

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

Washington, DC

July 19, 2013

## Advisory Council Members in Attendance

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

## General Proceedings

At 9:10 a.m., Chair Dr. Ronald Petersen called the meeting to order.

Dr. Peterson provided an overview of the agenda, which will include a summary of the current status of the National Plan to Address Alzheimer's Disease (national plan), information about several fields related to long-term care services, updates from the three Advisory Council subcommittees, and a discussion about how to plan for research in long-term services and supports (LTSS). Public comments will be received.

Mr. Johns reported that the Alzheimer's Association International Conference (AAIC), which concluded in Boston on July 18, 2013, had approximately 5,000 people in attendance. Researchers made presentations about excellent research being done across the spectrum of Alzheimer's disease. Approximately one-third of the research

presentations were from countries outside the United States. Media outlets were well-represented, so information is expected to be disseminated thoroughly to the public.

Mr. Vradenburg stated that British Prime Minister Cameron has made Alzheimer's disease and dementia a critical theme of the United Kingdom presidency of the G8 during 2013. A summit on Alzheimer's disease and dementia will be held in London, December 10-11, 2013, and will be attended by the health ministers of the G8 countries, along with representatives of the World Health Organization. For the first time, an agenda for a global response to Alzheimer's disease will be developed. The conference will address science, regulation, policy, caregiving and caregivers, social impact, finance, and investments. As a follow-up to the summit, four international workshops will take place in 2014 on the themes of finance and investment, caregiving, regulations and policy, and science.

Dr. Peterson introduced a new council member, Dr. Nicholas Kozauer, representing the FDA and noted that Ms. McMahon is retiring from the Iowa Department of Public Health.

Advisory Council members introduced themselves.

## **Update on National Plan to Address Alzheimer's Disease**

Dr. Lamont highlighted the progress made on the national plan:

- At the Alzheimer's Disease Research Summit 2012 (<http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention>), researchers developed recommendations on how best to advance research.
- New research projects funded include two major new clinical trials, research on genetics sequencing, and development of innovative new cellular models.
- Resources were provided to train more than 10,000 health care providers on topics ranging from dementia diagnosis to effective behavior management.
- The U.S. Department of Health and Human Services (HHS) launched the website <http://www.alzheimers.gov> to increase public awareness, provide resources for individuals with a diagnosis, and connect their caregivers with important resources.
- CMS and NIH identified a set of instruments that physicians can use to assess cognitive impairment.
- The Administration on Aging (AoA) and the National Institute on Aging (NIA) cosponsored webinars on clinical trial enrollment and supports and services,

providing information on resources to which researchers can refer families and patients.

- ACL partnered with the Alliance for Aging Research (AAR) and the MetLife Foundation to publish the report *Translating Innovation to Impact: Evidence-Based Interventions to Support People with Alzheimer's Disease and Their Caregivers at Home and in Their Communities*.
- HHS convened a Specific Populations Task Force that focused on the unique challenges faced by groups unequally burdened by Alzheimer's disease, including people with Down syndrome, racial and ethnic minorities, and people with early onset dementia. The task force report was released June 24, 2013.
- NIH held a meeting on Alzheimer's disease among people with Down syndrome in April 2013 and held a research summit on other dementias in May 2013.

Dr. Lamont summarized the national plan as it has been updated with 2013 recommendations made by the Advisory Council and gave examples of some of the strategic activities:

- Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025
  - Strategy 1A: Identify Research Priorities and Milestones
    - A research summit will be convened at 3-year intervals. The next Alzheimer's disease research summit is planned for February 9-10, 2015.
  - Strategy 1B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease
    - NIH has issued new funding opportunity announcements (FOAs).
  - Strategy 1E: Facilitate Translation of Findings Into Medical Practice and Public Health Programs
    - In February 2013, the FDA issued draft guidance about drugs for early Alzheimer's disease. Final guidance will be released by the end of the year.
    - The CDC is reviewing research on co-occurring conditions and dementias, an activity that relates to the Advisory Council's Recommendation 27--to improve chronic disease treatment and related services for people with Alzheimer's disease.
- Goal 2: Enhance Care Quality and Efficiency
  - Strategy 2A: Build a Workforce With the Skills to Provide High-Quality Care
    - On the basis of Recommendation 14, HHS will use geriatric centers to develop and disseminate a unified Alzheimer's disease curriculum for primary care.

- To ensure the aging network has research-based up-to-date information on Alzheimer’s disease, NIA and ACL cosponsored webinars.
  - To engage the public health workforce on brain health, in July 2013, the CDC, in partnership with the Alzheimer’s Association, released *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*.
  - Webinars for HRSA geriatrics program grantees have been developed to educate providers about programs for Alzheimer’s disease.
  - To address the recommendation to strengthen primary care teams in Indian country, training programs such as chief medical officer rounds and other programs for nurses and primary care providers are being enhanced to address dementia-awareness capabilities.
- Strategy 2C: Educate and Support People With Alzheimer’s Disease and Their Families Upon Diagnosis
    - Work is expanding with Alaskan Natives and American Indians, linking them to Alzheimer’s disease resources.
  - Strategy 2D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings
    - HHS is working with the National Quality Forum to develop a conceptual framework for measuring dementia care and identifying concepts for performance measures.
    - HHS is contracting with the Institute of Medicine (IOM) to convene a blue-ribbon panel of experts on advanced dementia.
  - Strategy 2E: Explore the Effectiveness of New Models of Care for People With Alzheimer’s Disease
    - The VA has created some innovative programs of patient-centered alternatives to institutional care that might be used as models.
  - Strategy 2F: Ensure That People With Alzheimer’s Disease Experience Safe and Effective Transitions Between Care Settings and Systems
    - HHS has a project in place to identify hospitalizations and emergency department use among people with Alzheimer’s disease, and the CDC has identified interventions that reduce avoidable hospitalizations.
  - Strategy 2G: Advance Coordinated and Integrated Health LTSS for Individuals Living With Alzheimer’s Disease
    - ASPE is evaluating evidence to determine the pros and cons of fully integrating clinical care and LTSS versus having them as separate systems that are coordinated but not integrated.

- Strategy 2H: Improve Care for Populations Disproportionately Affected by Alzheimer’s Disease and for Populations Facing Care Challenges
  - The Specific Populations Task Force has developed a report on populations disproportionately affected by Alzheimer’s disease that was published in June 2013.
- Goal 3: Expand Supports for People With Alzheimer’s Disease and Their Families
  - Strategy 3B: Enable Family Caregivers to Continue To Provide Care While Maintaining Their Own Health and Well-Being
    - ACL, CMS, and IHS are developing a webinar series to use with tribal providers.
    - The ACL National Aging Network and the VA are working together to educate one another about accessing services for family caregivers.
    - The IHS is piloting the REACH VA (Resources for Enhancing Alzheimer’s Caregiver Health in VA) program in Indian country.
  - Strategy 3C: Assist Families in Planning for Future Care Needs
    - ACL is implementing an awareness campaign using the website, <http://longtermcare.gov/>, and is building networks with other organizations to drive users to the site.
  - Strategy 3D: Maintain the Dignity, Safety, and Rights of People With Alzheimer’s Disease
    - The AoA is enhancing programs related to disseminating information on abuse of people with dementia and promoting dementia-capable legal service systems.
    - The Consumer Finance Protection Bureau (CFPB) has developed a guide for lay fiduciaries to provide information about managing the finances of people with Alzheimer’s disease.
  - Strategy 3E: Assess the Housing Needs of People With Alzheimer’s Disease
    - Information is being gathered to determine housing needs, and HHS is consulting with the U.S. Department of Housing and Urban Development to help ensure that housing is linked with services for people with dementia.
- Goal 4: Enhance Public Awareness and Engagement
  - Strategy 4A: Educate the Public About Alzheimer’s Disease
    - NIH and ACL routinely update their websites to provide more information for the public and ensure that the two websites are consistent and coordinated.

- Strategy 4B: Work With State, Tribal, and Local Governments To Improve Coordination and Identify Model Initiatives To Advance Alzheimer’s Disease Awareness and Readiness Across the Government
  - The AoA/ALC Alzheimer’s Disease Supportive Services Program (ADSSP) is developing practical tools to improve dementia capability of local and state agencies.
  - The AHRQ Dementia Capability Toolkit is being expanded.
- Goal 5: Improve Data To Track Progress
  - Strategy 5A: Enhance the Federal Government’s Ability To Track Progress
    - The CDC is analyzing data on cognitive impairment collected by the Behavioral Risk Factor Surveillance System in 32 states between 2009 and 2013. Such data may be used to make the case for incorporating cognition into preventive health practices and risk-reduction activities.
    - The CDC is developing measures of awareness of Alzheimer’s disease.

The following comments and responses were made following Dr. Lamont’s presentation:

- Many activities and initiatives related to dementia are also relevant to the broader long-term care population. Dementia adds complexity to the care of someone who may already have long-term care needs.
- Other topics that might be useful for the agenda of future meetings of the Advisory Council are the ADSSP; the innovative research projects at UCLA and Indiana; and data from CMS on conditions co-occurring with Alzheimer’s disease, state-level per-capita costs, and hospital readmission rates for people with Alzheimer’s disease.
- It is encouraging that government programs are getting outside their silos, as exemplified by the REACH VA program being used in Indian country.
- Incorporating the REACH VA program into the private sector and into Medicare would be a good idea.
- Information and data about the current state of LTSS are needed in order to direct resources appropriately. For example, without knowing what information is needed, it is hard to determine whether to prioritize resources toward tracking progress, funding research, or providing care.
- New data are available from CMS on the burden among Medicare beneficiaries of chronic conditions, including Alzheimer’s disease. State and county-level data can be obtained from the database. CMS has also released new data on conditions co-occurring with Alzheimer’s disease, including the most common dyads and triads. The following include data on patterns of chronic conditions

and MCC among Medicare fee-for-service beneficiaries at the national, state, and county levels:

- The *CMS Chartbook: 2012* (<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/2012ChartBook.html>).
  - The *CMS State Reports* (<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CCStateReports.html>).
  - The *CMS County Reports* (<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/County-Reports.html>).
  - The *CMS Chronic Conditions Dashboard* (<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CCDashboard.html>).
- *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* outlines how state and local public health agencies and their partners can promote cognitive functioning and address cognitive impairment. Since its release earlier in the week, a number of organizations, such as the Association of State and Territorial Health Officials, are taking initiatives to disseminate it to state, county, and city health officers. Webinars based on the road map are also being planned by the National Association of Chronic Disease Directors.

## **Consumer Protections for Older Adults with Cognitive Impairment**

Ms. Naomi Karp, a policy analyst in CFPB's Office for Older Americans, described the mission of CFPB and gave an overview of the bureau's initiatives related to older Americans.

- With a mission to make markets for financial products and services work for American consumers, CFPB's core functions are to educate, enforce, and study. An interactive online tool (<http://www.consumerfinance.gov/askcfpb>) allows users to browse by topic or population type and obtain answers to questions about financial services or products. CFPB responds to consumer complaints and will work with a consumer to obtain a satisfactory response.
- The Office for Older Americans provides education and training in two broad areas for consumers aged 62 and older: (1) protection from abusive practices aimed at seniors, and (2) making sound financial decisions as they age.
- A series of guides has been developed and will be published in October 2013 to provide help and information for four types of lay fiduciaries: (1) agents under

powers of attorney, (2) guardians of property, (3) trustees, and (4) Social Security representative payees and VA fiduciaries.

- CFPB is developing fiduciary guides for six states with a high proportion of older residents: Virginia, Illinois, Oregon, Florida, Arizona, and Georgia. These state-specific guides give legal requirements for various fiduciary responsibilities.
- To raise awareness about scams and fraud, CFPB collaborated with the Federal Deposit Insurance Corporation to develop a train-the-trainer program: *Money Smart for Older Adults* ([http://files.consumerfinance.gov/f/201306\\_cfpb\\_msoa-participant-guide.pdf](http://files.consumerfinance.gov/f/201306_cfpb_msoa-participant-guide.pdf)).
- CFPB is disseminating guidance for professional staff at financial institutions to assist them in knowing when and how to report suspected financial exploitation to appropriate agencies and law enforcement.
- CFPB is producing a national guide targeted to staff and owners of long-term care facilities, to provide awareness and skills to identify and intervene in exploitation of residents.

The following comments and responses were made following Ms. Karp's presentation.

- The guidance and training provided by CFPB is not specifically targeted to individuals with cognitive impairment, but they would apply to that population. A lot of the information is targeted to service providers who are in a position to assist individuals with cognitive impairment. Materials are available at the eighth-grade level and in Spanish, to reach as wide an audience as possible.
- Older Americans are at risk for being the victim of fraudulent practices and financial exploitation, but not enough is known about why they are more susceptible than younger individuals and who among them are more susceptible. Two factors that contribute to their being targeted by con artists are that they have more wealth than other population segments, and they often live in isolation.
- Dr. Daniel Marson and his team at the University of Alabama-Birmingham have developed an interview instrument for cognitive screening for financial capacity. In addition, some research is using brain scans to identify parts of the brain that might be responsible for recognizing cues in facial expressions that could, for example, help someone judge whether what they are being told is genuine.
- Often health care providers are the main contact for those with cognitive impairment, so it would be helpful for them to have information and referral resources for financial planning. The Elder Investment Fraud and Financial Exploitation Prevention Program is a collaboration, among medical organizations,



adult protective services, and securities regulators, with the purpose of training physicians regarding ways to recognize signs of financial exploitation.

- Scammers and financial con artists often continually change their identities and the state in which they practice, so it has not been effective to notify banking institutions or credit card companies of malfeasance to prevent future use.
- The American Bar Association Commission on Law and Aging collaborated with ACL on a series of webinars that addressed the kinds of planning needed for individuals with cognitive impairment. It also worked with CFBP in producing its lay fiduciary guides.

## **Private Long-Term Care Insurance**

Dr. Marc A. Cohen, chief research and development officer of LifePlans, Inc., described the current state of the private long-term care insurance industry.

- The annual number of sales of individual long-term care policies has been declining since 2002. In the last decade, the number of companies selling such policies has declined from roughly 100 to 12. Most policies are sold through employer-sponsored programs.
- Long-term care insurance began as insurance covering nursing-home care, but now the policies reimburse the cost of care given in the home, in assisted living facilities, day-care facilities, and a variety of community-based settings, in addition to nursing homes. The standard trigger to begin benefits, as specified by the Health Insurance Portability and Accountability Act (HIPAA), is the inability to perform two or more activities of daily living without human assistance, or severe cognitive impairment as measured by standardized tests.
- The average monthly premium is \$189 for individual policies, which have an average policy-holder age of 59 years, and \$57 for group policies, which have an average policy-holder age of 46 years.
- Over the last 20 years, the trend has been for purchasers of policies to be younger and wealthier, and for more of them to be college educated and employed. The share of sales to the middle-income market is declining.
- Market surveys show a variety of reasons for buying a policy, such as maintaining lifestyle, protecting assets, avoiding dependence on family, and guaranteeing affordability.
- Some states have programs that support long-term care insurance; 45 states allow purchasers to access Medicaid without having to spend down their assets;

more than half of the states provide an income tax incentive, although the tax benefit is too small to make much of a difference in purchase decisions.

- Claims from policy holders with Alzheimer's disease are increasing in number and in cost; they are more than three times greater than those from the next leading cause--stroke.
- More claims are paid for individuals who receive care in the community or at home than for individuals in nursing homes, but the percentage of money paid in claims is higher for individuals in institutional settings.
- Proposed solutions for addressing demand and supply problems related to long-term care insurance include simplifying and standardizing products, indexing premiums, educating the public, expanding employers' role, mandating availability of long-term care insurance, providing a reinsurance pool, and marketing long-term care insurance jointly with health insurance.

The following comments and responses were made following Dr. Cohen's presentation.

- States have a strong motivation to provide incentives for the middle class to buy long-term care insurance so that they will not spend down their resources and start receiving Medicaid benefits. Approaches that states may take include public education campaigns, providing long-term care insurance programs for state employees, streamlining the state insurance commission approval process, offering income tax credits or deductions, and implementing a partnership program in which individuals with long-term care insurance have quicker access to Medicaid benefits than individuals without insurance.
- Long-term care insurance is more efficient than savings as a way to address long-term care costs. Most people need long-term care for a period of 2 years or less. Insurance companies now have actuarial data and information about lapsed policies so that they could set aside enough capital to again enter the long-term care insurance market, but they have other, more profitable options for how to use that capital.
- Because the biggest risk of loss for insurers in the long-term care insurance market is dementia and cognitive impairment, early detection of such a condition could eliminate that person as a policy purchaser. Studies have shown that when individuals believe they are at higher risk for cognitive impairment, they are seven times more likely to buy long-term care insurance. A larger pool of insured individuals would spread the risk of loss for an insurance company.
- Public policies that promote home care are in the best interest of both the industry, because home care is less expensive than institutionalized care, and the public, because people prefer home care.

- Education about planning for long-term care is very important. For example, a widely held public misperception is that Medicare will pay for long-term care.
- Medicare costs are three times higher for someone with Alzheimer's disease or dementia than for someone without Alzheimer's disease or dementia, and Medicaid costs are 19 times higher.

## Long-Term Care Awareness Campaign

Mr. Hunter McKay, a program manager for long-term care planning at ACL, described activities undertaken in relation to Strategy 3.C.2 of the national plan, Expand Long-Term Care Awareness Efforts.

- The target market for the long-term care awareness campaign is individuals 45-70 years of age. This group of individuals has proved to be very hard to reach because the majority of them are unwilling to envision themselves in a future state of needing long-term care.
- Although a survey showed that Alzheimer's disease is the number-one health fear for both preretirees and retirees, ACL found that fear was not a good motivator for individuals to be open to the message of long-term care needs and planning.
- In the first year of the awareness campaign, a theme of "stay in charge" was used, emphasizing that planning would help individuals be the one to make choices rather than someone else. The campaign managers learned that this message was way ahead of the audience's understanding of the need for long-term care planning. Because the audience rejected the initial concept that they would need long-term care, being asked to make planning decisions made them feel unprepared and fearful.
- After analyzing user data from the website, <http://longtermcare.gov/>, the website was redesigned to incorporate a "plan builder" aimed at assisting individuals in planning for long-term care. This approach did not work because the target market was not ready to make decisions needed to build a plan.
- Focus groups were unsuccessful in eliciting information about how people felt about long-term care planning, but ongoing analysis of website use showed that the links to age groups were popular. The awareness campaign managers realized that digital metrics that showed user behavior on the website was the best way of understanding the target market.
- Using an analysis of website use as a guide for reaching the audience, the online "plan builder" was changed to "path finder." The options were changed from making decisions to choosing items on a checklist. Links were added for

additional information in which people were interested, such as Medicare, costs of foster care in various states, and costs of home care from a variety of vendors.

- The results of media buys are analyzed to determine which advertisements users click on, and how the position of the advertisement on the web page affects behavior.
- Continuing the awareness campaign calls for developing networks with partners, so that other organizations' websites will incorporate links to <http://longtermcare.gov/>. In addition, ACL will carefully determine to what nuanced messages the audience is open.

The following comments and responses were made following Mr. McKay's presentation.

- It is not possible to determine if website users are looking for information for themselves or for someone else, such as a family member. A tool that might be added to the site to gain such information is a short survey, similar to one in use on the website <http://www.alzheimers.gov/>.
- In Indian county, long-term care is provided by the family, and tribal leaders might be wary of strategies that undermine the role of families in long-term care. Accordingly, the notion of caregiver burden is not acceptable among Native Americans, although they acknowledge that providing care is difficult. Because of these cultural traditions, an awareness campaign that implies that one should plan for care outside the family would not be accepted and might be considered offensive in this population. Given cultural differences in users, it is important to know who is using the site when determining how to shape the message.
- In focus groups, views regarding the potential burden on family members differ distinctly by sex. Men tend to find it acceptable and appropriate for their daughters to take care of them, for example, while women are more apt to consider such a role to be a burden on their daughters, in some cases because the women are already taking care of their own parent(s).
- Launching a social media component of the long-term care awareness campaign is desirable, but currently limited resources are maximized in other tactics. In addition, it is challenging to use language and concepts related to long-term care planning in social media outlets in which more colloquial language and ephemeral concepts are common.
- Driving traffic to a government website is difficult, so it would be beneficial to have the financial community (insurance and banking industries, for example) embrace long-term care planning and direct the target audience to <http://longtermcare.gov/> in a systematic way.

- The diversity of the preretirement target market of <http://longtermcare.gov/> makes it challenging to provide nuanced messages that appeal to, for example, a career woman raising two children as well as a 65-year-old wanting information about a reverse mortgage.

## Updates from Federal Subcommittee Chairs

Dr. Hodes reported on activities related to the Research Subcommittee.

- The conference, *Alzheimer's Disease-Related Dementias: Research Challenges and Opportunities*, was held May 1-2, 2013, on the NIH campus. Draft recommendations were developed and will be presented to the Advisory Council at its October meeting. The webcast of the meeting is archived at <https://meetings.ninds.nih.gov/index.cfm?event=location&ID=4077>.
- The Alzheimer's Disease Sequencing Project (ADSP), with the goal of facilitating identification of new pathways for therapeutic approaches and prevention, is going well. Whole genome sequencing will be done on samples from approximately 100 families with two or more members with Alzheimer's disease. Another component of ADSP is to conduct whole exome sequencing on 5,000 cases and 5,000 controls. These samples have also been taken. Data will be posted in increments as it is available, so that it can be used by all researchers immediately.
- Applications have been received for four FOAs issued for FY 2013:
  - Interdisciplinary approach to identification and validation of novel therapeutic targets for Alzheimer's disease (R01)
  - Alzheimer's disease therapeutics program (U01)
  - Alzheimer's disease prevention trials (R01)
  - Alzheimer's disease phase 1 clinical trials (R01)
- NIA and ACL have collaborated on a series of five webinars on resources available for persons with dementia and their caregivers. The webinar schedule and descriptions are available at <http://www.nia.nih.gov/newsroom/announcements/2013/05/2013-webinar-series-alzheimers-disease-and-resources>.
- Recruiting Older Adults into Research (ROAR) is one of Disease Prevention and 13 new programs awarded through HHSignite, which supports short-term interdepartmental programs. The goal of ROAR is to improve recruitment of older adults for clinical research, beginning with research on Alzheimer's disease.
- The National Institute of Neurological Disorders and Stroke held a workshop June 20-21, 2013, titled *Improving Neurology Subject (and Provider) Participation*

*in the Research Enterprise*. Workshop reports will suggest concrete action steps to enhance recruitment into clinical trials.

- The National Institute for Nursing has awarded two grants focusing on caregiver interventions for diverse and minority populations.
- NIA has launched a searchable database that contains detailed information about more than 100 published instruments for detecting Alzheimer's disease and other types of cognitive impairment. The database is available at <http://www.nia.nih.gov/research/cognitive-instrument>.
- NIA has created a blog for researchers, available at <http://www.nia.nih.gov/research/blog>.
- The next Alzheimer's disease research summit will be February 9-10, 2015. The first research summit was in May 2012, and a research summit is being organized by a large consortium in New York, NY for November 6-7, 2013. These dates represent approximately 18-month intervals for research conferences.

Discussion related to Dr. Hodes's report included the following comments.

- Although there have been failures of some large-scale clinical trials, progress is being made. There is hope that the failures may be the result of starting interventions too late. New investigations of amyloid treatment, for example, are now beginning at an earlier stage of development.
- Another reason that success in research has been limited is that past research has typically dealt with a heterogeneous clinical population. Now research can be stratified by biomarkers. Because the pharmaceutical industry may have concerns about such stratification due to it potentially limiting the market for a drug, public-private partnerships are important.
- Research is moving into investigating the relationship between disease and cognitive impairment. Lifestyle changes have their most critical period before age 62, and behavioral interventions that prevent cardiovascular disease and diabetes, for example, can affect cognitive impairment later in life. Studies targeting prevention of diabetes or cardiovascular disease now have cognitive impairment measurements built into them.
- If the existing rotation holds, it is likely that a research summit on Alzheimer's Disease-Related Dementias will take place in late 2016 or early 2017.

Dr. Ling reported on activities related to the Clinical Care Subcommittee.

- The national Medicare 30-day readmission rate has gradually declined, and over the last year it has declined below 18% for the first time in more than 6 years. Although this rate is for all Medicare admissions, not just for patients with dementia, patients with Alzheimer's disease represent a big proportion of hospital readmissions. CMS is beginning to analyze the data to determine the prevalence of dementia reflected in the downward trend of readmissions.
- CMS published a proposed rule in the 2014 physician fee schedule that allows separate coding for chronic care and complex care management.
- In the Quality Improvement Organizations' Patient and Family Engagement Campaign, which supports person-centeredness and family engagement, five projects related to dementia have received funding:
  - Assisting Caregivers with Dementia Care (California)
  - Improving Quality of Life for Beneficiaries with Dementia through Patient and Family Engagement
  - Online Resource Center: A Unique Approach to Engaging Medicare Beneficiaries with Dementia and Their Families in Their Care (Kentucky)
  - Partners for Dementia Care (Michigan)
  - Self-Management and Empowerment Program for Caregivers/Medicare Beneficiaries with Dementia/Alzheimer's Disease
- Letters of intent have been received for Round 2 of the Health Care Innovation Awards, which fund models likely to transform the health care system and deliver better outcomes.
- The ACL issued a FOA for recompetition of the nationwide 24/7 call center.
- IHS made a presentation at the Nurse Leadership in Indian Care Conference outlining a strategic approach to improving care for persons with Alzheimer's disease and related dementias.
- NIA and HRSA collaborated in a teleconference for the HRSA Geriatric Education Center network, providing information on collaboration opportunities using NIH Alzheimer's Disease and Education and Referral Center resources and providing examples of work that some of the grantees are doing.
- CMS has issued a proposed decision memorandum on funding for beta amyloid positron emission tomography (PET) in dementia and neurodegenerative disease. The deadline for comments is August 2, 2013, and the final rule will be published October 1. Comments including new evidence that can better inform the final decision would be helpful.

Discussion related to Dr. Ling's report included the following comments.

- The Alzheimer's Association is disappointed in the proposed CMS decision on PET imaging because it does not include capturing information needed for this very difficult diagnosis. A patient might have something treatable, and Alzheimer's disease could be ruled out with PET. Outcomes under the Coverage with Evidence Development (CED) program raise concern about whether CED has fulfilled its surface-level appeal.
- The statute calls for the Secretary of HHS to improve the diagnosis of Alzheimer's disease. Requiring that PET be covered only in CMS-approved clinical studies seems to be a constrained and very long-term process, rather than covering the use of the device in medical practice and thereby facilitating the accumulation of evidence.
- It is not the intent of CMS to stifle innovation. Other processes, such as parallel review with the FDA, are in place that can facilitate innovation.
- In the proposed decision, clarification about what is considered an outcome is needed, such as whether "time to an event" an outcome.
- It is not known if diagnostic tools other than PET scans, such as neuropsychological testing, have the same diagnostic benefit at a lower cost.
- A CED clinical trial might last 5-10 years, followed by a period of time for the results to be peer reviewed before publication. If new evidence arises in the field sooner than that time frame, it is reasonable that CMS would change its policy.
- Additional guidance is needed on the HIPAA patient confidentiality restrictions as they relate to patients with dementia, because talking with the family is often important but not authorized.
- Projects are in place to analyze how emergency department visits and observation stays contribute to readmission rates.

Dr. Tilly reported on activities related to the LTSS Subcommittee.

- ADSSP issued a FOA that will provide grants for up to six states to implement dementia-capable home and community-based services systems.
- ACL/AoA and the VA cosponsored two webinars: (1) *Partnering to Serve Veterans and Family Caregivers: Collaborative Opportunities with the Aging and Disability Services Network*, and (2) *Partnering to Serve Veterans and Family Caregivers: Collaborative Opportunities with the Caregiver and Geriatrics and Extended Care Programs*. The goal of the webinars was to promote cross-



program collaboration between the VA and the aging and disability services networks at state and local levels. Webinar attendance totaled about 600.

- Tip sheets for Alzheimer's caregivers are now available for mobile devices on topics ranging from managing behavior changes to disaster preparedness. Users can download the tip sheets to their mobile devices at <http://www.nia.nih.gov/alzheimers/topics/caregiving>.
- A webinar series jointly sponsored by IHS, CMS, and AoA/ACL featured presentations by a Standing Rock Sioux tribal program using targeted case management services to support aging and a presentation by the Gila River Indian Community on services for persons with dementia in their adult day program. These webinars and other periodic updates targeted to American Indians are available at <http://www.olderindians.aoa.gov>.
- IHS began its solicitation for pilot testing of REACH VA in Indian country.
- The National Indigenous Elder Justice Initiative is addressing the lack of culturally appropriate information and community education materials on elder abuse, neglect, and exploitation in Indian country.
- CMS has a national project in place to partner with nursing homes to reduce antipsychotic use in residents by 15%--using training, education, and guidance about quality of care and unnecessary drug use. In developing the guidance, research was conducted using case studies on how decisions were made to use or not use antipsychotic medications. Since the start of the partnership in early 2012, antipsychotic drug use has declined in every Medicare region. Over the 2-year period ending with the first quarter of 2013, the national rate of use declined from 23.50% to 21.71%.

The following comment was made following Dr. Tilly's report.

- Significantly more money is needed for activities related to LTSS and clinical care in order to made changes sufficient to have a population-based impact.

## **Research Agenda for Long-Term Services and Supports**

Dr. Lamont reported that a group of staff from a number of federal agencies had met to develop a draft research agenda for discussion by the Advisory Council. The group agreed to use the following three principles in developing the research plan: (1) use the perspective of people with Alzheimer's disease and their caregivers to identify where they experience gaps in care and support, (2) identify existing research that might be ready for translation, and (3) focus on areas of care and supports specifically relevant for people with Alzheimer's disease and their caregivers.

Dr. Lamont presented a draft research plan that includes four steps.

- Step 1. Describe the experience of care and supports received by people with Alzheimer's disease and their caregivers.
  - Quantitative information will be compiled from national surveys and published research. Qualitative data will be gathered from a variety of stakeholders, asking questions addressing issues such as gaps in care experience, awareness of care and supports, appropriate communications, unique needs of people with Alzheimer's disease, and priorities.
  - Federal staff, partners, and representatives of the research community will synthesize the information gathered to prepare a report that includes a list of gaps in care and support.
- Step 2: Synthesize evidence on gap areas.
  - The evidence gathered will be synthesized and will include international comparisons and an examination of practices and policies in different delivery systems within the United States, such as those of the VA and managed care plans.
  - The synthesized evidence will be categorized into research results that are ready for translation and research results that might be ready for translation but face obstacles to implementation. Information needed will be identified.
- Step 3: Set criteria and principles of prioritization.
  - Stakeholders will convene to identify principles to be used in prioritization. For example, such principles might require that research have clearly defined outcomes or well-described patient populations that include comorbidities or disease severity indicators. Priorities might call for research that informs the management of patients with dementia, provides means to improve outcomes, or is able to be used to inform decision-making by patients and their families.
- Step 4: Prioritize and create a research agenda.
  - Applying the criteria established in Step 3, federal staff, partners, and researchers will develop a research agenda that identifies: (1) areas where research is needed, (2) research needed to find ways to overcome barriers to implementation, and (3) areas where existing research results could be implemented or used to make policy changes.

Discussion related to the draft research agenda included the following comments.

- After comments are used to revise this draft document, a research plan will be developed that includes responsible party, implementation strategies, and a timeline. Funding of a research agenda is challenging because the Federal Government is in a budget sequester.

- The patient-centered approach described in Step 1 is admirable, but may yield information that is generalizable to all people with chronic conditions rather than just those with Alzheimer's disease and dementia. However, limiting Step 1 to be applicable only to those with Alzheimer's disease might be easier but could have other limitations.
- When the Research Subcommittee created its research agenda, it started with the goal for 2025 and stepped backward. That might be a good approach here.
- Starting at the endpoint to state what care should look like might be a good approach.
- Stating improvement goals might be a good approach also, forcing us to say what elements are important and how to measure them. Examples of such goals are to improve the rate of diagnosis by X% over 10 years, improve the quality of care by X% in 5 years, and improve the availability and choice of service delivery. The cost of services, both to the individual and to the system, is another area in which improvement goals could be set. Improvement goals set initially could be adjusted over time as research shows what changes are most effective in affecting a goal, such as diagnosis rates.
- It is important to focus on identifying research areas and priorities along with the metrics for measurement. We do not want to be so goal-oriented that we miss the opportunity to develop new knowledge that will advance toward a different but equally important goal.
- The IOM panel of experts that is being convened can be asked to define outcomes and identify what the field does not know that will help focus advanced dementia research.
- A number of organizations can be helpful to this process, such as the Family Caregivers Association and provider organizations. Working on a research agenda in LTSS is challenging because of the complexity of the entities involved, including for-profit and not-for-profit organizations, and the reimbursement system. An issue to consider is over what the national plan has control.
- Dr. Hoffman, the chair of the LTSS Subcommittee, and Dr. Coleman, the chair of the Clinical Care Subcommittee will continue to work with Dr. Lamont and the staff to refine the research agenda. The next iteration of the research agenda for clinical care and LTSS will be discussed at the October Advisory Council meeting.

## **Advisory Council Operational Issues**

- The initial 2-year terms of the following six Council members end September 30, 2013: Dr. Matheny, Mr. Johns, Ms. Trejo, Ms. McMahon, Ms. Woolfolk, and Dr. Petersen. These individuals may be nominated by themselves or by others for a second term. New terms beginning in October will be for 4 years.
- A call for nominations will be issued in the coming week for nominations in six statutory categories. New council members will be announced around the beginning of October.
- Within the next few weeks, HHS will announce who will fill the two previously open positions for the Advisory Council, specifically for a representative from a voluntary health association and an individual with Alzheimer's disease or a related dementia.
- The process for developing recommendations for the 2014 revision of the national plan will begin with substantive discussion at the October meeting. The subcommittees will need to meet before then to submit discussion drafts. The council will then vote on the recommendations at its January 2014 meeting.
- The overall size of the recommendations should be reduced to make it more manageable. Some of the recommendations can be combined and elements that that have been completed can be dropped.
- Mr. Vradenburg reported that the Long-Term Care Commission has had an aggressive schedule to approve language for recommendations to Congress by September 12, 2013. He will give the Advisory Council a summary of the commission's work at the council's October meeting.

## **Public Input**

The format for public input at the Advisory Council meeting is being reassessed. At future meetings it will be changed to allow individuals more time to speak. To accommodate this, the total number of speakers at each meeting will be limited. A rotation system of some sort will be devised so that everyone wishing to address the council will have an opportunity at different meetings.

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

Nine members of the public presented testimony either in person or by e-mail. They included persons living in the early stages of Alzheimer's disease and related dementias, family members and caregivers of persons with cognitive disabilities, and representatives from the AAR, the Alzheimer's Association, the Alzheimer's Foundation

of America, the Association for Frontotemporal Degeneration (AFTD), Leaders Engaged in Alzheimer's Disease (LEAD), and the National Task Group on Intellectual Disabilities and Dementia Practices (NTG).

Speakers made the following recommendations and observations.

- When someone receives a diagnosis of Alzheimer's disease or a related dementia, communication and information about resources or what to do are often inadequate.
- The addition to the Advisory Council membership of someone with Alzheimer's disease or other dementia is a valuable and positive step. Individuals living with early-stage dementia still have a lot to contribute to society, and having representation on the Advisory Council will help reduce the stigma of dementia.
- AAIC, just completed in Boston, was very successful. The international exchange was especially noteworthy. Approximately one-third of the scientific presentations were from researchers outside the United States, and 32 funders from 12 countries met to talk about leveraging resources.
- The Alzheimer's Association and LEAD find that the individuals who can benefit from PET imaging are a limited but critical population who face an ambiguous diagnosis, and CMS should approve such imaging for coverage.
- Medicare coverage of PET scans to diagnose Alzheimer's disease is important. Individuals seeking a diagnosis sometimes spend a great deal of money and time having other tests, such as neuropsychological testing. Obtaining the correct diagnosis of Alzheimer's disease or a related dementia sometimes takes years. In addition, taking drugs intended for Alzheimer's disease can harm some people with frontotemporal degeneration (FTD).
- Members of the Advisory Council or others who are in a position to increase funding for research and support services are urged to do more, as funding for the disease is even less today than in earlier years.
- Public awareness and education about Alzheimer's disease is the biggest problem currently. The public should know that it is a disease, and one that affects all ages; it is not associated just with aging.
- State laws should be enacted so that individuals terminated from their jobs because of dementia can collect benefits immediately. Those trying to qualify for Social Security disability benefits should be fast-tracked for benefits.
- Driver licensing regulations should restrict driving privileges for those incapable of driving, but not those capable of driving safely.

- Clinical trials should become more flexible by using communication technology.
- Those with Alzheimer’s disease should have the right to end their lives in a dignified way. Discussion should begin about difficult issues such as this.
- In concert with the national plan’s Strategy 2A to build a workforce with skills to provide high-quality care, NTG has developed a national curriculum to enhance the skill levels of those who care for people with dementia or disabilities. NTG is working on this with HRSA and ACL and with universities and providers throughout the United States. The goal is to have the curriculum and train-the-trainer program in place by 2014.
- The work of the Advisory Council and hundreds of people volunteering to make the national plan as comprehensive and inclusive as possible is appreciated.
- Mobility and transportation are issues the Advisory Council should prioritize as it considers issues unique to dementia or complicated by dementia. The city of Vancouver offers a model for dealing with this, as it is trying to become a “dementia-friendly” community.
- The national plan’s recommendation of \$2 billion funding for research has an important impact in shaping the decisions of Congress in an extraordinarily difficult time. The Advisory Council is encouraged to continue to be aggressive about what is needed.
- The openness of federal agencies, such as the FDA, CMS, and NIH, to a collaborative process with stakeholders in the private sector is appreciated.
- The suggestion that individuals be allowed to speak longer during the public input session is supported, and consideration should also be given to having individuals from the public provide input over the telephone.
- People are encouraged to visit their congressperson and let him or her know that the Senate appropriations bill recently passed is appropriate and the increase in the NIA budget is important to advance research in Alzheimer’s disease. In addition, the White House is now beginning planning for the next fiscal year, and people should contact the President to express support for Alzheimer’s disease care and services as well as research.
- Yesterday, AHRQ released a report on long-term care for older adults and future research needs. The report is open for public comment.
- CMS and the Center for Medicare and Medicaid Innovation should require demonstration and pilot programs for Medicare beneficiaries to address cognitive

impairment. Such an inclusion is especially important for some of the ACL programs that continue to be implemented for care transition but have not included the Alzheimer's population.

- Inclusion of lifespan respite care in the national plan Goal 2.0 is appreciated. Respite for caregivers is an area that needs research and should be included in the research agenda for LTSS.
- AAR and the Gerontological Society of America are partnering with the Trans-NIH Geroscience Interest Group to hold its first conference October 30-31, 2013, at the Natcher Conference Center on the NIH campus. Registration is free and open to the public. The Division of Aging Biology at NIA initiated the interest group in 2011 with the goal of promoting the sharing of ideas and the coordination of aging research across NIH. Twenty institutes and centers, as well as the Office of the Director, now participate.
- The FTD community was very pleased to see the release in June of the Task Force Report on Specific Populations, to which AFTD had input. The NIH meeting May 1-2, 2013, represented a monumental step forward for the community of those with FTD and for researchers in FTD.
- FTD tends to affect people earlier in life than other kinds of dementia, so it takes away individuals' prime earning years. The Advisory Council is urged to push for continued awareness of Alzheimer's disease-related dementias, and specifically FTD. Misdiagnosis is a huge frustration, and the public and medical community need greater awareness of FTD.
- The U.S. Department of Justice administers the Missing Alzheimer's Disease Patient Alert program that trains first responders and law enforcement officers to help families identify and locate their loved ones who have wandered away from home. This program has been unfunded in the President's budget. Individuals are urged to tell their members of Congress how important this program is and that it needs to be restored.

## **Concluding Remarks**

Chair Dr. Ronald Petersen thanked the public participants for their input, noting that such contributions help ground the Advisory Council's feelings about dementia.

The next Advisory Council meeting will take place on October 28, 2013.

The meeting adjourned at 4:38 p.m.

Minutes submitted by Helen Lamont (ASPE).

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