

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

Washington, DC

July 21, 2014

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, Yanira Cruz, Harry Johns, Jennifer Manly, Helen Matheny, Jennifer Mead, Dennis Moore, David Hyde Pierce (by telephone), Laura Trejo, George Vradenburg, and Geraldine Woolfolk
- *Federal Members Present:* Lynda Anderson (Centers for Disease Control and Prevention [CDC], by telephone), 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 [HIS]), Richard Hodes (National Institutes of Health [NIH]), Nicholas Kozauer (Food and Drug Administration [FDA]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Anthony Pacifico (Department of Defense [DoD]), Anand Parekh (Assistant Secretary of Health), William Spector (Agency for Healthcare Research and Quality [AHRQ]), Amber Story (National Science Foundation, by telephone), Jane Tilly (Administration for Community Living [ACL]), and Joan Weiss (Health Resources and Services Administration [HRSA])
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Rohini Khillan (ASPE)

General Proceedings

At 9:09 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. Peterson outlined the planned meeting agenda.

Dr. Peterson announced that he had appointed a small group of council members to work with ASPE staff; Ms. Sheila P. Burke, strategic advisor with Baker Donelson; and Ms. D.E.B. Potter of AHRQ to assess progress on the National Plan to Address Alzheimer's Disease (National Plan) and the process being used.

Ruth Katz stated that a panel presentation about the National Alzheimer's Project Act and the activities of the Advisory Council has been proposed for the 2015 annual meeting of the American Geriatric Society.

Dr. Laurel Coleman reported that the Institute of Medicine (IOM) is convening three meetings focusing on advanced dementia. The first meeting, held in January 2014, addressed research. The second meeting will occur on September 8, 2014, and will focus on innovative care practices. Council members are encouraged to attend the day-long meeting, which is open to the public.

International Activities

Mr. George Vradenburg reported that the follow-up from the December 2013 G8 Summit has followed two main paths--a series of legacy meetings and the appointment of a World Dementia Council to raise funds for Alzheimer's disease (AD) research. The first legacy meeting, held in London in June, resulted in identifying seven priorities with related action plans and accountabilities. Subsequent legacy meetings will take place in Canada, Japan, and the United States. Following the legacy meetings, in March 2015 the World Health Organization will reconvene participating health ministers to assess progress and delegate leaders to a sustaining group. The World Dementia Council will meet quarterly and is holding its second meeting in Paris this week. Dr. Peterson and Mr. Vradenburg are members of that council, which is being led by Dr. Dennis Gillings, the World Dementia Envoy appointed by British Prime Minister David Cameron.

Mr. Harry Johns reported on the Alzheimer's Association International Conference (AAIC), held in Copenhagen July 12-17, 2014. Seventy-five countries were represented at the meeting. A significant research finding presented at the conference was that a 2-year clinical trial showed that lifestyle changes, including nutrition, physical exercise, cardiovascular management, and social engagement improved cognition in at-risk older adults.

Overview of Caregiving-Related Goals in the National Plan

Dr. Jane Tilly summarized the caregiving-related activities within each goal of the National Plan:

- Goal 1. Prevent and Effectively Treat Alzheimer's Disease by 2025
 - The NIH Alzheimer's Disease Education and Referral Center provides information for caregivers.
 - AHRQ is reviewing the effectiveness of strategies to manage agitated and aggressive behaviors, thereby improving the quality of life of dementia patients and their caregivers.
 - All of the work to search for a cure or treatment to slow the disease affects the family of those living with AD.

- Goal 2. Enhance Care Quality and Efficiency
 - HRSA and ACL are training paid and unpaid caregivers.
 - The Department of Health and Human Services (HHS) is creating a practice recommendations clearinghouse that includes practices related to unpaid caregivers.
 - CDC's Healthy Brain Initiative has a focus on unpaid care partners.
 - ACL is using grants to promote dementia-capable home and community-based services (HCBS) that incorporate services for unpaid caregivers.
 - ACL is making information about unpaid caregiver assessment and supports available to the National Aging Network of the Administration on Aging (AoA).
 - IHS is providing information to Indian Country about unpaid caregiving.
 - HHS is working with the National Quality Forum (NQF) on measures of quality services for unpaid caregivers.

- Goal 3. Expand Supports for People with Alzheimer's Disease and Their Families
 - HHS is reviewing materials for unpaid caregivers related to cultural sensitivity.
 - Health information technology is being used to promote aging in place and to address needs of unpaid caregivers.
 - ASPE is identifying unmet service needs through the National Health and Aging Trends Study (NHATS), an annual study of Medicare recipients.
 - ACL worked with private partners to produce a white paper on interventions for unpaid caregivers.
 - ACL is promoting dementia-capable HCBS and specialized services.
 - ACL operates the National Alzheimer's Call Center to provide information, advice, and support to people with dementia or their caregivers.

- Goal 4. Enhance Public Awareness and Engagement
 - The AD awareness campaign has received expanded funding this fiscal year.
 - Numerous websites providing information, such as alzheimers.gov and eldercare.gov, are maintained. The latter website facilitates finding local caregivers.
 - Several webinars on unpaid caregiver issues have been presented by various health agencies.

- Goal 5. Improve Data to Track Progress
 - ASPE and the National Center for Health Statistics are creating a dementia chartbook of data, such as demographics, comorbid conditions, levels of disability, and utilization of long-term services and supports (LTSS); the chartbook will include data on unpaid caregivers.

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

- Despite the many strategies related to caregivers throughout the National Plan, lack of access to health service and lack of awareness persist. Perhaps the 2015 National Plan should be restructured to consolidate family-related issues into one section.
- It is difficult to determine how to provide supports for the wide range of types of caregivers. The Advisory Council should devise a way to measure progress.
- Healthy People 2020 addresses the health of caregivers in general, but it may not be possible to separate out dementia caregivers specifically.
- The actual number of dementia caregivers is not clear. An estimate of 15 million has been projected for several years. An accurate estimate is difficult because counting a dementia caregiver depends on having a diagnosis of dementia for the person being cared for. One of the difficulties with counting the number of individuals diagnosed with dementia is that the dementia diagnosis is not primary but is secondary to other medical conditions.
- Regarding caregiver programs, while there have been education programs, promotion, and reports, little has been done to improve services that actually help caregivers. The council should champion at least one service or one model that delivers services to caregivers at the local level.
- Education for caregivers does in fact help people, but it is true that a model for service delivery is needed. Using a Center for Medicare and Medicaid Innovation (CMMI) grant, the University of California at San Francisco is developing a model that uses technology to reach out to caregivers. That is an exciting new area that can address the needs of caregivers.
- We need to agree on a single term for caregiver and use it consistently; other terms in use are care partners and carers.

Overview of ACL's Family Caregiver Support Programs

Mr. Greg Link, aging services program specialist, summarized ACL programs for family caregivers.

- ACL was created in 2012 to combine three HHS offices: AoA, the Office on Disability, and the Administration on Intellectual and Developmental Disabilities.

- AoA's National Aging Network is the lead agency for services, providing services to one in five seniors.
- ACL's National Family Caregiver Support Program (NFCSP) provides information, access assistance, counseling, support groups, training, respite services, and supplemental services, which can be whatever a caregiver needs, such as transportation, durable equipment, or medical supplies.
- A 2012 national survey found that 90% of caregivers felt NFCSP services made them better caregivers, 81% rated NFCSP services as "excellent" or "very good," and 77% were able to provide care longer because of NFCSP services.
- ACL's Alzheimer's Disease Supportive Services Program (ADSSP) gives grants to states to expand the availability of community-level supportive services for persons with dementia and for their caregivers.
- ACL's Lifespan Respite Care Program provides grants to states to resolve challenges and barriers associated with respite services.
- The ACL's caregiver support programs, including ADSSP, NFCSP, and the Lifespan Respite Care Program, currently support 45 grants in 18 states.
- The following are plans for improving family caregiver support:
 - Increase the focus on complex care and medical tasks, including accommodations and training.
 - Help caregivers develop natural and peer supports.
 - Increase use of evidence-based approaches.
 - Assess caregiver needs to target limited resources effectively.
 - Use technology to reduce caregiver burden and stress.

Discussion following Mr. Link's presentation included the following comments and clarifications:

- The 2012 survey was a phone survey of 1,600-1,700 caregivers who were randomly selected from the nearly 1 million caregivers served through Area Agencies on Aging; survey questions are posted on the ACL website.
- ACL has an outreach program to help families learn about available programs and services.
- To determine if caregivers were caring for someone with dementia, the survey asked whether a doctor had stated that the person being cared for has dementia; using this approach, the 2012 survey showed that 60–65% of caregivers are caring for someone with dementia. This survey approach is problematic because dementia is underdiagnosed.

- Individual Area Agencies on Aging have the latitude to scale programs according to needs. The grants specify that the most frail populations, such as rural and minority populations, be targeted. ACL has been pleased with ways the programs have approached this requirement, developing innovative models, such as the use of culturally competent outreach materials.

National Study of Caregiving

Dr. Brenda C. Spillman, a senior fellow at the Urban Institute, presented the findings from the National Study of Caregiving (NSOC), conducted as a supplement to NHATS.

- NSOC collected data by interviewing up to five informal caregivers to NHATS recipients living outside nursing homes who reported receiving help with mobility or self care.
- NHATS respondents were designated as having no dementia, possible dementia, or probable dementia, on the basis of a physician report, a score on a screening instrument, or results from cognitive tests.
- NSOC found that of 17,949 caregivers surveyed, dementia caregivers provide a disproportionate share of monthly care hours.
- Dementia caregivers are less likely to be spouses and more likely to be daughters than are caregivers of those with no dementia.
- Dementia caregivers are more than twice as likely to report substantial negative aspects of caregiving than are those caring for individuals with no dementia.
- Dementia caregivers are more than twice as likely to have used outside supports such as respite, financial help, training, or participating in a support group.

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

- To determine positive and negative aspects of caregiving, the survey solicited caregivers' feelings about feeling more confident about their abilities, feeling exhausted at the end of the day, having more to do than feasible, not having time for oneself, not being able to establish an ongoing routine because the recipient's needs change, learning to deal with difficult situations, becoming closer to the care recipient, and feeling satisfaction that the recipient is well cared for.
- The survey found that 90% of caregivers feel they are getting something out of caregiving.

- The survey did not correlate caregivers' reported well-being with reported positive and negative aspects of caregiving.
- There was a strong linear relationship between hours of care and a decreased sense of well-being.

Updates from the Second Dementia Thought Leaders Summit

Ms. Karen Love of the Dementia Action Alliance reported on the Dementia Thought Leaders Summit, held June 30, 2014.

- The Dementia Action Alliance comprises the organizations CCAL--Advancing Person-Centered Living (CCAL), Planetree, the Eden Alternative, and AMDA: The Society for Post-Acute and Long-Term Care Medicine.
- Seventy-two stakeholders were invited to participate in the 2014 Thought Leaders Summit, which had the objective of forming a consensus on what is needed to improve dementia care in the United States.
- The summit had three parts: an online discussion before the meeting, the summit itself, and the convening of a small group to synthesize the summit.
- Participants agreed on two preferred terms: "dementia, including Alzheimer's" rather than "Alzheimer's disease"; and a "person living with dementia" rather than "patient."
- The group adopted the following definition of person-centered care: "Person-centered dementia care is based on the fundamental premise that every individual has a unique background, human experience, and the right to determine how to live his or her own life. Person-centered dementia care is relationship-based and focused on supporting the individual's emotional, social, physical, and spiritual well-being (e.g., belonging, experiencing a continuation of self and normality, purpose, meaning, enjoyment, comfort, and opportunities for growth)."
- The summit developed five major strategies to achieve the agreed-on goal to "live fully with dementia":
 - Mobilize an infrastructure to address objectives using workgroups.
 - Address resources and capacity building.
 - Address awareness and education.
 - Address optimizing health and well-being.
 - Address accessing and utilizing resources and services.

- The following are examples of short-term objectives of workgroups appointed:
 - Develop consistent standards and expectations for dementia services and supports across all settings.
 - Create a consensus on an education curriculum that is optimal for each stakeholder group.

- The following mid-term objectives emanated from the summit:
 - Include dementia as a priority for the White House Conference on Aging.
 - Establish criteria for person- and family-centered assessments, resources, and settings that meet individual needs and choices.
 - Ensure development of national initiatives that coordinate the implementation of person-centered planning for everyone.
 - Ensure that person-centered care is the standard of care.

- The following long-term objectives emanated from the summit:
 - A national policy that fosters system change.
 - A system to ensure dementia-capable care by all those providing services and support.
 - A system to ensure care coordination and management.
 - A system to incentivize, empower, and retain a quality workforce needed for dementia care.
 - Practice models that offer best solutions.
 - A system to ensure that people are obtaining and using the resources they need in a timely manner.
 - A system to ensure that people are integrated and included in the community as fully as they want to be.

- *Person-Centered Matters*, a public-service videocast, is available at the following link, using the password ARDRAF:
<http://vimeo.com/pasternakmedia/personcenteredmatters>.

Discussion following Ms. Love's presentation included the following comments and clarifications:

- Summit participants recognized that the term "dementia" is pejorative in some other countries but agreed that a common term is essential and that, in the United States, "dementia" is the best term.
- Given that the National Alzheimer's Project Act (NAPA) already has a national policy that fosters change, to meet the summit's objective to have a national policy, the biggest change suggested is that NAPA work with a wider variety of stakeholders.

Panel on Caregiver Experiences

Ms. Carol O'Shaughnessy, former principal policy analyst at George Washington University's National Health Policy Forum, moderated a panel comprising Advisory Council member Mr. Dennis Moore, his wife Ms. Stephene Moore, Advisory Council member Mr. David Hyde Pierce, and Advisory Council member Ms. Geraldine Woolfolk. The panelists described their experiences in dealing with AD in their family. The following were points made about the effect of AD on the family.

- The emotional aspects of living with the disease are the hardest to deal with.
- The health toll on the caregiver is tremendous, but caregivers often neglect their own health care and well-being.
- A caregiver, such as a spouse, may conceal the situation from the rest of the family.
- Caregivers typically provide care as long they possibly can before turning to institutional placement for the person with dementia.
- It is healthier for a family member to continue working and pay for household and caregiver help than to quit his or her job and become a caregiver full time.
- Building a support system within the community is extremely useful and can reduce caregiver stress. For example, families should be open with the neighbors, the church or temple, the bank, and the grocery store staff about the diagnosis and should provide them with information about the disease and appropriate ways to interact with the person living with dementia.
- Building a sense of community is also very important after a person with dementia is placed in an institution for care, so that the staff and family work together in making all decisions.
- Rather than bemoaning the situation and saying "why us," having the perspective "why not us?" can have a positive influence in the family of someone with dementia.
- Relying on the "three Fs" of faith, family, and friends is helpful.
- The National Plan should aim at empowering caregivers rather than characterizing them as needing help and being victims of the disease.
- Physicians need to know that family members are part of the team and that their role is critical to the success of the caregiving team.

- Although physician guidelines note that physicians should ask the patient what he or she wants, often the person with dementia does not have the judgment to make good decisions.
- The Advisory Council should ensure that the language of the plan is not so tight that it does not allow for flexibility.
- It is important for the Advisory Council to keep the caregivers at the table.
- The challenges for caregivers are completely different at age 45, age 60, or age 85. In addition, the needs and challenges of a spouse of a person with dementia are different from those of another family member with caregiver responsibilities.
- When the diagnosis is first determined at the doctor's office, a family member should be given information about dementia and how to deal with it; too often families do not have a clue as to what to do.

Public Input

Rohini Khillan moderated the public comments portion of the meeting.

Seventeen 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, and representatives from the Alliance for Aging Research, the Alzheimer's Foundation of America (AFA), the Association for Frontotemporal Dementia, the Broyles Foundation Caregivers United, Connected Health Resources, the Hartford Change AGENTS Initiative Dementia Caregiving Network, Leaders Engaged on Alzheimer's Disease, the National Alliance for Caregiving (NAC), the National Association of Professional Geriatric Care Managers, the National Certification Board for Alzheimer's Care, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), and the University of Buffalo's Institute for Person-Centered Care.

Speakers made the following recommendations and observations:

- Dementia caregiving is physically and mentally exhausting. More than 90% of caregivers do not know how to do it. This situation is the same as it was 14 years ago. The system is broken, and we must address this together.
- Despite the heavy mental, physical, and financial demands of caregiving, it is not considered a job, and caregivers are not eligible for employment benefits.
- The number of family members available to be caregivers is decreasing. Certified nursing assistants need to be supported with training and decent wages.

- Language is important, and the term “dementia including Alzheimer’s” should be adopted to include all types of dementia. The term “patient” should not be used. “Care partner” or perhaps “supporter” is better than “caregiver.”
- Although NAPA has been in existence for about 3 years, a recent survey showed that 59% of people think that memory loss is part of aging. This finding shows that NAPA has failed in educating the public.
- The approach to dementia is a discrimination issue, and we should have been noting that it is a civil rights issue. People with dementia should have all the rights that others have, such as driving and controlling finances. The \$100 million of funding allocated by Congress this year is far below what is needed. Someone needs to have the courage to stand up and tell Congress what needs to be done. The President is asking for nearly \$4 billion to deal with the immigration problem. Why doesn’t someone stand up for our rights?
- Changing lifestyle behavior, as mentioned at the AAIC, will not prevent AD; we need to find a cure. What has been done is not working, and we need to stop doing it and redistribute funding.
- The number of dementia caregivers is underreported. In addition to the underreporting due to lack of a dementia diagnosis, caregiving involves the entire family, and often teenagers and children are involved but not counted.
- While hours spent in care can be reported, emotional stress cannot be documented, and such stress is present even when the caregiver is away from the caregiving situation.
- Because there are 250,000 caregivers under age 18, perhaps the laws about eligibility for NFCSP services should be changed. Parents and teachers typically do not educate children and teenagers about dementia and ways that they can best provide help.
- One-third of caregivers of someone with dementia are also caring for their own children. Parents do not know how to talk to their children about what is going on.
- A character in a television drama recently stated that nothing can be done for people with Alzheimer’s, and they will just end up in diapers. The majority of people in the United States have similar misconceptions and also do not know the early identifying signs of AD.
- Unit managers in the Mid-Atlantic Region of the National Association of Professional Geriatric Care Managers reported that 70%-90% of their caseload are dementia patients. The cost of caregiving, whether paid or unpaid, is huge. Because a cure is nowhere close, we need to focus on funding for care.

Everyone at this meeting needs to network with everyone they know about the best practices for caring for people with dementia and Alzheimer's.

- NAC and AFA have jointly issued a white paper titled *From Plan to Practice-- Implementing NAPA in Your State*. The paper makes recommendations for both new and existing state Alzheimer's plans. The paper describes best practices in implementation and includes case studies from three states (Indiana, Minnesota, and Rhode Island) that have successfully implemented plans. The white paper is available at <http://www.caregiving.org/advocacy/napaplan>.
- In May 2014, representatives from eight countries formed the International Alliance of Carer Organizations. Except for the United States, all of the English-speaking countries in this alliance use the term "carer" rather than "caregiver." NAC recommends adopting use of the term "carer" rather than "caregiver."
- A description about the White House Conference on Aging was distributed to the council. The conference is held every 10 years and will take place in 2015. The council is encouraged to support the inclusion of dementia as a topic in this conference.
- The Social Security Caregiver Credit Act of 2014 (HR 5024) was introduced in the House of Representatives in July 2014 by Rep. Nita Lowey. The bill is a tool to help family caregivers obtain Social Security credit for the months in which they provide caregiving services.
- In an attempt to remedy misallocations between Medicare Part D payments and Medicare hospice coverage of prescription drugs for hospice patients, guidance was issued in March 2014 that required all hospice patients' medications billed to Part D to be rejected for payment. An unintentional result of this guidance was that hospice patients were caught in the middle of payer disputes. New guidance was issued in July 2014 that is very helpful for people in hospice. This guidance is only temporary, and the Advisory Council and others are urged to support its adoption.
- A proposed change to the Medicare physician fee schedule provides for separate payments for non-face-to-face services for chronic-care patients. An example of such services would be developing a plan of care. This is a very positive and needed change.
- Topics suggested for future Advisory Council meetings are clinical trial recruitment and issues related to detection.
- CCAL and the University of Buffalo's Institute for Person-Centered Care conducted a national online survey about what people with personal or professional experience with dementia view as priorities. Results showed that

caregiver support and long-term-care needs tied for first priority. These results are consistent with the findings of the RAND Corporation report *Improving Dementia Long-Term Care: A Policy Blueprint*.

- Families dealing with frontotemporal dementia have the same costs for care as those dealing with AD, but frontotemporal dementia affects people at an early age, so, in addition, the patient loses prime income-earning years.
- Increased public education and awareness about dementia is critical because no one is prepared for the learning curve needed, and people are not aware that the first sign is paranoia.
- Education and training, even for professionals, is almost nonexistent and is inconsistent where it does exist. As illustrations of education needed by professionals, a patient with dementia had to wait 2 hours in the doctor's office before being seen for an appointment, and a dentist planned his visits to a nursing home at 5:30 in the afternoon, apparently unaware of sundowner's syndrome.
- Community partnerships are effective in awareness programs. For example, elementary school children participated in a program to help make people aware of dementia.
- Dementia education should be mandatory for certified nursing assistants and others working in community hospitals and nursing homes.
- A system to facilitate anonymous complaints from both families and staff at nursing homes and hospitals must be ensured.
- Caregiving should be a separate focus in the National Plan rather than being interspersed throughout.
- Often parents who have cared for a child with intellectual disabilities develop dementia in later years and then rely in part on help from that person. The National Plan should consider the caregiver's life span, should consider working with private or federal agencies to develop community caregiving, and should address a special program for families caring for those with intellectual disabilities.
- ACL and other agencies should consider collaborating with the National Down Syndrome Society and NTG to develop guidelines for families about aging. The complexity of care demands that guidance be provided for families of individuals with Down syndrome.

- Funding to address dementia must be increased, especially given the aging of the Baby Boomer population.
- The caregiving goals in the National Plan do not go far enough. They are not bringing needed services to the caregivers' door. The Area Agencies on Aging are underfunded and overwhelmed. Families need people they can call and up-to-date processes supported by technology. There is not an adequate infrastructure to care for the aging population. An example is the lack of adequate training requirements. The Advisory Council needs to take on these types of issues.
- Hartford Change AGENTS Initiative Dementia Caregiving Network is working to improve services, supports, and care for persons with dementia and their family caregivers. Two areas for immediate activity are the development and dissemination of a provider classification of available evidence-based programs and care practices and the creation and dissemination of practical tools for family members providing care for a person with dementia. Information is available at <http://www.changeagents365.org/change-agents-networks/dementia-caregiving>.

Comments from HHS Assistant Secretary for Planning and Evaluation

Assistant Secretary Dr. Richard Frank told the Advisory Council that he was very impressed with how far NAPA has come since its inception in 2012. He recognized Dr. Petersen for his leadership as council chair. He supports an evidence-based approach to policy and wants to develop data to inform policy. To that end, he is gratified to see the data produced by NHATS, which is an initiative for which he sought initial funding. Dr. Frank views AD and dementia as fundamental issues that are going to affect the well-being of our society in very basic ways, including having an effect on the economy and the ability to maintain our basic institutions, such as family. He stated that he is committed to keeping up the momentum of NAPA and will keep Secretary Burwell informed of NAPA activities.

RAND Corporation Blueprint for Improving Long-Term Dementia Care

- Dr. Regina Shih reported on RAND Corporation recommendations for policy changes and research included in its report *A Blueprint for Improving Long-Term Dementia Care*, available at http://www.rand.org/pubs/research_reports/RR597.html.
- RAND had previously completed a study showing that dementia is as costly as cancer or heart disease, and that 75-84% of dementia expenses are for LTSS, not medical care.

- Medicaid spending is 19 times higher for recipients with dementia than for those without dementia.
- The LTSS system is fragmented: Only half of dementias are diagnosed, dementia patients have many transitions across care settings, and coordination of care across settings is poor.
- The heavy reliance on family caregivers is unsustainable; the ratio of caregivers to seniors is expected to drop from 7:1 to 3:1 by 2050.
- To prepare the new report, RAND used 30 stakeholders from groups that represented patients, payers, researchers, policymakers, purchasers, producers, and providers to identify challenges and prioritize policy options for LTSS.
- The impact, equity, and feasibility of the 38 policy options that resulted were evaluated for their effect on areas such as access, quality, and cost.
- Using the results of this evaluation, RAND identified 25 high-impact policy options that were grouped into five objectives, listed below with the policy options that could be enacted in the short term.
 - Objective 1: Increase public awareness of dementia to reduce stigma and promote earlier detection.
 - Create specialized outreach and education programs about dementia signs and symptoms.
 - Encourage providers' use of cognitive assessment tools.
 - Objective 2: Improve access to and use of LTSS.
 - Broaden HCBS waiver programs, self-directed services, and states' infrastructures.
 - Integrate web- and other technology-based services.
 - Expand nurse delegation.
 - Objective 3: Promote person- and caregiver-centered care.
 - Standardize complementary assessment tools.
 - Identify a family caregiver for each person with dementia during emergency or acute care.
 - Disseminate best practices for training professional dementia care workers.
 - Objective 4: Support family caregivers.
 - Provide dementia-specific training and resources to family caregivers.
 - Offer tax incentives to employers to promote family caregiving.
 - Objective 5: Reduce cost burden.
- In addition to the 25 high-impact policy options, RAND identified four policy options that were not found in other reports or recommendations from other organizations:
 - Include HCBS in Medicaid plans.

- Establish teams across settings to reduce the duration of institutionalized care.
- Expand financial compensation programs to family caregivers.
- Link private long-term-care insurance to health insurance.
- The RAND Corporation plans the following activities as its next steps in this project:
 - Conduct more robust evaluations.
 - Build consensus about priority options.
 - Tailor approaches for vulnerable populations.
 - Establish metrics to evaluate progress.

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

- The different approach used by RAND is commendable and appreciated, and the challenge now is to move forward; the area of LTSS is "over-occupied," with different organizations and stakeholders forwarding different plans and priorities and having difficulty coalescing perspectives.
- Clinical services and LTSS are overlapping and in fact inseparable in dementia.
- Policy options on the short-term list were chosen because they were considered highly feasible. While tax incentives face challenges, they are more feasible than some other options, such as expanding the Family Medical Leave Act or providing more paid sick leave.
- Giving businesses tax incentives for options such as starting an adult day program is a new and creative idea.
- The report's appendix has details about all 38 policy options.
- The report did not analyze who would bear the cost of implementing these policies. It looked at the policies having costs that would accrue to the benefit of society as a whole.
- The report identifies the stakeholders that would be responsible for implementing the policies.
- The recommendation to establish centers of excellence does not specify whether the centers would be at the state, regional, or national level, or how they would be coordinated.

Ethics Subcommittee Update

Dr. Tia Powell summarized the work to date of the council's Ethics Subcommittee.

- The Ethics Subcommittee was created to identify and prioritize ethics implications of dementia and proposed health policies, specify the party appropriate to take the lead on specific issues, and indicate mechanisms, such as education or regulation, needed to address each issue.
- The effect of the Health Insurance Portability and Accountability Act (HIPAA) on persons with dementia and their families and providers is an example of an issue identified by the Ethics Subcommittee. The subcommittee is working on an educational initiative about HIPAA that includes a slide presentation that will be distributed more broadly to HRSA-funded geriatric education centers after the audio portion is completed. In addition, the subcommittee may write an article on the topic for the professional literature and may develop a list of frequently asked questions.
- The subcommittee has identified the following additional ethics topics:
 - Appropriateness of providers giving family members needed access to information. This issue includes determining appropriate access to web-based patient information portals and inclusion of the family in developing and implementing a care plan.
 - How to ethically use surrogate consent for research.
 - The potential benefits and harms of including research data in the patient's electronic medical record.
 - Balancing privacy protections with the benefits of using data in large-scale research.
 - Use of feeding tubes in severe dementia.

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

- Many ethics questions do not lend themselves to evidence-based study, so both consensus and evidence are used in addressing them. There are ways to apply evidence-based techniques to value-laden questions.

The HIPAA Privacy Rule and Alzheimer's and Related Dementias: A Resource List

Ms. Rachel Seeger of the HHS Office for Civil Rights gave an overview of a resource list being compiled to help providers and the public understand the role of HIPAA in cases of dementia. The draft resource list was distributed to council members to prepare input about what information will be most helpful to dementia care providers. Input will be

provided at the October Advisory Council meeting. Subsequently the resource list will be available on the Office for Civil Rights website and on the NAPA website.

- Although the Office for Civil Rights website is highly trafficked, it is difficult to navigate, so the resource list is intended to put the most popular resources in one place.
- Consumer resources include a video, a fact sheet, and brochures provided in eight languages; provider resources include frequently asked questions and guidance for when health care providers may communicate with the patient and family under the HIPAA privacy rule.

Discussion following Ms. Seeger's presentation included the following comments and clarifications:

- It would be helpful to require education about HIPAA privacy for professionals to be relicensed, similar to the 2012 relicensure requirements for education related to mental health. Those requirements were issued by an executive order signed by President Obama.

Subcommittee Updates

Dr. Richard Hodes reported on research activities.

- A number of research studies are focused on caregivers or will benefit them indirectly:
 - Resources for Enhancing Alzheimer's Caregiver Health (REACH) is an intervention to improve quality of life for caregivers and reduce the rate of institutional placement of care recipients. The study design was a randomized clinical trial at five sites.
 - The Daily Stress and Health study showed that adult day services had a positive correlation with reducing depressive symptoms in caregivers.
 - Lifestyle Interventions and Independence for Elders study showed that a moderate exercise program that was followed for an average of 2.6 years reduced by 18% the risk of major mobility disability in an older, vulnerable population, thereby making caregiving easier.
 - An award just announced this year will fund a 5-year randomized controlled trial on preventing injuries from falls.
- A new report, *65+ in the United States: 2010*, notes that increasing numbers of older Americans cannot afford to live in a nursing home, making HCBS more common; funding for HCBS increased from 13% to 43% of all Medicaid funding between 1990 and 2007.

- The February 2015 Alzheimer's Disease Research Summit is being planned. The draft agenda includes a report on progress in achieving the research milestones in the National Plan, plenary lectures featuring global updates, and sessions on new strategies for prevention and interdisciplinary research to understand the heterogeneity and multifactorial etiology of AD.
- Several NIH institutes and centers are collaborating on a 2-day workshop on small-vessel disease, September 18-19, 2014. This conference will inform research on vascular cognitive impairment/dementia, which is among research topics recommended at the 2013 Alzheimer's Disease and Related Dementias workshop.
- The International Alzheimer's Disease Research Portfolio (IADRP) database is gaining more international contributors. The most recent update will include 10 new partners, including the governments of Australia and Poland.
- The *2013-2014 Alzheimer's Disease Progress Report* is available at <http://www.nia.nih.gov/alzheimers/progress-report>.

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

- At the February research summit, the report on progress on the research milestones of the National Plan should include failures as well as successes.
- Scientists at the February research summit will provide information that will help update the National Plan and will also help integrate international research activities.
- Both NIH and the Alzheimer's Association promote the use of IADRP.
- The AAIC meeting in Copenhagen was important for science but was also extremely effective for facilitating collaboration among international agencies and funders of research.

Dr. Shari Ling, Dr. Joan Weiss, and Ms. D.E.B Potter reported on the activities of CMS, HRSA, and NQF.

- More than 37,300 health care providers have participated in the Medscape training *Case Challenges in Early Alzheimer's Disease*.

- HHS has funded a project for NQF to prioritize quality measure gaps. The project used a stakeholder consensus process to identify the following measures to be developed:
 - For the person with dementia, quality measures should address detection leading to evaluation, a documented diagnosis in a reasonable time, and the quality of hospitalization and transitions of care.
 - For family members and caregivers, quality measures should address assessment, communication, training, responsiveness to caregiver needs, and advocacy.
 - For both the person with dementia and his or her family and caregivers, quality measures should address shared decision making and a dementia-capable health care system and community.

- The draft report of all recommendations for quality measures will be issued August 22, 2014, and will be available at http://www.qualityforum.org/Prioritizing_Measure_Gaps_Alzheimers_Disease_and_Related_Dementias.aspx, followed by a public webinar August 27. The public comment period will end September 13, 2014.

- Two Health Care Innovations Awards (HCIA) projects include family caregiver aspects. A program at the University of California, Los Angeles, includes a structured needs assessment of caregivers, and a project at the University of Arkansas includes training of family caregivers.

- Six Round 1 (launched in 2012 and 2013) HCIA projects are directed at serving people with dementia. Two Round 2 HCIA projects, being announced in the summer of 2014, will target people living with dementia.

- The National Partnership to Improve Dementia Care is focused on ensuring that nursing home residents with dementia receive care that is person-centered, comprehensive, and interdisciplinary. Since the initiation of this program, the number of nursing home residents receiving an antipsychotic medication dropped from 24% in 2011 to 20% in 2014 (a 17% decrease). CMS has just set a new goal of reducing antipsychotic medication use by 25%.

Discussion related to CMS activities and the use of quality measures included the following comments and clarifications:

- Use of quality measures by CMS as a requirement for payment is in different stages of development. There is already authority to use quality as a requirement for payment in hospitals, but there are not specific quality measures for hospital care of patients with dementia.

- Quality measures for a physician reporting system would likely not be in place until 2017.

Dr. Jane Tilly provided an update on LTSS activities.

- The Brain Health Resource, developed jointly by ACL, NIA, and CDC, was made available online June 25, 2014, at http://www.acl.gov/Get_Help/BrainHealth/Index.aspx.
- NIA has released two online resources for long-distance caregivers: *Long-Distance Caregiving--Getting Started* (<http://www.nia.nih.gov/health/publication/long-distance-caregiving-getting-started>) and *Long-Distance Caregiving--A Family Affair* (<http://www.nia.nih.gov/health/publication/long-distance-caregiving-family-affair>).
- The CMS caregiver website addresses multiple planning and resource issues at <http://www.medicare.gov/campaigns/caregiver/caregiver.html>.
- The VA has a caregiver support website (<http://www.caregiver.va.gov>) as well as a caregiver support telephone line (1-855-260-3274). Additional VA resources for both family and professional caregivers include in-person classes, workbooks, online classes, and other telehealth modalities.
- AHRQ is sponsoring a 5-year demonstration study of remote sensor technology for persons with dementia. The study will assess the effect of the technology on the quality of life of caregivers, outcomes of persons with dementia, and use of health services.
- AHRQ issued a small research grant to study cultural and health system barriers and facilitators for Korean-American dementia caregivers who seek assistance.
- HRSA's New Jersey geriatric education center will expand and modify the dementia modules it developed for the national Aging and Disability Resource Center network.
- ADSSP is reviewing applications for grants to states for dementia capability. Awards will be announced around September 1, 2014.
- The Alzheimer's Disease Initiative: Specialized Supportive Services Project is accepting applications for grants designed to fill gaps in dementia-capable LTSS.
- Applications are being reviewed for the Evidence-Based Falls Prevention Program.

- ADSSP is offering three webinars:
 - *Elder Abuse and Neglect of Persons with Dementia--What We Know and Where We Are Going*
 - *Preferences for Care and Lifestyle as Expressed by Persons with Dementia*
 - *Strategies for Reaching Diverse Populations with Dementia*

Dr. Bruce Finke reported on pilot testing REACH-VA in Indian Country:

- REACH-VA was successfully piloted with public health nurses and community nurses in three tribal communities that represented different tribal cultures.
- REACH-VA training will be given to the Tribal Aging Network at the August 2014 AoA Title VI Training & Technical Assistance Conference. This will serve as a proof-of-concept study to test REACH-VA with Title VI directors.
- IHS is partnering with the University of Tennessee in proposing a grant to a private foundation to adapt and expand REACH-VA to 50 tribal communities.

Discussion of Implications for the National Plan

Dr. Linda Elam led a discussion about caregiver issues as addressed in the National Plan.

- We might consider use of the term caregivers rather than “families.” Use of the term “carers” should also be considered. Deliverables are not identified as much as they should be.
- Research on caregivers should specify detailed endpoints. The DoD is also interested in caregiver research.
- The plan should address how caregivers can protect their health and well-being.
- To identify gaps, it might be beneficial to consolidate all aspects of the National Plan dealing with caregivers and clarifying who is a caregiver. It is also important to encourage health care providers to ask who the caregiver is. In addition, the person who functions as the primary caregiver can shift, as multiple people may be involved, including members of the entire family or a respite person.
- Some council members do not care one way or another about whether the National Plan has a separate section on caregivers.
- We need to get to the point where services related to caregiving, such as having the health care provider talk to the caregiver, are reimbursable. Interventions that have been demonstrated to be effective should be taken to scale.

- We should look at what research needs to be done by CMMI or others. For example, the Alzheimer's Association has studied whether money can be saved while improving people's lives. It was found that while money savings worked in the microcosm, the net cost of programs increased because people became aware of more programs.
- As the council prepares to revise the 2014 National Plan, there should be sufficient time on the agenda for the full council to discuss the subcommittee reports and give guidance to the subcommittees for revision.
- Physicians are not reimbursed to talk with caregivers without the presence of the patient. Caregivers really want to have a plan to know what to do, but physicians' not being reimbursed for providing that service is a very big disincentive. Very few caregivers can afford a geriatric care manager.
- Expanding nurse delegation, as described in the RAND report, may be a good way to address the lack of physician reimbursement. The RAND report provides some good markers to consider for inclusion in the National Plan.
- The 2015 plan must take into account what we have heard from the public and emphasize urgency. The recommendations also need to be targeted to the state and local levels, not just the federal level.
- As technology makes home care more complex, we need to have a way to ensure quality of medical care at home.
- The 2015 National Plan could more directly involve governmental and private organizations at the state and local levels by engaging organizations such as the National Governor's Association and the National Council of State Legislatures. We need to identify champions at different levels. We could also bring teams together from different states.
- The NCOS is one index of how caregivers are doing. The survey should be repeated to provide a measure of changes, to see if interventions are working.
- Essential basic elements of measuring success are accurate identification of who are caregivers and how many there are.
- The report on the IOM's panel on advanced dementia should be delayed until after the panel's final meeting on policy in November 2014.
- The new group being convened to look at the progress of NAPA could report to the council at its October 2014 meeting to help provide direction for developing

the 2015 National Plan. Then the three standing council subcommittees could be charged to bring forward recommendations in January.

- At this time a decision has not been made about consolidating caregiving as a separate section of the National Plan. The LTSS subcommittee should discuss this issue on its next conference call and make a recommendation.

Concluding Remarks

The next Advisory Council meeting will take place on October 27, 2014.

The meeting adjourned at 4:20 p.m.

Minutes submitted by Rohini Khillan (ASPE).

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