of increased physical activity are strong enough and broad enough to promote it in this context, despite the absence of evidence specific to this study.

NASEM had four recommendations:

1. *Communicating with the Public*. NIH, Centers for Disease Control and Prevention (CDC), and other organizations should make clear that the positive effects of cognitive training, blood pressure management, and increased physical activity are supported by encouraging but inconclusive evidence.

2. *Methodological Improvements*. NIH and other interested organizations should perform the following tasks:
    - Support studies that identify individuals at higher risk of cognitive decline;
    - Increase participation of under-represented populations;
    - Begin interventions earlier with longer follow-up;
    - Integrate robust cognitive outcome measures with other trials;

- Include biomarkers as intermediate outcomes; and,
- Conduct RCTs in broad, routine clinical practices.

3. *Highest Priorities for Future Research*: NIH and other interested organizations should support further research to strengthen the evidence base on the following categories of interventions supported by encouraging but inconclusive evidence:
    - Cognitive training;
    - Blood pressure management; and
    - Increased physical activity.

4. *Additional Priorities for Future Research*: NIH and other interested organizations should support further research to strengthen the evidence base on specific topics:
    - New antidementia treatments;
    - Diabetes treatment;
    - Depression treatment;
    - Dietary interventions;
    - Lipid-lowering treatment/statins;
    - Sleep quality interventions;
    - Social engagement interventions; and
    - Vitamin B12 plus folic acid supplementation.

Other cross cutting considerations for research include multimodal approaches, optimizing doses and delivery, promotion and measurement of adherence to interventions, and use of new adaptive designs for clinical trials and statistical methodologies. This report was a snapshot of the science, which means both that new data are constantly emerging and that the recommendations will need to be reassessed periodically. NIA and other organizations should consider that RCTs might not be the best source for public health messaging. The review committee remains optimistic that much more will be known on preventing ARCD and dementia in the near future.

Comments and Questions

- ***Richard Hodes*** thanked the reviewers for taking on this challenging task. Even with imperfect information, it is important to draw conclusions and determine future directions. The recommendations will drive further studies. In some situations, it is not possible to do RCTs because of the ethical issues behind withholding interventions. A Lancet study just came out that included some recommendations consistent with those NASEM found to be most promising. ***Dr. Story*** explained that the committee worried about the long list of things that could be studied, but decided it was not their place to eliminate them.

- ***Harry Johns*** thanked the committee. The Alzheimer's Association is not yet prepared to go further with promotion, but it is encouraging to see that everyone is thinking of dementia as manageable in ways similar to cancer, cardiovascular disease, and diabetes. The need is for the science to get there.

- ***Mary Worstell*** noted that the sensory disabilities like hearing and vision are often overlooked, and that study of connections needs to be revived. She asked why vision was not included. ***Dr. Story*** said that the committee discussed going deeper, but they ultimately decided to restrict their recommendations to what the AHRQ report studied. ***Dr. Hodes*** agreed that sensory factors definitely constitute a risk and need to be considered.

PUBLIC INPUT

Steven Blumrosen, caregjver
Mr. Blumrosen attended as a caregiver. He cared for his father from 2011 through 2015. None of the biomarkers were examined and it would have been good to know about them. His father, who had been writing a book, turned to audiobooks and large font books in order to give Mr. Blumrosen a break as a caregiver. Resilience, perseverance, and resistance to going gently were valued more before we began transitioning to the Elizabeth Kubler Ross model. It would be a good idea to find a balance between the two. As a caregiver, he valued most those who came to the home to visit. He thanked the Advisory Council for their work.

Sandra Fournier, Neighborhood Health Plan of Rhode Island
Ms. Fournier is the project director for an ACL grant for persons with developmental disabilities and dementia. She thanked ACL for the grant. Her organization has developed a resource guide to help caregivers. She hopes that it can serve as a reference tool for caregivers in other states.

Mary Hogan, advocate
Ms. Hogan said that she represents persons with developmental disabilities and dementia, and she has been trying to be a voice in this forum. She thanked Dr. Petersen for his leadership. There has been progress over the last 6 years. However, she always wants to hear more at these meetings about persons with intellectual disabilities, and she hopes it will be on the agenda some day. Such individuals still have limited resources, difficulty with diagnoses, and issues with comorbid conditions being overlooked. Their families are often life-long caregivers who are frequently overwhelmed and lacking resources. She wants to improve the quality of life for individuals with intellectual disabilities.

Matthew Janicki, National Task Group (NTG) on Intellectual Disabilities and Dementia Practice
Dr. Janicki co-chairs the NTG. He is always concerned about getting information into people's hands. He described some resources and published articles, including a booklet from Ms. Fournier's organization. NTG was involved in its development. The Alzheimer's Association and the National Down Syndrome Association have produced a booklet as well, and there are additional resources available through NTG.

Christopher Laxton, Dementia Action Alliance
Dr. Laxton read remarks on behalf of Mary Marcus, a former college professor living with dementia. She is happy about the upcoming summit, but after reading the first background paper, the direction alarms her. Framing dementia as a challenge strips away the feeling of purpose, while in fact many people with dementia are engaged in activities, having relationships, and more. There is a need to expand the boundaries of the definition, and to recognize that the reality can be influenced by expectations. If the Summit focuses on the functional deficits and negative attributes, that is all that will be found. Neutral session titles would be helpful as opposed to the negative cast that they have. People with dementia need to be included.

David Dory, engineer
Dr. Petersen read Mr. Dory's comments, which described a medical concept and hypothesis he has developed. The hypothesis centers on the presence of polymers in the blood and attaching to vascular walls. Stress promotes this, and cerebrospinal fluid is also a factor. Tau tangles are the remnants of destroyed neurons.

RESEARCH SUMMIT ON CARE AND SERVICES UPDATE

Katie Maslow, M.S.W., Gerontological Society of America
The Research Summit on Dementia Care will take place October 16-17, 2017, at NIH. The summit goals are as follows:

- To identify what we know and need to know to accelerate development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and caregivers.
- To focus on research needed to improve the quality of person- and family-centered care and outcomes. Factors to consider include care settings, quality of life, and the lived experience of persons with dementia and their caregivers.

The highest priority of the Summit is to develop research recommendations and priorities to inform federal agencies and other entities that fund research on dementia care, services, and support. Other goals focus on identification of existing evidence-based programs and approaches that can improve care and services, identify methodologies to involve individuals with dementia and their families in shaping research, research advancement of evidence-informed care and services, and summarize the Summit in a range of publications.

Nine members of the steering committee are also on the NAPA Advisory Council, and two steering committee members are people living with dementia. Summit funding is almost complete. A complete list of sponsors and contributors is available online. The agenda is also complete. As additional speakers commit, their names will be added to the website.

Plenary speakers for the first day include Dr. Petersen, Maria Carrillo, Ken Langa, Jennifer Manly, and Maria Aranda. There are three additional sessions for Day One:

1. Research on Care Needs and Supportive Approaches for Persons with Dementia (Co-chairs: Richard Fortinsky and Ann Marie Kolanowski);
2. Research on Supportive Approaches for Family and Other Caregivers (Co-chairs: Linda Teri and Lisa Fredman); and
3. Involving Persons with Dementia and Family and Other Caregivers as Active Members of the Research Team to Identify Research Topics and Meaningful Outcomes (Co-chairs: Mark Snowden and Lee Jennings).

On Day Two, Dr. Petersen and Angela Taylor will chair the plenary session entitled "Nomenclature: Words Matter." The other three sessions for that day include the following:

1. Involving Persons with Dementia as Study Participants (Co-chairs: Darby Morhardt and David Bass);
2. Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers (Co-chairs: David Reuben and Vincent Mor); and
3. Thinking Outside the Box (Co-chairs: Chris Callahan and Alan Steven).

Organizers will ask speakers to include ideas and recommendations for the Summit's cross-cutting themes. The cross-cutting chairs will also review the research recommendations for the inclusion of cross-cutting themes. Cross-cutting themes include diversity; disparities; etiologies and disease stages; care settings; employment, training, and workforce issues; and technology. Cross-cutting chairs are Technology--Sara Czaja; Race/Ethnicity/Culture--Ladson Hinton; Etiologies/Disease Stage--Angela Taylor; Women's Issues--Mary Worstell and Jill Lesser. Recommendations will come from speakers, chairs, stakeholders, public listening sessions, pre-Summit activities, and audience members. In addition, recommendations and comments may be submitted to the Care Summit website.

Persons living with dementia and family caregivers have been participating in the stakeholder groups, discussing Summit-related issues, and providing feedback. A goal of the Summit is to model the involvement of persons living with dementia in research discussions.

The Summit will be open and free to the public. About 200 participants have registered to attend and another 250 have registered to participate online. The organizers had registered all members of the NAPA Advisory Council on the assumption that they will be participating. The Summit team will provide support for the session chairs and speakers, especially to develop recommendations. Current activities include development of a communications plan and work on logistics for participants, especially persons with dementia and their caregivers. The recommendations will go up on the

ASPE Summit website (https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers) shortly after the Summit ends. NIH is considering how to act on the recommendations, and the team hopes to present them to the NAPA Advisory Council.

FEDERAL WORKGROUP UPDATES

LTSS Committee Update

Erin Long, M.S.W., ACL
ACL is continuing to administer 52 ongoing grants. The 2017 Alzheimer's Disease Supportive Services Program (ADSSP) Funding Opportunity Announcement (FOA) review was complete, with a decision pending for an August 1 start date. The 2017 ADI-SSS FOA applications were under review. ACL was coordinating a special electronic Alzheimer's and Dementia edition of *Generations: Journal of the American Society on Aging* for later in 2017. ACL will continue funding the National Alzheimer's Call Center through July 31, 2018.

The Indian Health Service (IHS) Resources for Enhancing Alzheimer's Caregivers Health in Tribal Communities (REACH into Indian Country) program trains caregiving coaches. More than 160 coaches have received training, and more than 60 have received certification. The program has trained interventionists in close to 50 communities across the country and is now focused on enrolling caregivers. The program has hit a plateau, but outreach takes time and IHS has been building a pipeline.

Dementia Curriculum

Joan Weiss, M.D., Health Resources and Services Administration (HRSA)
The HRSA just released its ADRD professional training curriculum. It promotes professional teamwork in the care of persons with dementia and includes 16 modules addressing topics from ethics to pharmacy, and more modules are coming. Among the "live" modules are four that will address how to engage family members and persons with dementia in care. Another six modules, which were in clearance at the time of the meeting, will address how caregivers should care for themselves. The goal was to enable providers to access continuing education (CE) in 15-minute segments. The CDC will help convert these into CE modules. While users of the curriculum do not have to be professionals, the curriculum is geared to academics.

Clinical Services Subcommittee Federal Update

Shari Ling, M.D., CMS
Dr. Ling began her update with a discussion of beta amyloid PET in dementia and neurodegenerative diseases that was external to the Federal Advisory Committee Act process. CMS thought the preponderance of evidence was promising but not sufficient

to recommend full coverage. In the context of the study, a single PET scan could be covered by Medicare as long as it addressed one of four questions. Since that determination in 2013, CMS has approved three such studies.

Self-direction enables beneficiaries to direct many or all of their home and community-based services (HCBS), including managing service workers and budgets. CMS has issued guidance to train case managers in self-directed care delivery and the balance of responsibilities. In response to state requests, CMS also announced a 3-year extension for state Medicaid programs to meet the HCBS settings requirements for settings that operated before March 17, 2014.

CMS released a Notice of Proposed Rulemaking (NPRM) to update payment policies, rates, and quality provisions for services provided under the Medicare Physician Fee Schedule (PFS). Dr. Ling gave examples of some 2018 PFS proposals, such as telehealth, for which CMS is proposing to add several new codes that can be used in the context of managing care for persons with dementia and cognitive impairment. CMS also approved proposals for new care coordination services and payments for rural health clinics and federally qualified health centers, with reserved billing codes in addition to regular payment. Chronic care management has new codes, as does the area of office-based behavioral health services. These proposals are currently up for comment.

Comprehensive Primary Care Plus (CPC+) is an advanced primary care medical home model. CMS selected four regions for Round 2: Louisiana, Nebraska, North Dakota, New York (Erie/Niagara Counties). In September, CMS is having a 1-day, in-person summit to discuss potential behavioral health payment and care delivery models. The summit will allow public discussion. Among the topics under consideration for the summit is ADRD.

Also out for public comment is a NPRM to improve the arbitration process in long-term care facilities. This is relevant for nursing home care and those who reside in nursing homes. The Money Follows the Person annual report came out in May, noting that 2015 marked the largest number of people recorded as moving from nursing home care to home-based care. Finally, the National Partnership to Improve Dementia in Nursing Homes had a recent call focused on assessment and evaluation of schizophrenia and other mental disorders. There has been a 34% reduction in the use of anti-psychotics in nursing homes, and the national average is down to 15.7%.

Budget Development

Richard Hodes, M.D., NIA

From Fiscal Year (FY) 2015 to FY17, the NIA and NIH budgets for ADRD increased from $631 million to $1,414 million, a tribute to Congressional support. There is bypass budget language for each FY through 2025, in which NIH must submit a budget with the funding needed to achieve the goals of the National Plan, without considering fiscal constraints. NIH meetings have thus established priorities attached to milestones for

each of a number of areas, with dollar amounts. These goals have widespread involvement across NIH.

The eight common Alzheimer's Disease Research Ontology categories provide the overarching frame for the FY19 ADRD bypass budget. The increase would be $597 million above the base. The FY18 President's Budget Request (PBR) decreases the budget by $577 million, however, so the need is for $1,174 million more than the PBR, for a total of about $2 billion.

Comments and Questions

- ***Ron Petersen*** asked for clarification about the PBR. ***Dr. Hodes*** explained that it was based on the FY17 Continuing Resolution; the actual enacted budget was much higher. The PBR came out before the enacted FY17 budget and was not modified afterwards.

- ***Harry Johns*** asked if there is sufficient science to justify this budget, and if NIA can make it work. ***Dr. Hodes*** replied that the bypass budget must consider the current state of knowledge and the capabilities of the research community. Therefore, NIA is confident in the increase. This is a very serious question they address every time they propose a budget.

- ***Ron Petersen*** asked if the three bypass budgets have had a relative shift in expansion and proportion. ***Dr. Hodes*** replied that there have been some shifts. The budgets are not formulaic; they are based on real science opportunities. If there were an advance in the field, NIA might anticipate a clinical trial being launched in that area.

- ***Deborah Olster*** asked if the work is investigator-directed, targeted, or a mix. ***Dr. Hodes*** said that it is a mix. NIH believes in investigator research, but directed work is important as well. The opportunity announcements contain broad language to communicate to the public that NIA does not want to over-direct. If there is a need for something like clinical trial infrastructure, for example, the work is very targeted.

2017 RECOMMENDATIONS AND NATIONAL PLAN UPDATE

Rohini Khillan, ASPE

At the time of the meeting, the Plan was in clearance, which limited what ASPE staff could say. This is a National Plan with updated implementation milestones, and it includes recommendations from the NAPA Advisory Council, along with formal responses. The plan was particularly long this year, with over 100 new items. In addition, five states provided new items or ongoing work, and five non-federal organizations contributed items. ASPE removed items that have been completed, and added next steps. The Advisory Council will see the Plan once it has been approved.

Ms. Khillan then read the recommendations. Dr. Hodes provided the NIH response; Dr. Ling gave the CMS response; Ms. Long offered the ACL response; and Ms. Khillan read the IHS, ASPE and combined federal responses.

- ***Recommendation 1***: The 2017 National Plan should continue providing a roadmap for achieving the goals of prevention, effective treatment, and effective care and services for ADRD.
    - *NIH response*: NIH will continue engaging a broad range of stakeholders. There has been consistency between the plan and the NIH goals.
    - *CMS response*: CMS concurs with the importance of a transformative scientific roadmap, the challenge being how to enable uptake of science discoveries to improve care and services.

- ***Recommendation 2***: A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.
    - *NIH response*: NIH cannot comment on targets for total research funds needed beyond the PBR and the estimate that NIH submits as part of the bypass budget.

- ***Recommendation 3***: Develop research goals to improve uptake, spread, and delivery of evidence-based and evidence-informed care and services.
    - *NIH response*: This is a key research priority, and NIA looks forward to integrating recommendations from the 2017 Summit into its future planning and FOA development.
    - *CMS response*: CMS concurs. Quality measurement is a key element of alignment between research and uptake.

- ***Recommendation 4***: Emphasis should be given to standardization of terminology in dealing with cognitive and dementia disorders.
    - *NIH response*: NIH supports the effort to standardize language in this area of research and devoted a special session to this topic at the 2016 ADRD Summit. Dr. Petersen added that this will be a session topic at the October Summit.

- ***Recommendation 5***: The United States government should support continued global efforts to address issues of research, care, and services.
    - *NIH response*: NIH communicates regularly on global efforts in a variety of forums, including through an international database. NIA has met with international funders and hosted international organizations. NIH has made foreign institutions eligible to apply for research solicited through FOAs.

- ***Recommendation 6***: A major area of emphasis is the enhancement of recruitment efforts for RCTs for ADRD.
    - *NIH response*: NIA is leading efforts to provide practical approaches in this area. Recruitment for RCTs is challenging, especially for ADRD trials.

Recruitment of those who have no reason to think they are at risk or showing symptoms is especially difficult. To go forward, NIH must have the dedicated participation of willing individuals.

- ***Recommendation 7***: The National Plan should continue promoting early detection and diagnosis of ADRD by encouraging cognitive assessment, while at the same time CMS works to confirm measurement strategies to track progress through new implementation measures.
    - *CMS response*: New billing codes have been implemented. In addition, CMS has updated payment measures, and has updated tools and technical assistance. CMS has worked on developing two electronic clinical quality measures to address quality of care. There is still a need for testing locations.
    - *IHS response*: IHS will continue workforce training and community education strategies to enhance recognition and diagnosis of cognitive impairment.
    - *NIH response*: Early treatments are very likely to be most effective. Therefore, NIH released a new FOA to increase early detection of cognitive impairment. Regarding education on early detection and diagnoses, several NIA resources are already available to support clinicians. NIH strongly supports moving forward with educational outreach to clinicians.

- ***Recommendation 8***: CMS should annually report data by state/region and by diagnosis regarding use of the new G0505 billing code.
    - *CMS response*: This is a new service, so CMS does not have the data at this time. CMS may monitor utilization data in the future.

- ***Recommendation 9***: Federal agencies should offer and support educational efforts that improve health care providers' ability to recognize early signs of dementia.
    - *CMS response*: CMS continues its work in this area.
    - *NIH response*: NIA has a number of resources available in this area.

- ***Recommendation 10***: The Advisory Council on Alzheimer's Research, Care, and Services should devote one meeting to advancing the work that ASPE has conducted on defining best practices.
    - *ASPE response*: The April 2017 NAPA Advisory council meeting discussed a number of directions for future research. ASPE would welcome the opportunity to discuss these with the Council-at-large, or with one or more of the relevant NAPA subcommittees.

- ***Recommendation 11***: CMS should use the results of evidence-based programs, combined with definitions of best practices for comprehensive dementia care, to provide adequate payment and incentives for providing evidence-based care.

- *CMS response*: The CMS Innovation Center focuses on testing, evaluating, and sharing the results of new payment and service delivery models. Those models that meet statutory and other requirements are subject to formal rulemaking procedures that include opportunities for public comment.
- *IHS response*: The CPC+ model in testing is at least a partial trial of this approach within primary care.

- ***Recommendation 12***: Changes to national health care must ensure continuation of support for persons with dementia and their caregivers.
  - *CMS response*: CMS continues to empower beneficiaries, consumers, and providers to make decisions, take ownership of their care, and ensure they have the information they need to make informed choices.

- ***Recommendation 13***: Federal agencies and other stakeholders should identify ways to implement the recommendations that will result from the October 2017 Summit.
  - *Combined federal response*: The member agencies of the NAPA Advisory council are committed to considering these recommendations.

- ***Recommendation 14***: Congress, federal agencies, and states must expand efforts to address the needs of family caregivers. Particular support is needed to expand and scale effective caregiver interventions for diverse racial/ethnic/socioeconomic groups; address barriers to enable health care providers to provide care planning with family caregivers; increase support for respite care; and address financial burdens of family caregivers.
  - *ACL response*: ACL provides federal funding for dementia-specific programs that promote and expand care, while educating and supporting caregivers.
  - *CMS response*: CMS provides a number of supports for family caregivers and continues research into how best to expand these supports.
  - *IHS response*: IHS will review the findings of the October Summit to inform priorities in support of expanding evidence-based services in Tribal communities.
  - *NIH response*: NIH recognizes the importance of research to understand and address caregiver needs. To that end, NIH supports a number of interventions and a range of research.

- ***Recommendation 15***: Federal agencies, states, and health systems must take steps to increase identification of people with dementia who live alone, and to provide programs and services to meet their needs.
  - *CMS response*: While CMS has a number of programs such as the Medicaid Innovation Accelerator Program that can identify and help people with dementia who live alone, this is a responsibility that is state-centered. CMS works with states and communities to pay for services such as pest eradication. There are pieces of this that CMS can support outside of Medicaid.

- *NIH response*: NIH supports research to identify people with dementia who live alone.
- *ACL response*: ACL continues making federal funding available for dementia-specific programs that support such interventions.

- ***Recommendation 16***: Federal agencies, states, and health systems must increase efforts to assess, prevent, and manage behavioral symptoms associated with dementia.
  - *ACL response*: ACL continues to make federal funding available to support programs for such interventions.
  - *CMS response*: CMS supports such efforts.
  - *IHS response*: IHS will explore the use of Project ECHO to provide clinical consultation and training in the diagnosis and management of dementia in Tribal communities.

- ***Recommendation 17***: Federal agencies, states, national health and aging organizations, and community partners must expand public awareness and training, and help connect people to information and available resources.
  - *ACL response*: ACL continues to fund dementia-specific programs that promote outreach and services for diverse and underserved populations, including dementia-friendly community education efforts.
  - *IHS response*: IHS is working to grow understanding and awareness in Tribal communities.
  - *NIH response*: Beyond research-specific efforts, NIH is committed to enhance and provide evidence-based information, resources and referrals to individuals with ADRD and their caregivers.

2017 ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE (AAIC) MEETING UPDATE

Dr. Petersen reported that this conference was successful, with record attendance and a record number of abstracts. There were many ancillary meetings before, after, and during the conference. One of the expectations is that a large number of people in the field will be there. From a science perspective, there was a lot of good research and some good incremental science. There were no dramatic discoveries, but the conference presented a great deal of very important science, as well as some important advances in therapies, sleep research, and the interpretation of biomarkers. Dr. Hodes added that it provided a good opportunity for scientists in the field to interact.

Mr. Johns said that he appreciated the assessments. He spoke to hundreds of people at the conference. The upbeat feeling in the science community is noticeable from the layperson's perspective. There were a lot of opportunities, such as mentoring for young researchers and for women, which is critical for everyone. There is still so much to do, and it was good to see young people interested in the field.

REFLECTIONS FROM RETIRING MEMBERS

Dr. Petersen said that the Advisory Council has been around a long time, and now a number of members were leaving. He noted that ***Jennifer Mead***, who left the council after the previous meeting, provided excellent leadership on the LTSS subcommittee. She held numerous meetings that generated strong recommendations.

Helen Matheny said that participation on the council had been an honor and privilege. She thanked Dr. Petersen for his leadership, and for providing a framework and way forward. His calm approach was helpful. The people in the clinical care group were amazing, and they had good dialogues. She thanked Dr. Ling for pushing back when they put her on the spot. She also thanked the representatives of other agencies, as well as the other council members and the public.

Geraldine Woolfolk agreed with what Ms. Matheny said. The public comments have been invaluable. The LTSS subcommittee has been amazing. She believes that everything in life prepares us for the next thing to happen, and recently, she had been reflecting on the experience of her late husband's Alzheimer's disease. Little did she know that he was both preparing her for service that would transcend his life and training her to take the nuggets of their experiences together and share them in a larger arena. She used to say Alzheimer's disease was a blessing to her family. One caregiver could not understand that, but the blessing to her was always that it pointed her to hope. There had to be a greater outcome than the end of her husband's life. That strain of hope continues, and it is a blessing and joy. It is painful to know that her husband had more to give to the world. She recalled talking to Mr. Johns about the first meeting of the Advisory Council, and how they got in step right away. She wanted to end her tenure on the council the way she began, by saying that it was important for her that the members all knew that a man named Leonard Woolfolk lived and was important. She mentioned their children at the first meeting as well. It is personal, and that is what she wanted to bring. Through all the planning, they need to remember that it is about people, individuals who most people do not see. That was why she was so fervent, for her husband and her family. Her sister died 2 weeks before, not from Alzheimer's, but she supported the council's work. Ms. Woolfolk wanted to celebrate all of those people. She looks forward to the next chapter. She will visit from time to time because she is excited about what they have done, are doing, and will do. Every meeting has a "wow." She was leaving with the expectation of more wows, especially in 2025. She thanked everyone, and she was leaving with joy because she knew they were going to tackle it.

Myriam Marquez said that it is an incredible privilege to represent those who have a form of dementia. Three of her mother's four children have Alzheimer's disease, and her own 42-year-old daughter has it. Her father's mother had 13 children, and those who did not die young died of Alzheimer's. She hopes that there will be a cure, and the council has offered a platform from which to do so. The Advisory Council is like her family and she appreciates them all very much.

Harry Johns thanked Dr. Petersen and everyone who is a part of this, especially those who made the legislation possible. This is a terrible thing they all fight. There is no adequate way to thank everyone. The work the group does is important. He thanked Dr. Hodes, Dr. Ling, and all of their federal colleagues. The step of creating even the 2025 goal took guts and did not have to be done, but it was. Whether they make 2025 remains to be seen, but it is a driver to the potential. The collective effort is what they will ultimately achieve. The work that goes on in any capacity will help achieve a world without dementia.

Dr. Petersen presented each retiring member with a certificate of thanks from Secretary Price.

Ms. Khillan said that it had been a pleasure to work with ***Ron Petersen***. They have weekly calls, and she has learned so much from them. His leadership has been amazing. Dr. Hodes added that he was enormously in awe of the job Dr. Petersen did. The precedent he set will be a high bar for the next council Chair. Someone already on the Advisory Council will be the next Chair, and they should learn from him. Dr. Petersen said that it has been an honor. There have been disagreements, but they have all had the same purpose, which is most humbling. Each member of the Council is absolutely dedicated to this cause, and it is empowering. This Advisory Council has had an impact on the Federal Government, as with the research funding goal. It has been fun to watch the group evolve and an honor to watch the activities. The work of this Council and of the field is just beginning; it will not end in 2025. They jumpstarted the field and moved it forward. The public always reminds them of how important this is.

CONCLUDING REMARKS

The next NAPA meeting was tentatively scheduled for October 27, 2017.

Dr. Petersen adjourned the Council meeting at 3:53 PM.

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

Ronald Petersen, Mayo Clinic (Chair)
Marie Bernard, NIA
Gary Epstein-Lubow, Brown University
Bruce Finke, IHS
Richard Hodes, NIA
Harry Johns, Alzheimer's Association
Margaret Kabat, VA
Rohini Khillan, ASPE
Shari Ling, CMS
Erin Long, ACL
Myriam Marquez, person living with dementia
Helen Matheny, West Virginia University
Lisa McGuire, CDC
Deborah Olster, National Science Foundation
Angela Taylor, Lewy Body Dementia Association
Sowande Tichawonna, caregiver
Kara Townsend, ASPE
Donna Walberg, Minnesota Board on Aging
Joan Weiss, HRSA
Geraldine Woolfolk, caregiver
Mary Worstell, OWH

July 28, 2017 -- Advisory Council Meeting #25

The meeting was held on Friday, July 28, 2017, in Washington, DC. The Advisory Council spent the morning discussing information gaps across the three areas of research, clinical care, and long-term services and supports. There was also a presentation on the recently released National Academy of Sciences, Engineering, and Medicine (NASEM) report on preventing cognitive decline. Additional presentations included a presentation on planning and progress towards the October Care and Services Summit and federal workgroup updates. Material available from this meeting is listed below and is also available at https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Jul2017.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Presentation Slides

2017 National Plan Update and Non-Federal Recommendations	[HTML Version] [PDF Version]
Clinical Services Subcommittee Federal Update	[HTML Version] [PDF Version]
CommunityRx for Community-Residing People with Dementia and Their Caregivers	[HTML Version] [PDF Version]
Dementia Caregiving in the U.S.	[HTML Version] [PDF Version]
Development of the FY 19 NIH Bypass Budget for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Implications of a Biologically Based Definition of Alzheimer's Disease	[HTML Version] [PDF Version]
Increasing Opportunities for Choice and Control for Persons with Dementia	[HTML Version] [PDF Version]
Interventions to Prevent or Slow Cognitive Decline, MCI and Dementia in Individuals without Dementia	[HTML Version] [PDF Version]
Living Alone With Dementia	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Managing Chronic Conditions in People Living with Dementia	[HTML Version] [PDF Version]
Preventing Cognitive Decline and Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care	[HTML Version] [PDF Version]
The Many Challenges of Alzheimer's Disease	[HTML Version] [PDF Version]

Videos

Welcome thru Clinical Care	[Video]
LTSS Research	[Video]
Public Comments thru Federal Workgroup Updates	[Video]
Recommendations thru Adjourn	[Video]

Last Updated: 06/27/2018