

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

Washington, DC

January 14, 2013

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), David Hoffman, Harry Johns, Jennifer Manly (by telephone), Helen Matheny, Julie McMahon, David Hyde Pierce, Eric Sokol (sitting in for Eric Hall) Laura Trejo, George Vradenburg, and Geraldine Woolfolk
- *Federal Members Present:* Lynda Anderson (Centers for Disease Control and Prevention [CDC]), Regina Benjamin (Surgeon General), Bruce Finke (Indian Health Service [IHS]), Jon Fuller (Department of Veterans Affairs [VA]), Richard Hodes (National Institutes of Health [NIH]), Russell Katz (Food and Drug Administration [FDA]), Shari Ling (Centers for Medicare & Medicaid Services [CMS]), Donald Moulds (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Anand Parekh (Office of the Assistant Secretary of Health [OASH]) William Spector (Agency for Healthcare Research and Quality [AHRQ]), Amber Story (National Science Foundation [NSF]), Jane Tilly (Administration for Community Living [ACL]), and Joan Weiss (Health Resources and Services Administration [HRSA])
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)

General Proceedings

At 9:00 a.m., Chair Dr. Ronald Petersen called the meeting to order.

Advisory Council members introduced themselves.

Dr. Petersen provided an overview of the agenda. Each of the three subcommittees (Research, Clinical Care, and Long-Term Services and Supports) will report on progress made in addressing strategies of the *National Plan to Address Alzheimer's Disease* (national plan), and representatives from VA will describe VA dementia initiatives. During the lunch break, non-federal Advisory Council members will receive training on requirements related to ethics and financial disclosure. The three subcommittees will present recommendations to be submitted to the Secretary of Health

and Human Services (HHS) and Congress for consideration in approving the next version of the national plan. Public comments will be received. Finally, the Advisory Council will vote on the recommendations.

Research Subcommittee Report

Dr. Hodes presented an update from the Research Subcommittee.

- At the May 2012 summit meeting, a research timeline was developed to identify milestones between 2012 and 2025.
- This year NIH is funding new clinical trials to be conducted by the Alzheimer's Disease Cooperative Study network: (1) Anti-amyloid in Asymptomatic Alzheimer's, (2) Prazosin for Treating Agitations, and (3) Central Spinal Fluid Pharmacodynamics.
- The following are examples of activities for specific strategies under the national plan's Goal 1, "Prevent and Effectively Treat Alzheimer's Disease by 2025:"
 - *Strategy 1.A.4, Convene a scientific workshop on other dementias in 2013:* In May 2013 a workshop will be held on the NIH campus to define the state of the science and identify critical opportunities and barriers in each of the dementias. A workshop on Down Syndrome and Alzheimer's disease research was held in September 2012. To follow up on that Down Syndrome workshop, the National Institute on Aging and the Eunice Kennedy Shriver National Institute on Child Health and Human Development (NICHD) are planning a research workshop on Down Syndrome and Alzheimer's disease to be held in 2013.
 - *Strategy 1.B.2, Expand genetic epidemiologic research to identify risk and protective factors for Alzheimer's disease:* Dr. Hodes presented a timeline summarizing the progress in genome sequencing since 1991. Most recently, in 2012 the risk-factor gene TREM2 was identified. Extensive cataloging has been undertaken of individuals for whom genotyping and phenotypic data exist, providing a source for genetic sequencing which will begin early in 2013. Expert panels are currently analyzing cases to be used for studies.
 - *Strategy 1.B.3, Increase enrollment in clinical trials and other clinical research through community, national, and international outreach:* A registry of individuals willing to serve in clinical trials will be developed. A request for information about strategies to compile such a registry was issued broadly to interested community, research, and federal organizations in November 2012, with responses due in March 2013. In the spring and summer of 2013, workshops will be convened to plan the organization of the registry.

- *Strategy 1.C, Accelerate efforts to identify early and pre-symptomatic stages of Alzheimer's disease:* The Alzheimer's Disease Neuroimaging Initiative (ADNI) collects data and samples to establish a database to identify the best biomarkers or combination of biomarkers to follow disease progression in the brain. The goal is to use this information in clinical trials studying interventions aimed at altering disease progression. Amyloid images and CSF A β 42 are two markers that have been shown to be abnormal years before the clinical onset of Alzheimer's disease.
 - *Strategy 1.D, Coordinate research with international, public, and private entities:* The Common Alzheimer's Disease Research Ontology (CADRO) structure has been developed to ensure that the same terminology and definitions are used in categorizing research, funding in different categories, and identifying trends in funding over the years. The International Alzheimer's Disease Research Portfolio (IADRP) is a database that enables funders of Alzheimer's disease research to coordinate efforts. ADNI is an example of public and private partnerships, with more than 28 organizations collaborating. The Foundation for NIH raised \$23 million for the first phase of ADNI projects. ADNIs have been established all over the world. An Alzheimer's disease Measurement Improvement Conference took place in December 2012. In April 2013, NIA will host a public-private partnership meeting to share preclinical data, drug targets, and animal models in precompetitive space to facilitate new therapies for Alzheimer's disease.
 - *Strategy 1.E, Facilitate translation of findings into medical practice and public health programs:* NIH recently released its report to Congress on Alzheimer's disease research progress, 2011-12. The report is available online and is used to inform multiple levels of public research and private interest.
- In response to a question, Dr. Hodes said that the May 2013 workshop on Down Syndrome and Alzheimer's disease will focus on determining research priorities, but funding mechanisms will not be identified.
 - The European Union would like the United States to become a member of the Joint Program on Neurodegenerative Diseases.
 - It is hoped that all funders of Alzheimer's disease research worldwide will be able to enter data in the IADRP database, but that is not yet possible because of limited resources. In the interim, automated analysis by text assessment is being used to categorize the research portfolios submitted by organizations.

Clinical Care Subcommittee Report

Dr. Ling delivered a progress report from the Clinical Care Subcommittee.

- In January 2013, CMS is hosting a Medicare Evidence and Development Coverage Advisory Committee (MEDCAC) meeting on beta amyloid positron emission tomography (PET) in dementia and neurodegenerative disease that will review evidence regarding the benefit of beta amyloid PET for Medicare beneficiaries.
- A guidance statement on the pathway for coverage and the data required to create new evidence was published to support the Coverage with Evidence Development program. CMS concurrently reviews promising technologies or treatments being considered by FDA for approval.
- Alzheimer's Disease Measurement Improvement (AD-MI) has four workgroups focused on measurement and the evidence needed to generate meaningful outcomes for Medicare beneficiaries with Alzheimer's disease and their families. A summary of the AD-MI project, to be published in the spring of 2013, will be used to inform a CMS quality improvement program, and support innovation care models and the care transition program. NIH may also use the summary information to help focus outcomes and metrics of research.
- Dementia training conducted in 2012 at 45 Geriatric Education Centers (GECs) involved 10,976 trainees who participated in 178 interprofessional programs. Topics ranged across the care spectrum and covered appropriate and effective dementia management for persons with dementing diseases and their caregivers.
- Among the 2012 Center for Medicare & Medicaid Innovation (CMMI) awards, the following four are relevant to dementia/Alzheimer's disease:
 - Indiana University: "Dissemination of the Aging Brain Care Program"
 - University of California, Los Angeles: "UCLA Alzheimer's and Dementia Care: Comprehensive, Coordinated, Patient-Centered"
 - University of North Texas Health Science Center: "Brookdale Senior Living Transitions of Care Program"
 - University of Rhode Island: "Living Rite--A Disruptive Solution for Management of Chronic Care Disease (a focus on adults with disabilities: intellectual and developmental diagnoses and dementia patients with two or more chronic conditions)"
- Requests for proposals for the Patient and Family Engagement Campaign (PFEC) were sent to Quality Improvement Organizations to propose projects to encourage involvement of patients and families to take action for their own health care. PFEC focuses on four areas: (1) care for individuals diagnosed with dementia, (2) prevention of avoidable readmissions, (3) prevention of falls, and (4) improvement of cardiac health.

- CMS is currently accepting applications in the Community-based Care Transitions Program (CCTP), Section 3026 of the Affordable Care Act, for communities to develop partnerships to improve care transitions for high-risk Medicare beneficiaries. So far, 50 programs have been funded.
- As part of the National Partnership to Improve Dementia Care in Nursing Homes, CMS and both public and private partners have made major presentations to national, state, and local groups, educated providers, and completed 200 nursing home case studies focused on how decisions are made to use antipsychotic medication. The project has also developed two mandatory survey training videos being launched in January 2013. The analysis of the 2012 data on reaching the goal of reducing antipsychotic drug usage by 15 percent will be posted in the first quarter of 2013 on the Nursing Home Compare website.

Discussion following Dr. Ling's presentation included the following comments and questions:

- In response to the question of how interventions done to prevent hospitalization can be tracked as part of the Healthy People 2020 initiative, Dr. Ling said ideally we would know what interventions were done in specific communities or facilities, and that a metric would be in place to track progress. Dr. Ling will suggest to those in authority at CDC and HRSA that, given their different data sources, the two agencies should collaborate on that.
- In response to a question about how performance improvement might be measured and what criteria should be used, Dr. Ling said that some caregiver programs will be measured during the course of the PFEC. CMS does not have a method to determine the number of providers who identify and care for persons with dementia and put appropriate management strategies in place. Moreover, reporting is voluntary, even if metrics for reporting quality were in place. Both program cost and collateral cost are part of what the CMMI programs track. Population metrics about the number of people with cognitive impairment or dementia will rise as CMS gains detection tools and uses incentives to encourage providers to screen for dementia. At the end of January 2013, a group will be convened to discuss the population-based measures of progress and to start identifying how to measure progress on each of the goals and strategies in the national plan. Then CMS will try to determine how to ensure accurate measurement of progress. A council member suggested that it would be useful to gain the perspectives of nongovernment entities, such as corporations and families.
- In the care transition programs in Los Angeles, analysis showed that 25 percent of individuals returning to the hospital within 7-14 days had a coexisting diagnosis of dementia. In light of this, it was suggested that the demonstration projects be asked to try to quantify how many clients with dementia are in the system and determine how this comorbidity affects their care. Dr. Ling responded

that the demonstrations are already under way, and CMS cannot direct their activities, but CMS could suggest that it would be very helpful if they track dementia diagnosis codes.

- The Medicare cost for treating people with Alzheimer’s disease and other dementias is three times more than the costs for people who do not have dementia. The Medicaid cost for treating people with dementias is similarly very high. Because only an estimated half of those with Alzheimer’s disease are diagnosed, having an accurate number for these individuals would be very beneficial for Medicare planning. One way to accomplish this is having more Medicare beneficiaries participate in an annual wellness visit that includes a cognitive exam in order to obtain data on Alzheimer’s disease diagnoses in a timely way. Surveillance of and incentives for providers to include this cognitive exam as part of the wellness visit would increase the likelihood that more providers would conduct them. In addition, if a diagnosis of Alzheimer’s disease is made, it is important to have any hospitalizations recorded in the patient’s medical record. Having an electronic health record (EHR) in place would facilitate this effort.
- A question was posed about how soon CMS will have a package of incentives to obtain these data, given the technological hurdles, including EHR integration and surveillance in physician offices. Dr. Ling responded that the solution has three parts: (1) ease the documentation process for physicians and care providers, (2) work through the PFEC, and (3) use communities and networks. She stated that a timeline is not yet known but should be available by the next Advisory Council meeting because PFEC awards will be given in February.
- In response to a question, Dr. Ling clarified that the evaluation conducted at the end of the GEC dementia training sessions did not include an assessment of needs regarding other topics to be addressed.
- When MEDCAC is considering coverage of a given technology, such as beta amyloid PET, the committee considers whether the evidence is adequate to show that the new modality improves clinically meaningful health outcomes. At a second level, if MEDCAC finds the level of evidence insufficient but promising, it will provisionally cover it until further developments in evidence occur. Provisional coverage will result in broader use of the technology, thus assisting in the development of data that can be used for medical evidence.

Long-Term Services and Supports Subcommittee Report

Dr. Tilly presented a progress report from the Long-Term Services and Supports Subcommittee.

- The VA led an interagency call that focused on the presentation and discussion of the caregiver support program Resources for Enhancing Alzheimer's Caregivers Health in VA (REACH-VA).
- HRSA worked with 45 GEC grantees that trained provider groups across the care spectrum. In the past 6 months grantees delivered 178 educational programs to 10,976 providers on dementia-related topics. HRSA is developing a website with links to the guidelines and curricula.
- The CDC's Healthy Brain Initiative is a partnership between the national plan and state public health partners and state-level aging services. The initiative is designed to promote cognitive health and address cognitive impairment. CDC is developing a Healthy Brain Initiative road map for public health and has received input from many organizations at both national and state levels. The road map focuses on recommendations for use at the state level.
- The Administration on Aging (AoA)/ACL conducted a webinar series on legal issues for those with dementia and their caregivers. On average 300 to 400 people participated in each webinar.
- AoA/ACL developed a new long-term services and supports (LTSS) workforce competency model that addresses cognition, covering all of the needed competencies for the LTSS workforce to provide person-centered care.
- AoA/ACL provided training materials on ombudsman service to dementia practitioners.
- AoA/ACL developed standards for options counseling for people in the aging network to help individuals with dementia and their caregivers make choices about what type of care they want to receive in the future.
- AoA/ACL is developing a training and certification program for options counseling that includes dementia-capability core competencies.
- Available tools and resources for caregivers have been updated on Alzheimers.gov.
- AoA/ACL presented a webinar on advance health and financial planning that addresses caregiver issues and ensures that the preferences of the person with dementia are incorporated into the planning.
- CMS developed three quality measures as part of the National Partnership to Improve Dementia Care in Nursing Homes: (1) percentage of long-stay residents receiving antipsychotic medication, (2) percentage of short-stay residents of

nursing homes receiving antipsychotic medication in the absence of psychosis, and (3) unplanned readmission to the hospital within 30 days of discharge.

- ASPE reviewed available evidence for defining effective care coordination for persons with dementia and found the evidence inadequate to develop coordination models.
- ASPE found that the methods used for defining Alzheimer's disease/dementia must be clarified in order to analyze the data from the National Health and Aging Trends Study.
- AoA/ACL partnered with the Family Caregiver Alliance to publish the second edition of *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*.
- The Family Caregiver Alliance has conducted a state survey of caregiver assessment practices within Medicaid Home and Community-Based Services programs and will release the results in spring 2013.
- Expansion of Alzheimer's disease awareness efforts into long-term care awareness is awaiting decisions about the availability of funding.
- The Specific Populations Task Force has held a series of meetings to gather input from stakeholders from specific populations, such as the Down Syndrome community and the Association for Frontotemporal Degeneration, minority populations, and those who acquire dementia before age 65, regarding expanding long-term care awareness efforts.

Discussion following Dr. Tilly's presentation included the following comments and questions:

- While progress is clearly being made through the joint efforts of different organizations in working on a common goal, more urgency must be brought to bear in addressing these issues.
- While care coordination models for people with Alzheimer's disease exist and will be helpful for LTSS research, rigorous evidence on areas such as outcomes and cost effectiveness that could be replicated across the country has not been found. Many care coordination models for older adults, not just those for people with Alzheimer's disease, have difficulty showing efficacy because in general older people use more services and care is more costly.
- It was noted that until change actually occurs in the field, much of the activity being undertaken might be viewed as bureaucracy, and the question was asked about how AoA will ascertain whether its materials, webinars, and guidelines are

actually improving efficiency or outcomes. Dr. Tilly responded that there are legal limits on what kind of data can be collected and also that comprehensive enough data sets do not exist at this point to measure improvements in the field. She noted that education and other activities do help people who have a direct impact on the quality of care for individuals with Alzheimer's disease. Thus, providing education and information to caregivers and providers serving people with dementia is one approach being used to change outcomes in the field. Once services have been provided, AoA tries to ascertain the usefulness of its services by surveying *recipients* of services. Although these surveys address the broad array of AoA services, AoA is increasing the focus in these surveys on dementia and cognitive impairment.

- An Advisory Council member recommended that AoA include the commercial sector, such as employers and large provider systems, when gathering information about the impact of AoA programs. Dr. Tilly noted that the surveys are sent to individuals who receive program services from providers in both the public and private sectors.
- The Affordable Care Act gives providers and the aging network the opportunity, for the first time, to engage as equal partners in providing better levels of care. Demonstration projects are currently occurring across the country related to individuals who are eligible for both Medicaid and Medicare services. Community-based LTSS providers are being invited to talk with health care partners to plan interventions and strategies regarding how clients flow through the system and what relationships are desirable. ACL is involved with this effort.
- Providing training to representatives of the legal community who interact with people planning for retirement is a very positive initiative. It would be a good idea to offer training to other professions as well. Clinicians and medical professionals, for example, would benefit from having presentations on Alzheimer's disease from AoA and other organizations.
- The time is right to link different groups of people together, such as accountable care organizations, the medical home, county health departments, and employers, so that they are all working together to make outcomes successful.

Federal Budget Implications

Dr. Moulds reported on several budget-related matters.

- The package of federal budget changes passed at the beginning of January has extended sequestration by 2 months. The budgets of NIH and other federal agencies will be cut around March 1, 2013, unless Congress acts.

- Until March 27, 2013, the Federal Government is operating under a continuing resolution, meaning that government entities are operating under the FY 2012 budget. As a result, activities, including research funding, that have been included in the FY 2013 budget are pending.
- The budget agreement signed at the beginning of 2013 repealed the CLASS Act, which was the long-term care benefit included in the Affordable Care Act. In place of the CLASS Act, a Long-Term Care Commission is to be created by approximately February 1 for a period of 6 months. This legislative commission, which will reside in the Senate, will be charged with making recommendations to Congress for legislation affecting long-term care. The commission is to have 15 members--six from the Senate, six from the House of Representatives, and three appointed by the President. The commission will include providers, individuals with expertise in Medicaid programs, consumers of long-term care services, and others.
- In response to questions, Dr. Mould said that the Advisory Council can provide comments to the Long-Term Care Commission. However, because the council is a federal group, it cannot lobby the commission. Individuals who serve on the Advisory Council are free to lobby the commission as they wish and are free to submit recommendations for appointments to the committee. A subgroup of council members agreed to draft a letter for consideration later in the day.

National Plan Tracking Tool

- Dr. Moulds reported that a strategic planning tracking tool has been completed and is available for HHS users online. The tool allows users responsible for action items in the national plan to update deliverables for actions items for which they are accountable. Each update is designated with a green, yellow, or red light indicating whether the deliverable is on track for completion, with space available for comments if desired. The tracking report will be printed out for review at the next Advisory Council meeting. This tool should enable more meeting time to be devoted to other topics and less need for oral progress reports. Canadian and British representatives have been invited to the next Advisory Council meeting to present strategies under way in their countries.

Public-Private Partnerships

- Dr. Moulds reported that in each area of the national plan in which public-private partnership is called for, a consultation will take place between the government side and the non-government side to obtain the perspective of the nongovernment side. Ongoing conversations will occur to solicit the perspective of the private sector on areas of the plan. The perspective of the private

community will also be sought on areas of the national plan in which public-private partnerships might be useful.

VA Dementia Initiatives

Dr. Susan Cooley (by telephone), Dr. Pauline Sieverding, and Ms. Meg Kabat described VA dementia activities, research, and caregiver support.

- The VA's Dementia Steering Committee (DSC), which includes representatives from IHS and NIA, makes recommendations on dementia recognition and diagnosis, dementia care, and care coordination across stages of dementia and care settings.
- The VA Dementia Education and Training Committee (DET) helps prioritize training topics and projects for the VA employee education system support. The DET is also developing a comprehensive dementia curriculum for VA providers across settings of care.
- As part of the Veterans Integrated Service Network, dementia committees at individual medical centers in the network consider the DSC's recommendations and prioritize them for local implementation. These committees communicate practice ideas with each other through the central office.
- The Dementia Warning Signs Workgroup implemented a quality improvement pilot project that demonstrated the feasibility of warning signs work processes and materials at ten VA primary care sites. The workgroup also developed a toolkit that includes staff training slides, posters, and a template note for the VA's EHR. The workgroup developed a fact sheet on detection of dementia that is available online through the VA National Center for Health Promotion and Disease Prevention.
- The DSC is piloting a peer review of dementia workup data using a set of quality indicators related to the history, physical exam, and laboratory tests of frail elderly patients.
- The Patient Aligned Care Team (PACT), the VA's version of the patient-centered medical home, is a model of care for working collaboratively with the veteran and his or her family and coordinating care across specialties and settings. Local dementia committees are encouraged to find ways to integrate dementia care and care coordination into the PACT activities, and the VA central office is working to highlight dementia care needs into PACT training and provider tools.
- VA has funded 23 noninstitutional extended care pilot projects that include dementia care management, caregiver support, and care transitions.

- VA has implemented several activities to train staff regarding challenging behavior, including an educational conference, staff training in VA community living centers (nursing homes), developing DVDs on dementia communication strategies and on wandering, and satellite broadcasts on the use of continuous meaningful activities.
- VA has 19 Geriatric Research, Education, and Clinical Centers, 4 of which have a major dementia focus, and it has 10 Mental Illness Research, Education, and Clinical Centers, 2 of which have a major dementia focus.
- VA operates the nation's largest integrated health care system, with 6 million patients per year, 153 hospitals, 900 freestanding clinics, 135 community living centers, and 207 readjustment counseling centers. Its EHR provides a robust database for research because of its huge size; every day over 1 million orders and 2 million images are added to the EHR data warehouse.
- The VA Office of Research and Development has four sections: (1) Biomedical Laboratory Research and Development, (2) Clinical Sciences Research and Development, (3) Health Services Research and Development, and (4) Rehabilitation Research and Development.
- The following are examples of current VA-supported research projects related to Alzheimer's disease:
 - Injecting young mice with plasma from old mice to study how blood-borne factors affect neurodegenerative diseases (Palo Alto VA Medical Center [VAMC]).
 - Linking herbicide to cognitive impairment and amyloid genesis by exposing a transgenic animal model of Alzheimer's disease to an herbicide (San Antonio VAMC).
 - Discovery of neuropsychological markers of memory deficits/cognitive impairment and cerebrospinal biomarkers (Bronx VAMC).
 - Demonstrating in a mouse model of Alzheimer's disease that antisense oligonucleotide given intravenously completely reverses age-associated increase in amyloid protein precursor (Seattle VAMC).
- The VA's Cooperative Studies Program has completed a 7-year randomized clinical trial studying the use of vitamin E and memantine in treatment of Alzheimer's disease. Data from the study, which ended in September 2012, are being analyzed.

- Several research projects are focused on caregiver support and issues related to caregiving:
 - Testing the efficacy of a transformative patient-centric intervention to reduce the burden of behavioral problems in veterans with dementia who live at home (Gainesville, FL, VAMC).
 - Systematic evidence review of publications on nonpharmacologic interventions for behavioral symptoms of dementia (VA Evidence-based Synthesis Program).
 - Assessing whether a psychoeducational intervention (1) decreases incidence of aggression, (2) decreases pain, (3) decreases caregiver burden and improves caregiver-patient relationship, and (4) decreases injuries, use of antipsychotic medication, and nursing home use.
 - Determining that a home safety toolkit intervention was effective in improving caregiver competence to create a safer home environment, and that it decreased the risk and accidents to veterans with dementia living in the community. The toolkit comes in a canvas bag and contains practical items such as doorknob covers and sticky tape for rugs.
- VA conducted a systematic evidence review on usage and effects of mobile tools on caregiver burden outcomes, patient outcomes, clinical process measures, and health care utilization.
- In research projects that are part of the Long-Term Care CREATE (Collaborative Research to Enhance Transformation and Excellence), health care providers and care settings are actively engaged at the outset of the research, a fact that speeds up implementation of research findings. The following three CREATE studies are coordinated, multisite research projects focusing on long-term care:
 - The INTERACT program, a staff training and process control system that could be readily adopted if found to be successful in VA community living centers.
 - The discharge study, which evaluates geriatric and extended care efforts to reduce length of stay at community living centers and reduce readmission rates.
 - The Medical Foster Home study, which characterizes and evaluates the treatment of veterans in community foster homes; these homes have been developed as an alternative to institutional long-term care.
- VA has a comprehensive caregiver support program with the following goals:

- Allow veterans to remain at home in the community
 - Address specific needs of family caregivers with a menu of programs and services
 - Promote veteran and caregiver health and well-being
 - Provide one location to obtain needed information
 - Provide training and information on common conditions
 - Reduce isolation with professional and peer support
 - Provide options to give caregivers respite
 - Sensitize health care providers to the caregiver's role
- A staff caregiver support coordinator is located in each VAMC to serve as a resource for caregivers. This person is knowledgeable about VA and other resources, assists with applying for benefits as needed, organizes activities and services for caregivers, and creates programs for National Family Caregiver Month in November.
 - VA offers the following services: in-home care; respite care; services to address mobility issues, such as equipment and home and auto modification; education and training; financial support; information and referral; and caregiver support
 - A caregiver support line, launched in February 2011 and available 24/7, has proved highly successful in meeting a need, and has received more than 64,000 calls in its first 2 years.
 - The caregiver support program website, which has a wide range of support services and tools such as checklists, tips, and a series of videos, has also proved to be very successful, with about 1,200 visits a day and an average of three pages viewed during a visit.
 - REACH VA is a hands-on program currently available at 78 sites in which a provider visits the veteran's home and works with the caregiver to identify issues and problem solve. Research has shown it to be highly effective, so it will be expanding to additional sites.
 - Building Better Caregivers is a 6-week interactive web-based workshop designed to provide education and support and teach problem solving to caregivers. Topics include stress management, difficult behaviors, sleep, healthy eating, exercise, difficult emotions for both the care recipient and caregiver, decision making, resources, and planning for the future.
 - A Peer Support Mentoring Program, launched in January 2012, pairs new caregivers with more experienced caregivers. The mentors receive additional orientation and ongoing support from the national program manager. The mentor/caregiver dyads are contacted regularly by the local caregiver support coordinators and the national program manager to ensure successful matches. So far, 30 dyads are in place, with additional mentors in training. The roll-out is at

a deliberately slow pace to ensure high quality, with 50 dyads anticipated by the end of FY 2013.

Discussion following the presentations on VA dementia initiatives included the following points:

- The VA dementia services are very impressive, and extending the training, tools, and possibly the actual services to non-VA service providers and patients and caregivers would be beneficial if possible.
- VA is very interested in establishing veteran-community partnerships and has efforts under way to do so, such as the “We Honor Veterans” campaign that collaborates with community hospices. VA is also exploring how to leverage needed services beyond VA and to seed pilot projects for challenging patient populations.
- VA has a number of collaborations with NIA, such as the REACH program, which is funded by NIA. VA also partners with the Alzheimer’s Association in Partners in Dementia Care, which conducted a randomized control trial that is now moving into the implementation phase.
- Many veterans do not access the VA health care system, so it is important when working in the community with individuals with dementia to ask if they are eligible for VA health care.
- In a program called Veterans Directed Home and Community-Based Services, VA contracts with local-area agencies on aging to serve veterans.
- VA has a memorandum of understanding with IHS to coordinate care of Alaskan Native veterans.
- The VA system of using diverse resources concurrently and the VA’s experience with EHRs are examples of processes from which the nonveteran health care community can learn, embracing those that have proven effective.
- The VA system of providing home health aid and home respite as a basic benefit entitlement is commendable and is unmatched in any system.
- The VA’s integrated system that facilitates the progression from research to pilot demonstrations to large-scale implementation produces better quality of care at lower cost. VA should provide persuasive documentation of this so that its approach of focusing on a model of earlier intervention and prevention might be adopted by others.

Research Subcommittee Recommendations

Dr. Petersen presented the Research Subcommittee 2013 recommendations for revisions to the national plan. The following four themes underlie the Research Subcommittee recommendations:

1. Commit resources with accountability
 2. Accelerate basic and translational research toward development of effective treatments, with concrete emphasis on the process of developing interim milestones and the importance of including these milestones in the next version of the national plan
 3. Maximize private investment to develop treatments and improve disease monitoring technology
 4. Meaningfully coordinate with global partners
- *Recommendation 1:* The subcommittee supports and applauds the goal of the national plan to prevent and effectively treat Alzheimer's disease by 2025 and recommends that interim milestones be explicitly stated, by developing a clear roadmap of research and treatment discovery priorities and timelines, to assure continuing and successful progress toward achievement of this goal.
 - *Recommendation 2:* There is an urgent need for annual federal research funding to be increased to the level needed to fund a strategic research plan and to achieve the breakthroughs required to meet the 2025 goal. Initial estimates of that level are \$2 billion per year but may be higher. That investment would be applied to Alzheimer's research initiatives spanning basic, translational, and clinical research.
 - *Recommendation 3:* HHS should continue to develop, execute, and regularly update a strategic research plan and priorities to accelerate breakthroughs in Alzheimer's disease research.
 - *Recommendation 4:* To address disparities, clinical research studies and activities aimed at translation of research findings into medical practice and to the public should include specific targets for outreach to specific populations by racial/ethnic group, sex, and socioeconomic status, as well as to populations at high risk for Alzheimer's disease (e.g., people with Down syndrome).
 - *Recommendation 5:* HHS, in partnership with experts from the research community and industry, should take steps to accelerate public access to new therapeutic interventions by compressing the current average time that it takes to identify therapeutic targets, validate those targets, develop behavioral and pharmacologic interventions, test efficacy and safety, and conduct regulatory review.

- *Recommendation 6:* The HHS Secretary should develop a continuing process by which research priorities aimed at accelerating the delivery of effective treatments would be set, including input from scientific experts.
- *Recommendation 7:* HHS should develop accurate and relevant metrics for assessing the impact of Alzheimer’s disease on the U.S. economy.
- *Recommendation 8:* HHS should commit to an effort to maximize private investment in the development of treatments and improvements in disease-monitoring technology by identifying policies that would encourage private industry to invest aggressively in disease-modifying interventions, to support technologies that improve our ability to detect the disease as early as possible, and to monitor the disease accurately so that the effectiveness of interventions can be tested.
- *Recommendation 9:* The administration should continue to expand and enhance meaningful coordination with global partners and move forward to establish a global Alzheimer's disease action plan to respond to the global scope of the problem.
- *Recommendation 10:* The administration should designate specific offices and officials within the White House and the Office of the Secretary of HHS with responsibility and accountability for effective implementation of, and timely, transparent reporting on, all aspects of the implementation of this national plan, including responsibility for issuing statutorily required reports to Congress on behalf of the Secretary, reports to the Advisory Council, and other reports as warranted.

Clinical Care Subcommittee Recommendations

Ms. Matheny presented the Clinical Care Subcommittee recommendations. The recommendations below include friendly amendments accepted by Ms. Matheny.

- *Recommendation 1:* Launch a nationwide public awareness campaign to promote early detection and diagnosis of Alzheimer’s disease.
- *Recommendation 2:* Gather data on the detection of possible cognitive impairment as part of the Medicare annual wellness visit.
- *Recommendation 3:* Clarify the privacy protections under the Health Insurance Portability and Accountability Act to ensure that health care providers can engage in care planning with family members of those diagnosed with Alzheimer’s disease or other dementias.

- *Recommendation 4:* Develop a unified curriculum for primary care practitioners to become more knowledgeable about Alzheimer’s disease and enhance the skills necessary to deliver dementia-capable care.
- *Recommendation 5:* Develop a pathway towards execution of models of payment and care delivery reform on the quality and cost for the subpopulation of participants with Alzheimer’s disease.
- *Recommendation 6:* Form a blue-ribbon panel of experts on advanced dementia to develop innovations in clinical care practice and quality, including palliative care, for people with advanced dementia.
- *Recommendation 7:* Expand funding and incentives to encourage individuals to pursue careers in geriatric specialties.

Long-Term Services and Supports Subcommittee Recommendations

Mr. Hoffman presented recommendations from the Long-Term Services and Supports Subcommittee.

- *Recommendation 1:* States should ensure that they have robust, dementia-capable long-term services and supports (LTSS) systems.
- *Recommendation 2:* HHS should provide federal funds to support a lead entity in every state and territory. This entity will facilitate development of the state’s dementia-capable systems, coordinate available public and private LTSS, conduct service gap analysis, identify opportunities for efficiency, and enable ongoing stakeholder input to address needs across all sectors and systems. HHS should use available funds to begin this process in 2013.
- *Recommendation 3:* HHS should engage all relevant federal agencies to include research on LTSS that addresses dementia capability in their research agendas. The following topics are among those needing further research:
 - Interventions for persons in the early stages of dementia, including interventions that mitigate symptoms of the disease.
 - Interventions for persons with Down Syndrome and other intellectual disabilities that are at high risk of acquiring dementia as they age.
 - Impact of caregiving on health and quality of life of caregivers.
 - Translation of interventions for persons with dementia and their caregivers into culturally appropriate programs.

- Translation of interventions for persons with dementia and their caregivers into community settings.
- *Recommendation 4:* State education and health agencies and others should include key information about Alzheimer's disease in all curricula for any profession or career track affecting LTSS.
- *Recommendation 5:* State, local, and private-sector organizations should ensure that paraprofessional caregivers in every venue are adequately trained and compensated.
- *Recommendation 6:* Congress and CMS should redesign Medicare coverage and physicians' and other health care providers' reimbursement to encourage appropriate diagnosis of Alzheimer's disease and to provide health care planning to diagnosed individuals and their caregivers.
- *Recommendation 7:* LTSS systems should refer people to a health care provider for diagnosis whenever they are admitted to or assessed for eligibility for LTSS and exhibit signs of cognitive impairment.
- *Recommendation 8:* Providers engaged in diagnosis should consider NIA's 2011 guidelines for diagnosis of Alzheimer's disease and rule out and treat any conditions that may mimic this disease.
- *Recommendation 9:* The process of diagnosis should include engaging individual and family in advance care planning (health, legal, estate, and financial).
- *Recommendation 10:* HHS should ensure that health and related systems funded with federal resources should improve chronic disease treatment and related services for people with Alzheimer's disease.
- *Recommendation 11:* HHS should develop quality measures and indicators for the comprehensive care and treatment of individuals with Alzheimer's disease.
- *Recommendation 12:* Practice recommendations for care in every setting should be embedded in CMS's federal and state surveillance and quality improvement systems.
- *Recommendation 13:* Recommendations for end-of-life and palliative care should be incorporated into all CMS surveillance and quality improvement systems at the earliest possible time.
- *Recommendation 14:* HHS should provide grants through CMMI for medical home pilot projects specifically targeted at improving medical and chronic

condition management for individuals with Alzheimer's disease, and coordination with family and community care providers in the full array of settings.

- *Recommendation 15:* HHS should convene a blue-ribbon panel of experts to recommend one or more models of palliative care for people with advanced dementia, including eligibility criteria and financing mechanisms, and provide grants through CMMI to implement and evaluate the models.
- *Recommendation 16:* HHS should create a specific grant round of pilot projects through CMMI to implement and evaluate ways to reduce preventable emergency department visits, hospitalizations, and length of hospital stays for individuals with Alzheimer's disease who are living in the full array of settings.
- *Recommendation 17:* HHS and state lead entities should partner to ensure access to the full array of LTSS for specific populations of people with Alzheimer's disease, including younger people, non-traditional families, people with intellectual disabilities such as Down Syndrome, and racial and ethnic minorities who are at increased risk of acquiring Alzheimer's disease.
- *Recommendation 18:* Incorporate the following in the federal funds (\$10.5 million) currently proposed for use by AoA:
 - HHS should issue state grants to seed the development of state action plans and state lead entities that maximize use of public and private resources to support dementia-capable LTSS.
 - Governors should designate the state lead entity and commit to sharing publicly a state plan with recommendations for action.
 - State agencies and relevant partners should be included in the state action plan.
 - Legislation enacting this program should require matching funds in order to expand program impact.
 - This program should be expanded in future years with additional resources.
 - Additional funding available at HHS or other operating divisions in FY 2013 and beyond should support this activity.
 - The funds necessary to fully fund all states' action plans are estimated to be \$85 million.
- *Recommendation 19:* Restore funding for the Alzheimer's disease Supportive Services Program to the FY 2003 level of \$13.4 million.

- *Recommendation 20:* Fully fund caregiver support under AoA.
- *Recommendation 21:* HHS, state lead entities, and providers should ensure that caregiver physical health/ behavioral health risk is assessed and addressed regularly. Caregiver illness and mortality contribute to the enormous personal and financial cost of Alzheimer’s disease.
- *Recommendation 22:* The Office of the National Coordinator for Health Information Technology, in partnership with the private sector, should work to ensure that development of health information technology includes tools that assist caregivers of persons with Alzheimer’s disease. Tools could assist caregivers by helping them organize the care they provide, educating them about dementia and multiple chronic conditions, and providing tools to help them maintain their own mental and physical health.
- *Recommendation 23:* HHS should launch a nationwide public awareness campaign to increase awareness and to promote early detection of Alzheimer’s disease.

Public Input

The public comments portion of the meeting was moderated by Dr. Lamont.

Thirteen members of the public presented testimony, including a person living in the early stages of Alzheimer’s disease, a researcher in basic mechanisms of Alzheimer’s disease, a consultant to family caregivers, family members and caregivers of persons with cognitive disabilities, a neuropsychologist, and representation from the National Task Group on Intellectual Disabilities and Dementia Practices (NGA), Leaders Engaged in Alzheimer’s Disease, the American Health Assistance Foundation, the Association for Frontotemporal Degeneration (FTD), the National Alliance for Caregiving, and the Alzheimer’s Association.

Speakers made the following recommendations and observations:

- The recommendations made by the three subcommittees are commendable and supported. Specific recommendations receiving strong support were Research Subcommittee recommendation 10 (designating a central national office responsible for effective implementation of the national plan), LTSS recommendation 9 (including legal and other professionals in advance care planning), and LTSS recommendation 17 (ensuring access to the full array of LTSS for specific populations of people with Alzheimer’s disease).

- Include caregivers in clinical trials, making accommodations for them as needed, such as using Skype or telephone interviews because they may not be able to take time away from work.
- A large-scale public awareness campaign should be undertaken to increase awareness of the needs of those living with Alzheimer’s disease and the need for increased federal funding to reach the goals in the national plan.
- To help eliminate the stigma that exists regarding both individuals living with Alzheimer’s disease and their caregivers, the Advisory Council should publicly declare that individuals living in the early stages of Alzheimer’s disease are capable of making meaningful contributions to society and should solicit input from those living in the early stages of Alzheimer’s disease when recommending policy changes.
- Everything possible should be done to ensure that Alzheimer’s disease receives the commitment and funding necessary to change the course of the disease.
- It is urgent for more support to be offered to caregivers and individuals with Alzheimer’s disease who need options for living facilities, and especially for better coordination of the resources that exist such as those from ACL, the Administration on Developmental Disabilities, and AoA.
- The National Task Group on Intellectual Disabilities and Dementia Practices (NGA) is developing and distributing practice guidelines on various topics, has developed a screening tool, and is providing workshops and webinars on dementia and on intellectual and developmental disabilities. NGA encourages the Advisory Council to integrate the screening tool into its recommendations.
- NGA is working with the Commission on the Accreditation of Rehabilitation Facilities to develop accreditation standards for organizations serving persons with intellectual and development disabilities and dementia.
- The Advisory Council should communicate its recommendations with less complexity and with less of an “inside Washington” nature, so that they can be better understood by the lay public. Although the overall goal to be reached by 2025 is clear, the plan should contain interim goals that articulate why the changes to the system are recommended and what will be achieved by making the recommended changes.
- The Advisory Council should solicit input from the community of multiple dementing disorders.

- In promoting public-private partnerships, organizations representing nondementing disorders that have a high rate of comorbidity, such as diabetes, should be involved both formally and informally.
- The Advisory Council should include, either as appointees or informally, federal agencies outside the traditional health sphere, such as the Department of Justice, the Department of Commerce, the Department of Labor, and the Federal Emergency Management Agency.
- The coming year is a pivotal and critical time to see whether the administration and Congress approve funds needed to fully implement the national plan.
- Achieving the goal of effective treatment or prevention of Alzheimer's disease by 2025 is extremely ambitious and will be possible only through continued and substantial increases in research funding. Currently only 10-12 percent of applications for research grants from various federal and non-federal sources are funded. The inadequate funding of research is leading to researchers' leaving the field as well as decisions by young people to not pursue the field of Alzheimer's disease research.
- Research funding should be targeted to a wide variety of research domains, including preclinical trials, development of biomarkers and diagnostics, identification of disease mechanisms, and identification of new targets.
- A year-old Cape Cod program providing billable in-depth family counseling services has been successful in mitigating high stress, anxiety, and depression among primary caregivers.
- A number of tools would be helpful to families of individuals with dementia. These include a financial calculator to help families understand financial implications of selecting care options (e.g., daycare, assisted living, or respite care); a flow chart of expected symptoms for different types of memory loss (e.g., memory loss accompanying head trauma); a flow chart of symptoms or conditions a caregiver might experience (e.g., depression or declining health due to chronic lack of sleep and stress); a clearinghouse or directory of support groups (with descriptions of populations/genders that the groups are tailored to); a flow chart indicating when a family should seek certain kinds of professional advice (e.g., elder care lawyer or financial advisor).
- The cost of supporting efforts to treat Alzheimer's disease is miniscule compared to the cost of failing to do so. Fully funding the national plan recommendations would be transformative for U.S. research and would improve the lives of tens of millions of people in the United States and countless millions worldwide. The \$2 billion requested for research should not be viewed as benefiting only Alzheimer's disease; it would have ancillary benefit across hundreds of disease areas.

- Following months of extensive input from practicing physicians, a statewide collaboration in Minnesota called Act on Alzheimer's has developed a practice parameter--a one-page guideline on cognitive screening, dementia workup, diagnosis, and disease management--accompanied by educational modules and presentations for local use in physician education. Information and materials are available to the Advisory Council.
- In the recommended national awareness campaigns, attention should be made explicitly to the differences between Alzheimer's disease and other dementias.
- The national plan emphasizes recommendations related to health care practitioners, and more support for family caregivers is needed including the following: (1) training about the best way to deal with different aspects of Alzheimer's disease and with behavioral issues, (2) respite care, and (3) financial support.
- PCORI--the Patient-Centered Outcomes Research Institute--would be a good candidate for a public-private partnership.
- Data drawn from actual research rather than extrapolated data are important, especially when presenting issues to Congress. Examples of such needed data are the money saved when an individual is not readmitted to the hospital within 30 days, outcomes related to a patient's family, and quality of life for both the patient and the family.
- Recommendation 10 of the Research Subcommittee--the designation within the White House and HHS of an office dedicated to overseeing the implementation of the national plan--is especially important to orchestrate research across the many government agencies, including NIA, the National Institute on Neurological Disease and Stroke, the National Institute of Mental Health, NICHD, other NIH Institutes and Centers, the Department of Defense, VA, and the National Aeronautics and Space Administration. An office within NIH to coordinate and facilitate Alzheimer's disease research would also be useful. Whichever approach to coordination is used, the initiative should be supported by a diverse scientific advisory panel.

Voting on Recommendations

Mr. Hoffman moved that the national plan recommendations of the subcommittees be accepted and that ASPE be charged with eliminating any redundancy in them. The motion was seconded by Mr. Vradenburg. The non-federal members of the Advisory Council voted unanimously to pass the motion.

Letter from the Advisory Council to the Long-Term Care Commission

Mr. Hoffman moved that ASPE construct a letter, in consultation with the Advisory Council, to be sent to the Long-Term Care Commission and posted on the web page. Ms. Woolfolk seconded the motion.

Discussion indicated that the letter should express the urgent need to address both human and financial costs of Alzheimer's disease and other dementias and that it should indicate the importance of the following:

- For persons with dementia, early identification, financial and health planning, and access to dementia-capable services as the disease progresses.
- For caregivers, education regarding Alzheimer's disease, self-care support, and, particularly in the workplace, access to dementia-capable supports.
- For both health care providers and long-term care providers, linkages between health care and LTSS, including care transition.
- Dementia-capable services, including care coordination, direct-care workers, and awareness and treatment of comorbid conditions.
- For payers, including the government, identification of persons with dementia and their caregivers.
- State lead agencies for Alzheimer's disease to coordinate activity at the state level.
- Dementia-capable workers and requirements of providers.
- Quality assurance systems for dementia outcomes and service quality.

Further discussion directed ASPE staff to work with legal counsel to ensure the letter does not violate the limitations on lobbying by the Advisory Council. Depending on advice from counsel, the letter may come from the entire Advisory Council or from only the non-federal members of the council.

The Advisory Council voted unanimously to pass the motion.

Concluding Remarks

Chair Dr. Ronald Petersen thanked the participants for their moving input and important insights regarding Alzheimer's disease and the national plan.

The next Advisory Council meeting will take place on April 29, 2013.

The meeting adjourned at 4:38 p.m.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at <http://aspe.hhs.gov/daltcp/napa/>.