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

Washington, DC

April 29, 2014

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Ronald Petersen (Chair), Laurel Coleman, Yanira Cruz (by telephone), David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, Jennifer Mead (by telephone), Dennis Moore, David Hyde Pierce, Amber Story, Laura Trejo, George Vradenburg, and Geraldine Woolfolk

- *Federal Members (or representatives) Present*: Neil Buckholtz (National Institutes of Health [NIH]), Susan Cooley (Department of Veterans Affairs [VA], by telephone), Linda Elam (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Bruce Finke (Indian Health Service [IHS]), Nicholas Kozauer (Food and Drug Administration [FDA]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Anthony Pacifico (Department of Defense [DoD]), William Spector (Agency for Healthcare Research and Quality [AHRQ]), 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 9:08 a.m., Chair Dr. Ronald Petersen called the meeting to order.

Dr. Petersen introduced himself and welcomed meeting participants. Advisory Council members introduced themselves. Dr. Petersen outlined the planned meeting agenda.

Dr. Linda Elam noted that she is looking forward to working with the Advisory Council. She emphasized that Alzheimer's disease (AD) is an important priority for the Department of Health and Human Services (HHS) and for the White House.

Mr. Harry Johns reported that the Alzheimer's Accountability Act being proposed in Congress has bipartisan support in both the Senate and the House of Representatives. The legislation is aimed at attaching the cost of meeting each of the milestones in the research portion of the *National Plan to Address Alzheimer's Disease* (National Plan).

Mr. George Vradenburg reported on initiatives emanating from the December 2013 G8 Summit, at which health ministers committed to a number of steps to address AD globally. Over the next year, legacy events will be held in Britain, Canada, Japan, and the United States. In addition, a small conference will take place in Scotland in June 2014 to explore how to have clear post-diagnostic follow-up pathways and how to determine if care interventions that are done are actually improving patient outcomes. Great Britain has appointed a World Dementia Envoy who will lead a new World Dementia Council to raise funds for AD research. Dr. Peterson and Mr. Vradenburg are members of this new council. A movement toward dementia-friendly communities is taking place in several other countries but has not yet reached the United States. Ms. Laura Trejo stated that a representative from the British Embassy in Washington, DC, has started discussions in Los Angeles about service modes and interventions in the community.

Update on Federal Activities

Dr. Neil Buckholtz provided an update on AD research.

- An AD Research Summit will take place February 9-11, 2015. The first 2 days will focus on research and will be a follow-up to the research summit held in May 2012. The third day is a G8 Summit legacy meeting that will address international coordination of AD research.

- To provide stable availability of funds in future years, a new strategy will be used in allocating the $100 million in new funds for AD research. Using $80 million, multiyear projects will be funded up front for their duration. The remaining $20 million will fund the first year only of multiyear projects; subsequent years of those projects will be funded from the regular budget.

- Four new funding opportunities have been announced for 2014:
    - Human Cell Reprogramming for Functional Genetics of AD, research expected to identify new gene or cellular networks and molecular targets underlying the etiology of AD.
    - Optogenetic Tools for the Study of Neural Systems in Aging and Alzheimer's Disease, research using animals to investigate and promote applications of optogenetic tools to study AD.

    - Analysis of the AD Genome Sequencing Project (ADSP) Data, a cooperative agreement to analyze the ADSP data already collected.
    - Planning grants for AD translational centers, aimed at bringing studies into phase 1 clinical trials.

- The National Institute on Aging (NIA) is developing a process to correlate the ongoing progress of individual research projects to milestones in the National Plan.

- A major public-private partnership was created in 2012-2013 to speed up the process of identifying and validating promising disease targets to develop new drugs. Ten pharmaceutical companies, several nonprofit organizations, the FDA, and NIH formed the Accelerating Medicines Partnership (AMP). AD, type 2 diabetes, and rheumatoid arthritis/systemic lupus erythematosus are the diseases being targeted initially. AMP has proposed 2 goals for AD research: Identify biomarkers correlated with therapeutic benefit, and identify and validate new targets in human brain tissue. Two NIA-funded projects already under way support these goals.

- AMP currently has 2 major AD-related projects:
    - Add tau PET imaging to the biomarker panels already included in 3 recently announced NIH clinical trials.
    - Integrate effective data across 3 recently announced NIH initiatives, working with Sage Bionetworks to create open-source data for public use.

- The industry arm of AMP is contributing $67.4 million to these projects, in addition to in-kind contributions such as database availability.

Discussion following Dr. Buckholtz's presentation included the following comments and clarifications:

- While current clinical trials address milestones in the National Plan, it is not possible to say that research is looking at all potential targets. For example, inflammation is a known target, but there is no way to monitor inflammation in the living human brain. The National Plan provides the framework and gives NIA the flexibility to identify new targets as they emerge.

- Network analysis will provide answers more quickly than will clinical trials, because data coming into the database is publically available immediately to use in studying new targets. Data from clinical trials cannot be made available until the trial is unblinded.

- It is not a given that to have a product by 2025 it must be in a phase 1 clinical trial today. For example, tau imaging is now making it possible for new therapeutic compounds to be developed that many believe are advances toward actual changes in cognition.

- Industry researchers have not adequately addressed representation of minorities in clinical trials, but NIH-funded clinical trials watch representation of ethnic and racial minorities more closely; some NIH trials have a diversity requirement. The

February 2015 research summit will specifically address diversity and minority recruitment.

Dr. Shari Ling and Dr. Joan Weiss provided an update on the activities of CMS.

- Evaluations of the Patient and Family Engagement Campaign (PFEC) awards are in progress.

- In May 2014, the awards for the second round of the Health Care Innovation Awards will be announced. One of the 4 categories prioritizes persons with AD.

- From 2009 to 2013, the rate of hospital admissions for patients with AD or dementia decreased from 80 per 1,000 Medicare beneficiaries to 58 per 1,000 beneficiaries. Readmissions of Medicare beneficiaries decreased from about 4 per 1,000 to 2 per 1,000 during that same period.

- Five Quality Improvement Organizations (QIOs) that received awards for demonstration projects to improve care for individuals with dementia have completed their projects, which directly reached a total of 2,939 people.

- The QIOs reported the following lessons learned from these projects:
    - Beneficiaries are receptive to using technology to actively engage in their health care.
    - Hispanic communities have providers of care, but many speak English as a second language and are located in a high-crime area.
    - Many beneficiaries have limited knowledge of dementia-care best practices and resources and may be unaware of evidence-based quality-of-life practices.
    - Dementia-care resources exist, but beneficiaries have limited understanding of how helpful these resources can be to caregivers.
    - Beneficiaries and families require education regarding the need to be responsible for their health care decisions.
    - Care is poorly coordinated between hospitals and community resources.

- HRSA is reviewing 45 applications submitted by Geriatric Education Centers (GECs) for workforce education on dementia care.

- HRSA is preparing a contract for development of unified GEC curricula.

- Some GECs have identified training needs related to intellectual disabilities, and a national task force is developing a curriculum focused on intellectual disabilities and dementia.

- HRSA grantees are participating in monthly conference calls with other federal agencies to share information about programs related to dementia.

- HRSA is partnering with ACL to provide training to the Aging and Disability Resource Center network.

- As of April 2013, 50% of eligible physicians and hospitals received incentive payments for meaningful use of electronic health record (EHR) technology. EHR standards that can support the thoughtful integration of detection, diagnosis, and care planning are essential.

- A workgroup is identifying high-level clinical workflow involving detection, diagnosis, and treatment for persons with AD and related dementias (ADRD). The group is looking at the available health information technology (HIT) standards to see if they support the assessment tools used in detection and diagnosis as well as electronic consultation requests to a specialist.

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

- Lessons learned from the QIO projects are already well known and need to be addressed, rather than repeating activities resulting in new lessons learned.

- The readmission rate should be correlated with care given in post-acute care settings that report quality.

- The EHR has to be informed by content, such as diagnosis codes that include dementia. Unfortunately, the admission diagnosis code does not typically reflect a diagnosis of dementia, even when the patient has dementia. The forthcoming *International Classification of Diseases, 10th Revision* (ICD-10) might include diagnosis codes that have a consolidated set of labels.

- The tremendous underreporting of ADRD diagnoses results in not capturing the enormous cost to the health care system of the care of people with dementia. We should have specific goals for the rate of diagnosing people with dementia.

Dr. Jane Tilly provided an update on ACL activities related to long-term services and supports (LTSS).

- ACL, NIH, DoD, and the Centers for Disease Control and Prevention (CDC) have collaborated on the Brain Health Resources Initiative program. A fact sheet, PowerPoint presentation, and handout that were developed for the program are written at a level that seniors can understand and will be available in 2 weeks.

- As recommended by the National Plan, ACL's LTSS awareness campaign will address recognition and diagnosis of AD, the importance of talking to a health care provider about worsening memory problems, and talking with family and health care providers about preferences for care. An interagency group, including ACL, ASPE, HRSA, CMS, CDC, VA, and NIA, will guide the campaign.

- AD Special Services and Supports (ADSSP) New York University Caregiver Intervention (NYUCI) program, which includes 6 counseling sessions, was implemented in Minnesota community settings. In Minnesota, it resulted in decreased depression and stress among caregivers as well as delayed institutionalization. Over the next 15 years the delayed institutionalization is projected to save Minnesota an estimated $996 million in direct care costs.

- Using $10 million in funding for new initiatives, ADSSP is developing a funding opportunity announcement for 2014 grants to states and other entities to enhance services for people living alone with dementia, people with intellectual or development disabilities and dementia, and people with behavioral symptoms of dementia. The focus is person-centered care within a dementia-capable system.

- Applications are due June 11 for 3-year ADSSP grants to states for expanding support services for dementia capability in home and community services. Six to 10 grants of up to $450,000 each will be awarded.

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

- Several hundred people were involved in the Minnesota study.

- Given the cost savings projected by Minnesota, CMS should require this approach.

- While the tools developed to address LTSS needs are appropriate, the pace and scale of implementation is inadequate and extremely frustrating. Mary Mittleman's NYUCI program was introduced in 1996 and is still being reproduced on a small scale. A professional judgment budget, which includes an assessment of the employees of an agency of what it would take to address a problem, is needed.

- Educational materials need to be appropriate for culturally diverse communities and to accommodate low literacy. Because the contract for the awareness campaign has not yet been awarded, these requirements can be included.

- The alzheimers.gov website has a Spanish version, but many of the documents linked to it are in English. Dr. Tilly will communicate this to the webmaster.

- The council appreciates how the ACL and the interagency workgroup have responded to the council's input.

Dr. Bruce Finke reported on IHS activities related to LTSS.

- The VA’s Resources for Enhancing Alzheimer’s Caregivers Health (REACH) program has been piloted for Native veterans with dementia and their caregivers. Six nurses from 3 sites have completed certification. The VA is supporting this staff training as a proof-of-concept trial for possible implementation among Native Americans who are not veterans.

- IHS presented a webinar on disaster preparedness that addressed the special considerations of families with special-needs children, older frail individuals, and individuals with dementia. The webinar offered suggestions for how disaster preparedness programs can better serve these groups. More than 300 people viewed the program, and nearly 500 dialed in to listen. It will soon be available online.

Military-Relevant, Peer-Reviewed, Alzheimer's Disease Research Program (MRPRA)

Dr. Anthony Pacifico reported on the DoD’s MRPRA program.

- MRPRA’s mission, developed 3 years ago, is to build an integrated program devoted to understanding the association between traumatic brain injury (TBI) and AD and to reduce the burden on those affected by TBI or AD symptoms, especially in the military community.

- TBI and AD have numerous common symptoms, such as depression and anxiety.

- Challenges for the MRPRA program are the paucity of research on the relationship between TBI and AD; the lack of technology, tests, and interventions to diagnose AD at its earliest stages; the lack of technology or interventions to benefit individuals with TBI or AD; and the lack of validated best clinical practices to benefit individuals with TBI or AD.

- MRPRA research focuses on imaging, genomics/proteomics, quality of life, and the pathology of tau.

- MRPRA participates in the International AD Research Portfolio (IADRP). Using IADRP ontology criteria, about two-thirds of MRPRA research addresses molecular pathogenesis and physiology, diagnosis, assessment, and disease monitoring.

- The following are 4 representative MRPRA-funded projects:
  - Arizona State University: Oligomeric Neuronal Protein Aggregates as Biomarkers for TBI and AD.

  - Cleveland Clinic: Novel Genetic Models to Study the Role of Inflammation in Brain Injury-Induced Alzheimer's Pathology.
  - Northern California Institute of Research and Education (NCIRE): Endophenotypes of Dementia Associated with TBI in Retired Military Personnel.
  - NCIRE: Effects of TBI and Post-Traumatic Stress Disorder on AD in Veterans, Using Imaging and Biomarkers from the AD Neuroimaging Initiative.

Discussion following Dr. Pacifico's presentation included the following comments and clarifications:

- It is not known if DoD funding for this research will increase in the future.

- The difference between AD research funded by DoD and that funded by NIH is that DoD research includes TBI.

- Some researchers receiving DoD grants also have NIA grants. Although well-known researchers are leading the 4 projects presented, young investigators have also received some of MRPRA's 21 grants.

Comments from HHS Secretary Sebelius

Secretary Kathleen Sebelius thanked the Advisory Council for its efforts. She noted that progress has been made because of its efforts, but the task is far from over. A major challenge is getting the public to understand the tsunami that is coming because of the dramatic increase in the number of those with AD. AD is more costly than any other condition, with an estimated $159 billion in direct health care costs, a figure that does not include the toll taken on individual lives and families and the costs borne by them.

The promising advances in research, such as the identification of 11 individual genes, are exciting. The extra $100 million provided for research in the fiscal year (FY) 2014 budget is the result of the Advisory Council's and other advocacy efforts. The President's FY 2015 budget includes additional funding for related projects, such as the BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative. The President is dedicated to finding funding to address AD. The partnership to improve dementia care in nursing homes is a significant effort. CMS has been addressing reducing the use of antipsychotics in nursing homes, resulting in a 15% decrease in use over 2 years. HRSA is focusing on training providers. ACL works on the entire long-term care system. Even though the budget is not what the council hopes it might be, HHS is trying to reach the National Plan goals.

Updates to the National Plan

Dr. Helen Lamont reported on the changes to the National Plan that were made using the Advisory Council's recommendations. She noted that by May 2, 2014, the online version (http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.shtml) of the National Plan will include links to additional material and will update action items with more detailed information.

- Goal 1: Prevent and Effectively Treat AD by 2025:
    - 1.A.7: Create milestones for goals based on the ADRD workshop recommendations.
    - 1.A.8: Regularly convene an ADRD research summit; the next one will be in 2016.
    - 1.E.6: Provide educational materials to aging, disability, and public health networks.
    - 1.E.8: In leveraging collaboration between the DoD and the VA on neurodegeneration research, focus on health care delivery, quality of life, access to care, and building partnerships.

- Goal 2: Enhance Care Quality and Efficiency:
    - 2.A.1: Expand workforce training; HRSA is doing this.
    - 2.A.13: Strengthen states' ability to provide dementia-capable services.
    - 2.A.14: Expand the availability of services to underserved populations.
    - 2.A.15: Strengthen the long-term care workforce; the Department of Labor has revised fair labor standards, such as overtime and minimum wage requirements, to cover home health care workers.
    - 2.A.16: Improve home and community-based services provided through Medicaid waivers; the final regulations, issued in January 2014, offer more flexibility.
    - 2.D.1, 2.D.2, 2.D.3, and 2.D.4: Continue work on measuring high-quality dementia care and identifying meaningful outcomes; HHS is working with the National Quality Forum and the Institute of Medicine and is convening listening sessions to address this goal.
    - 2.D.5: Clarify and disseminate information on privacy, autonomy, and safety; the Advisory Council is establishing an ethics subcommittee to address these issues.
    - 2.F.5 and 2.G.4: Explore opportunities to use HIT to enhance care; the Office of the National Coordinator is working on standards for ADRD care plans and for information exchange in transitions of care; AHRQ is doing research on remote sensing technology and impacts on family caregivers.
    - 2.H.3 and 2.H.4: Improve care for populations disproportionately affected by AD; ACL's dementia webinar series will discuss younger-onset dementia; HHS will identify characteristics that facilitate or hinder the ability of families to provide home-based care for individuals with intellectual disabilities as they age.

- Goal 3: Expand Supports for People with AD and Their Families:
    - 3.B.15: Provide webinars on disaster preparedness for family caregivers and aging and disability networks.
    - 3.D.10: Engage law enforcement by using Department of Justice trainings and resources.
    - 3.D.11: Develop and share a guide to best practices; information about state programs will be compiled as a resource.
    - 3.B.16: Provide detailed regulatory information from each state about policies on residential care and adult day health.

- Goal 4: Enhance Public Awareness and Engagement:
    - 4.A.1: Conduct a national education and outreach initiative; an interagency workgroup is collaborating on a national campaign focused on awareness of cognitive impairment.
    - 4.B.5: Improve coordination among IHS, tribal, and urban Indian health programs and the aging network, addressing 4 person-centered goals.
    - 4.C.1: Enhance global collaboration; HHS is building off the commitments made at the December 2013 G8 Dementia Summit; United States representatives will participate in legacy meetings and will host the February 2015 legacy meeting on AD research.

- Goal 5: Improve Data to Track Progress:
    - 5.A.6: Summarize data on people with AD and their caregivers; HHS will develop a chartbook of data such as demographics, comorbid conditions, levels of disability, and utilization of LTSS; the National Center for Health Statistics will compile government-sponsored data from several sources for this chartbook.
    - 5.A.7: Develop ICD-9/ICD-10 codes for analyses of administrative data; HHS is convening a group to develop consistent codes and correlate them to the *Diagnostic and Statistical Manual of Mental Disorders*.

Following Dr. Lamont’s presentation, the following comment was made:

- This report is an update on activities, not outcomes. The Advisory Council needs to know how much progress has been made toward the National Plan’s 2025 goal.

Public Input

Dr. Lamont moderated the public comments portion of the meeting.

Sixteen members of the public presented testimony either in person or by email, including persons living in the early stages of AD, family members and caregivers of persons with dementia, a neurologist, and representatives from the Alliance for Aging Research, the Alzheimer’s Foundation of America (AFA), the Association for

Frontotemporal Dementia (AFTD), the Broyles Foundation, the Consumer Consortium on Assisted Living (CCAL), the Elder Care Workforce Alliance, Leaders Engaged on AD, and the National Certification Board for Alzheimer's Care (NCBAC).

Speakers made the following recommendations and observations:

- AFTD's science director has completed a report that gives an overview of research and drug development related to frontotemporal dementia (FTD).

- A guidance document issued in 2013 by AFTD emphasizes that the needs of the FTD community should be included in state plans.

- The efforts of Secretary Sebelius are very much appreciated. The council members should find ways to tap her knowledge and insight by including her on boards or other groups.

- It would be helpful if the council meeting slides were made available earlier.

- It should be a priority to include price tags for each of the recommendations in the 2015 update to the National Plan.

- The research updates at the council meetings focus on NIA research, and it would be informative to hear about AD-related research being funded by other Institutes and Centers, including the National Institute of Mental Health and the National Institute of Neurological Disorders and Stroke. Other non-NIH research on issues such as adult day care and depression in family caregivers might also be of interest to the council.

- HHS and NIH leadership should examine the distribution of funds at NIH and take into consideration mortality rates, incidence, and the impact on entitlements cost and caregiver costs in determining fund allocation.

- The work at CMS in reducing hospitalizations and improving care transitions is groundbreaking and excellent.

- More effort should be made to consider the possibility of extending Medicare coverage to the REACH program, which has an excellent record of effectiveness in delaying institutionalization.

- Experts agree that a person-centered model of care should be the standard of care. Care that engages an individual in nonphysical ways (e.g., psychosocial, spiritual) is essential. The 15% reduction in the use of antipsychotics will not be sustainable without a change to a more holistic approach. A Dementia Action Alliance has been created to promote person-centered care.

- The Institute for Person-Centered Care at the University of Buffalo is conducting a national survey about priorities in dementia care.

- The pace and scale of advances in LTSS are inadequate, and the research related to care is underresourced.

- While the National Plan notes that related dementias are included in the term “AD,” the council and the plan should change terminology to use the term “dementia,” because using the term “AD” makes 1.6 million Americans and their networks feel excluded.

- Although the National Alzheimer’s Project Act (NAPA) is a public-private partnership, it is not perceived as public by the care community, which has a sense that NAPA is insular. A number of organizations representing key stakeholders, such as the Society for Post-Acute and Long-Term Care Medicine, the Council on Gerontological Nursing, and the National Association of Professional Geriatric Care Managers, are excluded. For example, nobody from NAPA has ever spoken to the National Association for States United for Aging and Disabilities, even though state-based agencies are the ones that would be tasked with carrying out specific recommendations. A suggestion is for the council to write a short description of how people can get involved and what the process is, so these stakeholders know how to have an impact. To encourage a diversity of perspectives, the council should let stakeholder organizations know that they are invited to come and make recommendations.

- At the council meetings, it would be helpful if the public could comment by telephone, to accommodate those who cannot travel.

- The public-private partnership established for research is excellent, and a coalition such as AMP should be created to address care and support. A visionary leader is needed in the LTSS area, pushing aggressive implementation of a few key projects that will transform the understanding of care and support. The Dementia Action Alliance would be happy to coordinate a public-private meeting to discuss this.

- The AFA has issued a cost-of-care report that makes proposals that offer the potential for savings in implementing the goals in the National Plan. Among the actions the AFA has analyzed and proposed are medical homes, models of hospital safety, models for effective care transitions, and caregiver training and supports.

- A Rand study found that in 2010 the cost to care for persons with AD was $215 billion.

- Mortality reports recently released indicate that only around 80,000 people are dying of AD rather than the more realistic estimate of a half million. This underreporting represents challenges in stigma, rates of diagnosis, coding, and the passivity and lack of funding present along the disease continuum. Further, after death, bereavement issues and coping with what the disease has done to the family are not addressed.

- Outcome measures for the council to consider are diagnosis rates, falls, depression, impoverishment, premature institutional placement, wandering, and community inclusion.

- Development of community integration philosophies that were initially focused only on dementia inclusivity would also benefit other subpopulations and the entire community.

- While the council recognizes the importance of research experts, caregivers who are real-life experts are somewhat ignored.

- The council's recommendations for each state to have a robust LTSS system will result in uneven implementation and duplication of effort. Instead, to maximize time and effort, a centralized independent group whose sole purpose is to help caregivers nationally should be created, creating cohesion across the country and centralizing resources. It could identify areas of weakness and strength in each state and pair states together for mutual support.

- CCAL has a book available for caregivers that has been translated into 11 languages.

- The mentality of hospital staff needs to be changed so that they are aware of how to accommodate the needs of people with dementia. People with dementia need to have in place planning directives such as living wills and do-not-resuscitate orders, and these need to be clearly communicated to hospital staff.

- The council should promote the plan that is in place in Britain in which businesses are asked to train staff to be dementia-aware. When a business has completed training for 95% of its employees, it is given a sticker to display in its window certifying that it is a dementia-aware business.

- The council and advocates need to push harder for research funding. The successful HIV model is a good model. For every $100 that NIH spends for AD research, Medicare and Medicaid spend $26,500 caring for those with the disease.

- A system should be put in place to track what each state is doing regarding dementia, including a rating system for state plans and their execution. Such a rating system will provide incentive, identify the best state models, and even encourage competition.

- The council should encourage members of Congress to sponsor the Alzheimer's Accountability Act (S.2192 and H.R.4351).

- The statistics given in the 2014 facts and figures book from the Alzheimer's Association are conservative. Statistics incorporating all dementias should be included, not just AD. Not enough is being done to combat AD, from which more than 500,000 people die each year. Breast cancer has a 98% survival rate, but there are no survivors of AD, no one to stand up and say, "I had this disease, but thanks to the wonders of medicine, I'm cured and free to live a normal, healthy, productive life."

- Organizations representing people with various kinds of dementia seem unwilling to work together with those representing other kinds of dementia. Many individuals with dementia still do not know about NAPA. The council should invite people with dementia to its meetings.

- It is of concern that public comments, which used to be available on the NAPA website, have been removed.

- The council and NAPA should use the logo of the purple angel on its website and awareness campaigns. It was created in Great Britain with the intention of serving as a universal symbol to raise awareness, hope, and empowerment for all people living with dementia, their families, and their care partners.

- Certification of caregivers would be an appropriate way to address 2014 recommendation 17, which states that "state, local, and private-sector organizations should ensure that paraprofessional caregivers in every venue are adequately trained and compensated." Certification would also address strategy 2.D of the National Plan to identify measures for high-quality dementia care. Certification of staff enables employers and administrators to be assured of competence, slows down turnover, and provides satisfaction and a sense of pride to employees.

- NCBAC is going to conduct a nationwide survey about certification examinations and would like the council to provide input on the survey and help publicize it. NCBAC would then share the survey results with the council.

- Family members constitute a huge proportion of caregivers, and, as the population decreases, people will not have adult children who will be able to fill that role. This situation will increase the costs of health care even more than projected.

- The dietary supplement Axona is recommended for treatment of AD. Other therapies encouraged are a Mediterranean diet, acupuncture, exercise, and compound J147. It is important to look "outside the box" of traditional medicine to see what else is available. Support for the research of Dr. Dave Schubert is encouraged.

- The additional $4 million in the budget for education and outreach of GECs is encouraging, but more funding is needed. The public members of the council are urged to include the following 2 recommendations from last year: Geriatric competence, and specifically dementia training, should be included in the training of all primary care practitioners and any professionals affecting LTSS; and Congress should pass legislation to provide loan repayment for those who go into studies of geriatrics or gerontology.

- Research, clinical care, and caregiving are the 3 legs supporting AD, but the council's recommendations do not give enough weight to caregiving. Family caregivers save the United States $450 billion per year.

- Health care professionals should talk to the patient's caregiver, and they should also be trained to identify dementia within a few minutes of talking to a patient.

- The council should unequivocally and specifically recommend that when dementia is diagnosed the cause should be determined. Without a known cause, treatment is chaotic, fragmented, and ineffective, and the prognosis is uncertain, with inadequate care, planning, and support. Moreover, contraindicated treatment for other symptoms may be prescribed. Patients and families cannot make difficult, life-changing decisions when they are uncertain about the cause of the problem and its likely course. National medical specialty societies and the U.S. Preventive Services Task Force have not recommended adequate measures for screening and diagnosis. This diagnostic nihilism has resulted in lack of insurance reimbursement for testing and leads to therapeutic nihilism. The council should prioritize research that expands the evidence for the value in clinical practice of knowing the cause of dementia.

Ethics Subgroup Introduction

Dr. Tia Powell presented the role of ethics in health policy for AD.

- Ethics plays a role in AD because of the tension between supporting the autonomy of the individual while protecting his or her vulnerability, balancing the rights and needs of AD patients with those of the family and community, and promoting research while protecting research subjects.

- The new Advisory Council Subcommittee on Ethics has the following goals:
  - Identify key ethics issues around ADRD.
  - Determine which issues have highest priority.
  - Determine the scale and impact of the identified issues.
  - Determine which issues might be actionable.

- Examples of issues the subcommittee may address are health privacy, use of feeding tubes, and the ethics related to research enrollment and specific research topics.

- Advisory Council members appointed to the Subcommittee on Ethics are Laurel Coleman, David Hoffman, and Jennifer Manly. Monthly subcommittee calls will take place, with findings presented at the July 2014 Advisory Council meeting, followed by preparation of a final document on ethics in ADRD.

Alzheimer's Disease State Plans

Mr. Matthew Baumgart gave an overview of state AD plans.

- Currently 35 states have published AD plans, and 8 states are writing plans.

- The values of state plans are that they can target state and local funds and address gaps in care that are not addressed federally.

- The National Plan, state plans, and the public health road map all have exclusive areas that they address, and they overlap in some areas. For example, both state plans and national plans address the elder abuse workforce, and both state plans and the public health road map address the integration of services and needs assessment.

- The Alzheimer’s Association worked to get states to develop a state plan through a 4-phase process: (1) Winning a state mandate through a law or executive order, either of which calls for public buy-in; (2) developing the plan, which involves task force appointments and public input; (3) changing policy, which includes prioritizing recommendations and deciding what is winnable; and (4) ensuring enforcement.

- The 35 existing state plans include recommendations in the following 16 areas, with the number of states that include the topic shown in parentheses:
  - Training (33)
  - Care and case management (32)
  - Caregivers (30)
  - Home and community-based services (28)
  - Data collection (27)
  - Public awareness (27)
  - Quality of care (27)
  - Safety (27)
  - Research (25)
  - Health care system capacity (20)
  - Workforce development (20)

  - State government structure (19)
  - Early detection and diagnosis (18)
  - Long-term care (18)
  - Legal issues (16)
  - Brain health (14)

- The following are examples of initiatives in 4 state plans:
  - North Dakota has a Dementia Care Services Program that includes 3 in-person visits and the availability of phone consultation at all times. An assessment of the caregiver is made at each contact. This program has resulted in decreased or delayed placement in nursing homes and decreased use of medical services.
  - The Texas plan resulted in the development of guidelines and best practices for physicians to recognize and diagnose AD and best practices for management of coexisting chronic conditions. In addition, the Department of State Health Services began education and outreach, especially to physicians in rural areas, through the state medical association.
  - Massachusetts has engaged in training caregivers and family members, who are also provided with a support group. Persons living in Soldiers' Homes receive regular assessments and are counseled and referred to services if they have a diagnosis of AD.
  - Colorado's plan recommends voluntary certification of facilities and individuals. Facilities have been very enthusiastic about obtaining certification.

- Eighteen state plans specifically recommend that their states collect data through the Behavioral Risk Factor Surveillance System, an annual survey conducted in every state with technical and financial support from the CDC. But in practice, from 2011 to 2013, 45 states and territories have used the cognitive module to begin to collect data on the impact and burden of memory problems.

- All of the state plans are available at the website alz.org, which also includes a comparison of the state plans in 16 categories.

ACT on Alzheimer's

Ms. Olivia Mastry presented information on the Minnesota initiative ACT on Alzheimer's.

- ACT on Alzheimer's is a voluntary statewide organization of more than 60 organizations and 300 individuals. It has a Leadership Council of more than 45 advisors, strategists, and champions, and a Management Steering Committee of more than 10 organizations actively involved in day-to-day operations.

- From the initial 30 recommendations filed by a legislatively mandated AD working group in January 2011, 5 goals were established:
  - Identify and invest in promising approaches.
  - Increase detection and improve both clinical and community care.
  - Sustain caregivers.
  - Raise awareness.
  - Equip communities.

- To increase detection and improve care, provider tools were developed for primary care providers, community-based organizations, professional school faculty, and others.

- The development of a community toolkit to foster dementia-friendly communities had 4 phases:
  - Convene key community leaders among health care, government, faith, financial, business, educational, and other stakeholders to create an action team.
  - Assess current strengths and gaps within the community by use of a questionnaire.
  - Analyze the questionnaire's findings to develop an action plan, looking for high-priority, low-activity areas of need.
  - Act together to pursue priority goals that foster community readiness for dementia.

- To date, Minnesota has 19 action communities, with 11 more expected in the next few months. Examples of community initiatives are creating a business training program to recognize cognitive impairment; training rabbis to be able to support individuals with dementia and their families; and developing "dementia friends," in which a group of people are trained as champions and then address book clubs, churches, housing associations, and other groups, training them to be compassionate neighbors to those with cognitive impairment.

Comments and clarification about the Minnesota initiative included the following:

- The program is evaluating its success through some markers established for both clinical care and community-based care. Another measure is aimed at changes in businesses in creating dementia-friendly workplaces. Results are to be analyzed in 2015, with a final report in early 2016.

- Momentum is sustained because the action groups are community based, so people are in touch with each other and realize the power they have at the local level. Seeing progress first-hand motivates them.

- The dementia-friendly community is helping people with dementia who live alone, without a caregiver. The entire community becomes the caregiver, thereby allowing the person to live at home longer.

- Although the community toolkit was initially created in a metropolitan area, a situation that often makes tools difficult to use in rural areas, the opposite was found to be true in Minnesota, where the rural communities could take action faster because the population is smaller and people know each other. In urban settings it has been important to carve out smaller neighborhoods for implementation.

- The Federal Government has been helpful by granting money that allows states to experiment. It is most helpful to have national resources and allow the state or community the flexibility needed for appropriate local implementation.

- Work with a tribal government has just started in one of Minnesota’s communities.

- The start-up cost in a metropolitan area is often borne by a business, which allows a full-time employee to spend 25% of his or her time as a local champion. Implementation has additional costs. ACT on Alzheimer’s has contracts with area agencies on aging and Alzheimer's Association chapters.

- The formal state structure of ACT on Alzheimer’s will end at the end of 2015. After that, the plan is that existing structures will absorb and sustain the work to be done. Physicians will have resources in their electronic medical record systems, community websites will have resources, and communities will have more caregiver supports in place. In the next 6 months the Leadership Council will identify anything else they have to do to sustain the program.

New York State Alzheimer's Disease Plan

Mr. David Hoffman provided information about the New York State AD plan.

- Governor Mario Cuomo convened a Blue Ribbon Panel in 1987 that issued a report that was basically the state’s first AD plan. The current coordinating council began meeting in 2007, resulting in a new report that is required to be updated every 2 years.

- The goals of the AD program are to use evidence-based strategies to ameliorate the impact of AD on both individuals with the disease and on their family, to delay the institutionalization of individuals with AD, and to maintain the quality of life of both the patient and his or her family.

- The state has 9 centers of excellence, geographically distributed, that serve as clearinghouses of information and provide diagnosis and assessment, patient management and care, training, education, and consultation. The centers are typically affiliated with universities and hospitals.

- Services are provided through 7 Alzheimer's Association chapters in the state. Community-based support services for patients and family members include the following:
  - Support groups.
  - 24-hour helpline.
  - Training and education of family and nonfamily caregivers, volunteers, and home health care personnel.
  - Volunteer respite services, including provider training.
  - Care consultation and outreach.

- The Coordinating Council for Services Related to AD and Other Dementias has quarterly meetings that incorporate input from consumers, providers, advocates, and several state agencies.

- Recent actions include a "Dear Colleague" letter about early detection, sent from the commissioner of public health to all physicians in the states; a briefing for the governor's staff on AD issues; meetings between the state health commissioner and the director of the state Office for Aging; updated webpages on AD and other dementias; and exploring collaboration with long-term care rebalancing initiatives.

- In the near future the program will develop more health promotion messages for seniors, work with AD assistance centers to develop curricula for preservice and inservice training for professionals, review training opportunities for the direct-care workforce, expand awareness on advance care planning, focus on early detection, promote the Reaching Older Americans with Research program, and conduct a focused demonstration project to impact health disparities.

Dr. Petersen asked Dr. Jennifer Manly to chair the balance of the meeting, as he and Dr. Vradenburg had to leave to travel to the World Dementia Council meeting.

San Francisco's Strategy for Excellence in Dementia Care

Ms. Ruth Gay reported on San Francisco's program for dementia care.

- In 2007 the Long-Term Care Coordinating Council identified the need to focus on people with dementia and their caregivers. After funding was allocated in 2008, an AD expert panel developed the Strategy for Excellence in Dementia Care, which had 35 recommendations for implementation between 2010 and 2020. The panel estimated that San Francisco had 35,000 people with dementia.

- Four workgroups who reported to an oversight committee were formed to implement programs and policies in the following areas:
    - Training, education, and standards.
    - Medical resources.
    - Additional services and settings.
    - Waivers, pilot projects, demonstration projects, and advocacy.

- The groups established measurements for success in the following goals:
    - Education and training.
    - Service coordination.
    - Shared client information.
    - Team-based care.
    - Standards and guidelines for care.
    - Education and training for service providers.
    - Access to resources and services.
    - Delayed need for more intensive services.

- A $20,000 grant in 2010 was used to contract with the Alzheimer's Association to implement education and training for the community, dementia care professionals, medical providers, first responders, and airport security. Over 2 years, 5,000 people received training.

- In 2010, a $320,000 award was received from the Administration on Aging to improve diagnosis capabilities and connect caregivers of high-risk individuals to needed educational and support services. In this project, 105 pairings were made between a dementia expert at Kaiser and an individual with dementia and his or her caregiver. A dementia care plan was developed for each individual, who was also referred to the local Alzheimer's Association chapter. The result of this program was a 40% reduction in hospitalizations and the establishment of connections for better care and support services to help individuals live in the community.

- The workgroup dealing with waivers, pilot projects, and advocacy sought grants to take advantage of opportunities to improve systems. Examples of the workgroup's efforts are improving hospice care and having the Medicare annual wellness visit include a cognitive assessment.

- San Francisco has no skilled nursing beds, so when an individual is discharged from the hospital, there is no place to send them, especially if they are eligible for Medicaid assistance. The additional services and settings workgroup is exploring ways, such as an assisted living waiver, to qualify temporary housing situations for Medicaid.

- The medical resources workgroup is looking at best practices for serving people with mild cognitive impairment and the possibility of a mobile medical record that identifies individuals as having AD.

- A Brain Health Center has been developed at the California Pacific Medical Center. This program has a neurology team and social workers who focus on cognitive impairment and coordination of services and education for families of those with AD.

- An emergency department (ED) perceptions survey conducted in February 2013 in all San Francisco hospitals found that as many as 60% of people arriving at the ED have some form of dementia, as many as 70% have no true medical reason for an ED visit but no alternative place to get help, and 40-95% of those with dementia arrive at the ED alone.

- In February 2013, a hospitalization conference targeted to physicians, social workers, and geriatricians focused on the importance of identifying cognitive impairment and dementia and how to address the needs of patients admitted with delirium. Follow-up hospital conferences are planned.

- The Bay Area Collaboration for Cognition Education is a new partnership among several intuitions that is offering free grand rounds to San Francisco hospitals.

- A new opportunity being undertaken is long-term care integration to integrate home and community-based LTSS with primary and acute-care services. One goal of this project is to allow community-based adult services, in-home supportive services, multipurpose senior services programs, and skilled nursing facility services to be part of a MediCal and Medicare managed care service delivery system.

Comments and clarifications about the San Francisco initiative included the following:

- The San Francisco initiative predates the California state plan, which does not mandate county efforts.

- Other California counties do not have similar projects, but some have requested meetings with the San Francisco leaders, and some aspects of the San Francisco program might be transportable to other counties.

- To be implemented in a rural setting, such a program might need several counties working together.

Council Discussion

Council members made comments about state and local programs and how lessons from them might inform the council's recommendations.

- Collaboration is an element of all of these initiatives. Perhaps there is a way for the council to help facilitate collaboration and proliferation of best practices. A clearinghouse where information is easily accessible might be helpful.

- Rather than having the Federal Government provide a clearinghouse, it may be more appropriate for a partner organization to do so, one that could provide more nuanced information that would be useful for a variety groups. Perhaps some detailed information could be provided on the ACT on Alzheimer's website.

- Grassroots efforts are key. Consideration should be made for how to get such efforts initiated.

- Early adopters are inspiring. It would be helpful to have legislators from other states hear what is being done by states that are funding projects like those in Minnesota and San Francisco. Sharing of information needs to take place at multiple levels so people are hearing from their peers. For example, legislators tend to listen to the National Conference of State Legislatures, and Medicaid directors listen to the National Association of Medicaid Directors. Such groups need to be partners of NAPA in order to reach different audiences efficiently.

- A question is how to set up partnerships so that the available information is disseminated. A website clearinghouse would need to be curated to ensure that information posted is credible.

- A model for information exchange has been used for other diseases and conditions. For example, the heart disease health policy forum and the obesity health policy forum, funded by the CDC, foster an exchange of information among partner organizations.

Concluding Remarks

Dr. Elam remarked that she was encouraged by the caliber of the work and by the participants in today's meeting.

The next meeting will take place July 21, 2014, with a theme of informal caregiving.

The meeting adjourned at 4:33 p.m.

Minutes submitted by Helen Lamont (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/daltcp/napa/.