

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

Washington, DC

October 27, 2014

## Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, Yanira Crus, David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, Jennifer Mead, Dennis Moore, Laura Trejo, George Vradenburg, and Geraldine Woolfolk
- *Federal Members Present:* Lynda Anderson (Centers for Disease Prevention and Control [CDC]) (by telephone), Linda Elam (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Bruce Finke (Indian Health Service), Richard Hodes (National Institutes of Health [NIH]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Anthony Pacifico (Department of Defense), Anand Parekh (HHS Deputy Assistant Secretary for Health), William Spector (Agency for Healthcare Research and Quality), Amber Story (National Science Foundation) (by telephone), Jane Tilly (Administration for Community Living [ACL]), and Joan Weiss (Health Resources and Services Administration [HRSA])
- *Other Federal Representatives Present:* Susan Cooley (Department of Veterans Affairs [VA]) (by telephone), Ruth Katz (ASPE), Marianne Shaughnessy, Veterans Health Administration (VHA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Rohini Khillan (ASPE)

## General Proceedings

At 9:10 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.

## Long-Term Services and Supports: An Overview

Dr. Helen Lamont, from the ASPE Office of Disability, Aging, and Long-Term Care Policy, presented an overview of Long-Term Services and Supports (LTSS).

- LTSS provide assistance with routine daily activities to people with functional limitations because of physical cognitive or mental disability. It includes services such as personal care, homemaker services, meal assistance, transportation assistance and case management.
- Use of LTSS is most prevalent among the 65 or older population but not exclusive to this population. The majority of those using LTSS are not in nursing homes, contrary to common misconception.
- LTSS providers are, in 95% of cases, family members and friends. Two-thirds of people receiving LTSS rely strictly on family and friends. Only one-third use formal (paid) services, and very few (5%) use paid services.
- These informal caregivers account for 18 million and provide 1.3 billion of unpaid hours annually. Of those caregivers, 62% are women, and half of them are between the ages of 45 and 64.
- Almost 70% of caregivers report positive aspects of caregiving and find it rewarding. About 15% report significant negative aspects such as financial difficulties, stress, or physical strain. These negative aspects have higher prevalence among those who care for a person with dementia. Caregiver stress is associated with poor health outcomes and increased likelihood of nursing home placement for the care recipient.
- LTSS settings include home, community settings, assisted living, and nursing homes.
- Nursing facilities are compensatory, rehabilitative, psychosocial, and social services to residents. They are regulated by states with federal rules because payment sources are largely Medicare and Medicaid. In 2012, these facilities had 1.4 million residents.
- Residential care facilities offer 24 hour supervision, assistance with activities of daily living (ADLs), but not skilled nursing care. They are regulated by states and paid for mostly by private pay and Medicaid. In 2012, these facilities had 713,300 residents.
- The paid workforce comprises approximately 1.9 million direct care workers who deliver formal LTSS, including nurse aides and home health aides. The challenges of this demanding profession continue to be the low wages, limited benefits, and low retention.

- In 2011, estimated expenditures for LTSS were \$425 billion (\$291 billion for home and community care and \$134 billion for institutional care). The next highest payers were in the following order:
  - Medicare
    - Designed to cover post-acute care; covers limited services: up to 100 days in a skilled nursing or rehabilitation facility after a hospitalization and home health to the homebound who meet certain need requirements (recertified every 60 days). It does not, however, cover most LTSS.
  - Medicaid
    - Offers health care coverage for the poor and LTSS for disabled persons with limited financial resources, and it is financed roughly 50/50 by states and Federal Government. Nursing home care is a required benefit. States can choose to cover home and community-based services (HCBS) through “waivers,” but states can also limit the number and type of beneficiaries who receive these services.
  - Private out-of-pocket costs
    - Average annual costs for a nursing home: \$85,235 single occupancy, \$78,110 double occupancy; for assisted living: \$41,724; for home care: \$20 per hour; 10 hours per week = \$11,400; 8 hours per day = \$58,240.
  - Long-term care insurance
    - Purchased by middle-aged and older adults with higher-than-average income who are healthy enough to pass underwriting. Insurance payments account for 3.3% of spending on LTSS annually. There are 7.7 million policies in force.
- The Aging Network, established under the Older Americans Act (OAA) through the ACL Administration on Aging (AoA), provides funding for LTSS to states and the network of regional Area Agencies on Aging (AAA) or Aging and Disability Resource Centers (ADRCs). In fiscal year 2014 funding distribution was as follows: \$347 million for HCBS, \$811 million for meals, and \$146 million for caregiver supports.
- Recent trends and developments include the 1999 Supreme Court Olmstead decision requiring states to eliminate unnecessary segregation of persons with disabilities and to provide services and supports in least restrictive settings; the Community Living Assistance Services and Supports Act and Long-Term Care Commission, which added a new option to financing long-term services and care in the event of a disability in the form of self-funded and voluntary long-term care insurance; planning for LTSS; HCBS quality measurement; and the potential for technological solutions and different housing options.

Discussion after the presentation included the following comments and clarifications:

- There is a 3-night stay hospitalization requirement after admission from the emergency room. Hospitals are very difficult places for people with dementia but because of that requirement, they are forced to stay in the hospital instead of being moved to a more appropriate setting. With that issue in mind, some demonstration projects decided to waive the requirement. Some of the bundled programs try to provide more continuous care and look at the effects of not having this policy in place. The data are still forthcoming.
- Medicare covers up to 100 days in the nursing facility for each admission to a nursing facility. For example, if a patient in a nursing home gets sick, is sent back to the hospital, and stays there for 3 days, Medicare will cover the next 100 days. There may even be incentives for that to happen if a person is a Medicaid beneficiary because the Medicaid rate is lower than the Medicare rate. CMS is currently looking at balancing incentives for hospitals and nursing facilities in several demonstrations.
- Tribal members are eligible for funding for LTSS under Title III of the OAA and through the Tribal Aging Network. In addition, LTSS are covered at 100% by the Federal Government as part of the government-to-government relationship.
- VHA plays a big part in institutional care, community living centers, community nursing homes, and state veterans' homes. With the increasing number of veterans in need of LTSS, there are concerns about the workforce, which may need to be shifted toward informal caregivers.
- Studies on informal caregiving are under way, and ASPE is funding the next round of projects to look at the changes in the dynamics in the network and how people choose their caregivers and who the caregivers are.

## **Medicaid and HCBS Basics**

Ralph Lollar, Director of the Division of Long Term Services and Supports of the Disabled and Elderly Health Programs Group at CMS, provided an overview of the Medicaid program.

- Medicaid authorities that include HCBS:
  - Medicaid State Plan Services--Section 1905(a) of the Social Security Act (the Act).
  - Medicaid HCBS Waivers--Section 1915(c).
  - Medicaid HCBS State Plan Option--1915(i).
  - Medicaid Self-Directed Personal Assistance Services State Plan Option--1915(j).

- Medicaid Community First Choice Option--1915(k).
  - Medicaid Managed Care Authorities.
  - Section 1915(a).
  - Section 1915(b).
  - Section 1115.
  - Section 1115 demonstration programs.
- In brief, states determine their own unique programs and develop a plan outlining the nature and scope of provided services. This plan and any amendments must be approved by CMS. Although some services, called “mandatory services,” are mandated by Medicaid, states may elect to provide other services called “optional services.” States also choose eligibility groups, services, payment levels, and providers. Therefore, these services may differ from state to state.
  - There are several Medicaid state plan requirements:
    - States must follow the rules in the Act, the Code of Federal Regulations (generally 42 CFRs), the State Medicaid Manual, and policies issued by CMS.
    - States must specify the services to be covered and the “amount, duration, and scope” of each covered service.
    - States may not place limits on services or deny/reduce coverage because of a particular illness or condition.
    - Services must be medically necessary.
    - Third-party liability rules require Medicaid to be the “payor of last resort.”
    - Generally, services must be available statewide.
    - Beneficiaries have freedom of choice of providers.
    - The state establishes provider qualifications.
    - The state enrolls all willing and qualified providers.
    - The state establishes payment for services.
    - Reimbursement methodologies must include methods/procedures to ensure that payments are consistent with economy, efficiency, and quality of care principles.
  - Mandatory services include physician services; laboratory and x-ray; inpatient and outpatient hospital; Early and Periodic Screening, Diagnosis, and Treatment; family planning; rural and federally qualified health centers; nurse-midwife services; nursing facilities services for adults; and home health.
  - Optional services include dental services, therapies: physical/occupational/speech/audiology, prosthetic devices, glasses, case management, clinic services, personal care, self-directed personal care, hospice, intermediate care facilities for individuals with intellectual disabilities, psychiatric residential treatment facility for those younger than age 21, rehabilitative services, 1915(i) State Plan HCBS, inpatient hospital services (other than those provided in an Institution for Mental Diseases [IMD]), services for individuals age 65 or older in IMDs, and the 1915(k) Medicaid Community First Choice Option.

- Medicaid waivers can complement and/or supplement the services that are available through the Medicaid State Plan; other federal, state, and local public programs; or supports from families and communities. There are more than 315 waivers in operation nationally.
- CMS published final regulations on January 16, 2014, that became effective on March 17, 2014, to implement changes in the current regulations for 1915(c) waivers. Changes in the current regulations for 1915(c) waivers include the option to combine multiple target groups in one waiver, home and community-based settings, person-centered planning, public notice, and additional compliance options for CMS. More information about the final regulations is available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>.
- Under Section 1915(c) HCBS Waivers, permissible services include home health aide, personal care, case management, adult day health, habilitation, homemaker, and respite care, and for chronic mental illness: day treatment/partial hospitalization, psychosocial rehabilitation, clinic services, and other services. CMS approves a new waiver for a period of 3 years. States can request a period of 5 years if the waiver will include persons who are dually eligible for Medicaid and Medicare. States may request amendments at any time. States may request that waivers be renewed; CMS considers whether the state has met statutory/regulatory assurances in determining whether to renew. Renewals are granted for a period of 5 years. Version 3.5 HCBS Waiver Application is web-based and available at <https://wms-mmdl.cdsfdc.com/WMS/faces/portal.jsp>.
- Section 1915(i) was established by the Deficit Reduction Act of 2005 and became effective on January 1, 2007. Each state has an option to amend the state plan to offer HCBS as a state plan benefit. This is a unique type of state plan benefit with similarities to HCBS waivers. This type of waiver breaks the “eligibility link” between HCBS and institutional care required under 1915(c) HCBS waivers. It was modified in 2010 to add a state option to include a new Medicaid categorical eligibility group to provide full Medicaid benefits to individuals with incomes up to 150% of the Federal Poverty Level and/or with incomes up to 300% of the Supplemental Security Income federal benefit rate and who are eligible for a waiver to disregard comparability (target populations) for a 5-year period with the option to renew with CMS approval, and states can have more than one 1915(i) benefit, to expand the scope of HCBS states can offer, and to remove the option for states to limit the number of participants and disregard statewideness.

- Under 1915(i), each state can provide an option to include services that are planned and purchased under the direction and control of the individual (or representative).
- New regulations for 1915(i) state plan HCBS were published on January 16, 2014, effective on March 17, 2014. More information about the final regulations is available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>.
- HCBS are usually provided as “fee for service” but can also be provided as part of a managed care delivery system, which generally offers a capitated payment arrangement, using one of several Medicaid authorities:
  - 1915(a)--voluntary contract with a managed care organization that agrees to provide certain state plan services, including HCBS, in a capitated arrangement.
  - 1915(b) waiver--managed care delivery system for state plan services that may restrict providers, use selective contracting, use locality as the central broker, and use “savings” to provide additional services generated through savings.
  - 1115--demonstration authority.
- 1915(j) is an option that allows people to make more decisions; 1915(k) Community First Choice Option offers additional payment to the state for personal needs services; it can serve only Medicaid-eligible individuals.

Discussion after the presentation included following comments and clarifications:

- It is not clear how many states offer optional services. More information will be forthcoming.
- Is dementia a mental health condition? It depends on how the state defines mental health. It could be, but it does not have to be. It is based on needs criteria.
- HCBS are set by states themselves. There is a new flexibility over time after the Affordable Care Act (ACA).
- Because only very poor people qualify for Medicaid and some people impoverish themselves to meet the requirements, spousal impoverishment was added.
- Alzheimer's and dementia are specific conditions with unique needs. The services must be tailored to the individual.
- There is a conflict between individuals in the disability community and those in the dementia community. People with dementia wander and have a high risk of

injury and death, proving a high need for devices in home and community settings. Those who have the means can find the care they need. Those who do not have the resources are not getting the accommodation and services they need. This problem needs to be addressed.

- Janet O’Keeffe mentioned a primer titled “Understanding Medicaid Home and Community Services,” published by ASPE, as a good resource. The printed copies were available to all attendees on the day of the meeting. [Available at: <http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm>.]

## **Institutional and Community-Based Long-Term Care for Persons with Dementia**

Dr. Janet O’Keeffe, senior researcher and policy analyst at RTI International, presented an overview of community-based and institutional long-term care options for people with dementia.

- There are three care settings options for persons with dementia: nursing homes, residential care facilities, and adult day services.
- Payment for services in community-based settings can be through private payment, Medicaid (several authorities/programs), or nonMedicaid state programs. All publicly funded services, however, have financial eligibility requirements, and that can cause necessity for spend down.
- In nursing homes, services and the level of care provided are closely linked with Medicare and Medicaid reimbursement. There is the skilled level of care, which is similar across the states because of Medicare requirements, and the intermediate/minimum level of care, which varies because states decide how it is defined; therefore, people with the same condition can meet the criteria in one state but not another.
- Persons with dementia who do not have skilled nursing care most often need an intermediate/minimum level of care, which provides protective supervision, assistance with ADLs and medication management, nursing oversight, and interventions to manage behaviors.
- Residential care settings are regulated by states, require licensure, and are an alternative to an intermediate level of nursing home care for individuals who need considerable supervision and little or no nursing care. Medicaid only pays for services in these facilities and not room and board. There is an issue with quality of care because sometimes these facilities retain people who should not be there.

- Adult day services are regulated by states and funded by Medicaid and non-Medicaid programs to provide nonresidential service outside of an individual's home for less than a full day. There are four models:
  - Social model--provides a secure environment, assistance with some ADLs, and therapeutic activities aimed at helping participants to achieve optimal physical and mental functioning.
  - Medical model--provides skilled nursing and rehabilitation.
  - Combined model--provides both social and medical services.
  - Specialized model--targeted to specific groups; for example, persons with dementia.
- In addition, adult day services can potentially delay placement in a nursing home by providing support to the informal caregivers and can reduce care costs by providing health monitoring, which is shown to reduce hospitalization.

Discussion after the presentation included the following comments and clarifications:

- Assisted living is mostly paid for by private insurance. Adult day services are paid through a combination of funding sources such as grants, Medicaid, private donations, and volunteers, depending on the neighborhood in which the facility is located.
- Programs and services are state specific.
- Adult day services are struggling; this is an ongoing concern. Rural areas have issues with transportation and the facilities not covering cost of transportation. Training requirements for the staff are also very limited.
- ASPE will share data on preventable hospitalization once they become available.
- Training requirements are very basic, and states continue to reduce these requirements from 8 hours to 4 hours.

## **Innovative Practices in Care for People with Advanced Dementia**

Dr. Laurel Coleman reported highlights from the second meeting of experts on advanced dementia regarding innovative practices. The meeting, conducted by the Institute of Medicine for the U.S. Department of Health and Human Services (HHS), was held on September 8, 2014, in Washington, DC.

- The third meeting in this series will be held on January 21, 2015, in Chicago. Formal invitations will be distributed.
- There were seven presentations grouped by care setting: nursing home, community, hospice, and hospital and emergency department, and three

presentations on information and training for care providers, families, and the public that covered a range of approaches from education to more hands-on care and palliative care. Among the attendees, there were seven experts, ten presenters, staff from several agencies, and approximately 45 others, including those on the phone.

- The nursing homes setting featured the following:
  - Beatitudes Campus in Phoenix initiated Comfort Matters in 1998. It focuses on maintaining comfort for people with advanced dementia. Through this initiative, training approaches and competencies for all staff were developed. Results seen so far include low use of medications; reduced hospital and emergency department use; and high satisfaction of patients, families, and staff (presented by Tena Alonzo).
  - The Alzheimer's Association's New York City Chapter's Palliative Care in Nursing Homes is involved in a 30-month study to bring Comfort Matters to New York City nursing homes. It focuses on increasing patients' comfort and staff training. Results of this study are expected in 2015 (presented by Ann Wyatt).
  
- The community setting featured the following:
  - IN-PEACE Collaborative Care Model to provide palliative care for community-living people with moderate to severe dementia in Indianapolis. The focus is on symptom management and education and support for family caregivers. Published results show IN-PEACE patients are less likely to die in the hospital, have significantly lower pain levels, and exhibit reduced behavioral symptoms and distress (presented by Greg Sachs).
  - The VA medical foster homes are for veterans who cannot live independently and are cared for 24 hours a day, 7 days a week. The focus is on providing a home-like care setting and ongoing medical care, allowing for palliative care and hospice care at "home" (presented by Dayna Cooper).
  
- The hospice setting featured the following:
  - Hospice of the Valley in Phoenix is a large, nonprofit hospice that began a dementia program in 2003. It provides inpatient hospice care, training, and consultations for hospice staff, nursing homes, families, and community providers. Published results show lower use of restraints and feeding tubes, effective symptom management, reduced hospitalizations, and high family satisfaction (presented by Maribeth Gallagher).
  
- The hospital and emergency department setting featured the following:
  - The Advanced Dementia Consult Service at Beth Israel Deaconess Medical Center in Boston provides team consultations to improve care for patients with advanced dementia and focuses on appropriate clinical care, family counseling, and physician feedback. Published results show increased family knowledge and satisfaction with care and fewer treatments, feeding tube insertions, and rehospitalizations (presented by Susan Mitchell).

- The ED Project at Mount Sinai Hospital in New York City provides consultations for family caregivers of patients with advanced dementia and focuses on care planning and goal discussions. Early results show an increased percentage of families choosing comfort and quality-of-life goals, a reduced percentage of families choosing life prolongation goals, and no change in the percentage of families choosing both goals (presented by Ashley Shreves).
- The information and training for care providers, families, and the public presentations were as follows:
  - Memory care and dementia care information and training programs provide specialized medical care and support for people with dementia; information, counseling, and referrals for families and the public; and training for care providers. The focus is on identifying goals of care and anticipating and addressing common medical concerns (e.g., swallowing difficulties and feeding). Results show high satisfaction for patients, families, and care providers (presented by Peggy Noel).
  - *How to Talk to Families about Advanced Dementia: A Guide for Health Care Professionals* is a handbook that will be made available at the next Advisory Council meeting (presented by Jody Comart).
  - ADvancing Care and Care Advocate are specific newsletters of the Alzheimer's Association New York City Chapter that were developed for families dealing with advanced dementia and are available online through the network chapter (presented by Jed Levine).
- These programs convey a positive message about what can be done for people with advanced dementia. It was very encouraging to see that some of the programs existed for years, but it was concerning that they have not spread to more communities. The question remains of how to spread these programs throughout the community so that many more people with advanced dementia and their families can benefit from them now while we are waiting for medicines and the cure.

Discussion after the presentation included the following comments and clarifications:

- The secret to a successful program is training and education for family and caregivers.
- There is a problem with how we pay for the services.
- The focus needs to be on the person with dementia and on what works for that individual and not what works for the staff. It is as simple as allowing people to eat when they are hungry and sleep when they are tired. There needs to be flexibility when working with people with dementia.

- It is important to remember what is possible, who is receiving the care, and designing the care around those people. The key elements to success are recruiting and retaining quality staff, leadership with purpose, and teamwork.
- The Five-Star Quality Rating System review from the Nursing Home Compare Web site is a great marketing tool and a way to share this information with the public.
- Very good advanced care planning has a lot to do with family satisfaction and liability.
- Beatitudes Campus is relatively small, with only 38 people admitted at a time.
- In FY 2013, VA has taken care of 2,900 patients through the medical foster homes. These foster homes have a limit of three residents, and most of the services are HCBS. Of those patients, 30%-40% have dementia or Alzheimer's disease.
- CMS conducted an evaluation identifying a subset of nursing homes that consistently received five stars in quality over time. CMS visited ten of those nursing homes. The common characteristics of those ten nursing homes were teamwork and the continuous learning requirement. A nursing home best practices report published in July 2014 validates the importance of recruiting and retaining quality staff but noted that it begins at the leadership level.
- The Independence at Home demonstration project is still ongoing, and the information is forthcoming; the goal is to avoid readmissions by having services available at the facilities.

## **National Alzheimer's Project Act (NAPA) Review Meeting**

Ms. Sheila Burke reported on the NAPA Review Meeting and the main points taken from that meeting.

- Three years after the establishment of NAPA and the Advisory Council, with the first work plan released in May 2012 and updated in 2013 and 2014, it is time to reflect on progress and consider new strategies moving forward.
- The Advisory Council was originally charged with the following:
  - Advising the Secretary in an effort to carry out an annual assessment of the nation's progress in preparing for the burden of Alzheimer's.
  - Evaluating federally funded efforts.
  - Providing recommendations for priority actions.

- Making initial recommendations focused on reducing the financial impact on federal programs and families and improving health outcomes for people with dementia.
- Evaluating progress annually.
- The meeting participants included Laura Trejo, Jennifer Mead, Helen Matheny, Ron Petersen, D.E.B. Potter, Linda Elam, and Rohini Khillan.
- The group discussed accomplishments so far, areas that need to be reevaluated, and the next steps. To show that progress is being made, appropriate metrics are needed. In addition, the process used to develop recommendations and the length and detail of those recommendations and priorities need to be reevaluated. Increased collaboration between federal and nonfederal members is essential moving forward, and subcommittees and federal work groups should organize around the goals.
- Next steps to be considered by Federal Advisory Committee Act (FACA) include the following:
  - Review goals and strategies, determine whether the goals need to be updated, and consider whether the right questions are being asked.
  - Consider the audience for the plan. Revisit the structure of the annual update to the Plan to more clearly articulate goals and measurable progress on goals.
  - Possibly create two separate lists of recommendations: One short-term and one long-term would allow FACA to be bold and still be practical.
  - Agree on metrics to be used to measure progress in achieving goals to ensure that the data are supported and credible.
  - Determine whether the right people are around the table to ensure a strong presence on different levels. It is important to find out who is not present.

Discussion after the presentation was moderated by Chair Dr. Ronald Petersen and included the following comments:

- There is an expectation for some of the recommendations to become part of the national strategy.
- The Plan itself has largely focused on available resources.
- The recommendations should contain aspiration to the national level.
- The Council provides the update to the plan and progress to the Secretary and Congress. There is an opportunity for the Council to go to the higher level and to have more collaborative effort. The biggest objective is to have treatment by 2025.

- According to the current process in place, the recommendations go to the Secretary, and how much of them are incorporated into the Plan is up to the Secretary.
- It is the Council's responsibility to provide the recommendations to Congress and the Secretary, but if the process is insufficient, it needs to be communicated as well in order to be able to reach the goals by 2025.
- The Council's recommendations go to Congress along with the Plan. There is a lot of great information on what federal agencies are doing, but there is a lot of good work happening in the private sector as well, and that needs to be included in the Plan. Better coordination between the federal and the private sector and communicating the recommendations more efficiently and clearly is vital, as more people in Congress need to be engaged.
- The way that the Council is communicating the recommendations to Congress should be improved so the message is heard clearly because these issues are very important and urgent and will affect many people in the upcoming years. It is also important to engage the states in this process.
- The process of sending recommendations is inadequate and should be improved. More resources are urgently needed, and the National Plan should address this issue.
- The work plan in its current form is ineffective.
- No difference is seen between now and 3 years ago. Aspirational goals are not embraced, which is discouraging.
- Aspirational goals that are grounded would be more likely to be facilitated.
- Use of metrics has been already implemented in international work by many other countries. These metrics are very simple and easy to use and show potential for use in longitudinal studies.
- Alzheimer's disease and dementia should not be a political "football game" when determining the budget. Alzheimer's is a devastating condition, and the need for process change is urgent.

## **Public Input**

Rohini Khillan moderated the public comments portion of the meeting.

Fourteen members of the public presented testimony either in person or by email and included persons living in the early stage of Alzheimer's, family members and caregivers

of persons with dementia, and representatives from the National Certification Board for Alzheimer Care (NCBAC), Connected Health Resources, Alzheimer's Foundation of America, Association for Frontotemporal Degeneration (AFTD), Alliance for Aging Research, AMDA - The Society for Post-Acute and Long-Term Care Medicine, Alzheimer's Association, and National Task Group on Intellectual Disabilities and Dementia Practices.

- Copper Ridge expanded its services to outpatient clinics by creating Centers of Excellence for Alzheimer's Care for the greater community. Many families, however, cannot afford these services, and the need is overwhelming. The Centers provide skills training, education, and even meals for persons with dementia and their families.
- Glen Campbell's movie *I'll Be Me* is opening nationwide.
- Training for the health care workers and direct care workers is of paramount importance. Some states have some training requirements, but some still do not. NCBAC set the benchmarks for competencies and core knowledge, which should be used instead of the old system based on hours completed; 1.9 million people provide in-home care, and about 1.6 million provide long-term care. These people need to have appropriate training.
- NCBAC is currently performing job test analysis and conducting survey, which includes the caregiver's perspective and people who train caregivers. The survey can be accessed at <http://www.ncbac.net>.
- The Medicaid eligibility process is lengthy and very complicated. The players in the Medicaid eligibility process cover a broad range of federal, state, and local agencies, down to the individual facilities themselves, and they do not communicate and share information with each other.
- The resource depletion of a surviving spouse of someone with Alzheimer's is a little-talked-about consequence of the disease and one that quickly turns Alzheimer's into a multigenerational problem as adult children struggle to fill the financial void.
- The area AoAs and ADRCs are well meaning, but they are overwhelmed.
- November is Alzheimer's Disease Awareness Month, and as part of that celebration, the Alzheimer's Foundation of America will hold a National Memory Screening Day on November 18, 2014, and provide free, confidential memory screenings and information about memory concerns, Alzheimer's disease, depression, successful aging, resources, and tips on brain health. Memory screenings are not used to diagnose any illness but are a first step toward proper evaluation and treatment of possible memory disorders. More information on how

to access the toolkit or get involved can be found at <http://www.nationalmemoryscreening.org>.

- AFTD recognized lack of awareness as a problem underlying all professional service, not just health care services. The fact faced by most persons with frontotemporal dementia (FTD) is that most people and providers have never met or served a client with FTD before, and many people will have never heard of it before. More public awareness and greater understanding will benefit all constituents of NAPA.
- In consideration of the public audience for the National Plan, AFTD suggested changing the structure so it allows readers to easily identify whether the goal they are looking at and strategies and actions apply to all types of dementia regardless of the clinical diagnosis, whether it applies to Alzheimer's disease or whether it applies to related dementia or a subpopulation identified in the Plan. This simple restructuring will make the Plan easier to understand.
- The state of long-term care in the United States is not acceptable. Families have little to no financial help for long-term care unless they descend to a level of poverty many would argue is inhumane. Adult day, respite, and other services provide a haven for families and delay institutionalization.
- CMS is doing great transition work in clinical care and workforce training, but most of it is happening in small segments or settings. Recommendation in the next update should include a CMS-wide initiative.
- Findings from the 2015 NIH Alzheimer's Disease Research Summit should be accompanied by cost estimates necessary for funding them.
- Reprioritization at NIH is in order. More money is needed for research and innovation as the prevalence of Alzheimer's is rapidly increasing. This needs to be reflected in the FY 2016 budget. Other diseases' morbidity and mortality rates have gone down, and the aging is happening rapidly right in front of us.
- Requesting funding estimates for all the recommendations in the next work plan is in no way prohibited and would be helpful for those reviewing it on Capitol Hill and at HHS to see the funding needs.
- Close to 50% of residents of nursing homes have dementia, including Alzheimer's. This percentage will only continue to increase across all settings: post-acute and long-term care. The burden of these conditions, as we know, falls heavily on caregivers and care partners, both formal and informal, and they are not prepared to shoulder this burden.
- AMDA provides the Arc funded training program on dementia, free of charge for both subscribers and nonsubscribers. It is available at <http://www.amda.com>.

- In 2014, AMDA joined a leadership group of a unique coalition of providers, researchers, advocates, and people living with dementia called the Dementia Action Alliance. The other leaders include CCAL, Planetree, the Eden Alternative, LeadingAge Georgia, and CareGivers United. The main goal is to promote citizens' ability to live fully with dementia, by advancing person-centered dementia care in the United States. The population living with dementia is expected to exceed 13 million. Until there is a cure, an entire generation of people living with dementia and their care partners need and deserve the nation's help. It is time for an expanded focus on the domain of person- and family-centered care in the 2015 recommendations of the National Alzheimer's Plan.
- Detection and diagnosis should be included in the plan because they drive the success or failure of almost everything else inside and outside the plan.
- In terms of government operations, and in terms of the way institutions, families, and individuals deal with this disease or have the opportunity to deal with dementia in any of its varying forms, the sooner a person is diagnosed, the sooner he or she has the opportunity to address it constructively and proactively. The longer the person is kept in the dark about what is causing any variety of symptoms he or she may be experiencing, the more he or she is predisposed to be guided toward the wrong answer and the wrong intervention, and the longer the delay will be in getting to the right interventions: social, medical, legal, or financial.
- Annual wellness visits are underutilized. Quality of the annual wellness visit assessment needs to be improved, and targets for increased utilization should be set via use of quality measures.
- Stigma around the way the country, at the community level and the individual level, looks at this disease needs to be addressed at its roots, not by hope but by action. That will change the environment in which people who receive an earlier diagnosis live their lives. People should be able to live fully with this disease, but that can happen only if they are integrated into a community.
- The overwhelming consensus in the scientific community is that despite the fact that there had been a series of failures in therapy development, the prospects are good and optimistic, but the biggest barrier to progress is the lack of budget and inadequacy of funding for drug development, drug discoveries, and scientific work. Therefore, adding a budget to the upcoming recommendations is crucial.
- There seems to be an absence of partnerships between the Council, federal parts, nonfederal parts, and the rest of the world. The National Task Group on Intellectual Disabilities and Dementia Practices has developed a curriculum addressing workforce training across the country and has begun to pilot it. Many people are signing up to attend from different parts of the country. The need to

enhance the training of individuals who work in the field is there. Efforts such as this one need partnership, especially with the 2025 time frame in mind.

- Because of the complexity of the federal programs, it would be helpful to have a user-friendly guide for people affected by dementia and their family members. This guide would list programs available in their community and that might be available to them, and it would state eligibility criteria in a way that can be easily understood.
- The National Task Group on Intellectual Disabilities and Dementia Practices developed an instrument that might be useful for at least alerting people to some of the issues that they are facing in terms of intellectual disabilities and would like to convey the instrument to people who perform cognitive assessment annually.
- The United Kingdom is now paying physicians £55 per each person diagnosed with dementia.
- The use of devices to help quickly locate a person who wandered off should be implemented in every state. Project Lifesaver International is one example of a company that provides a timely response for those who wander because of dementia, including Alzheimer's. The task of searching for wandering or lost individuals with cognitive impairments is a growing and serious responsibility. Without procedures and commitment, searches can involve multiple agencies, hundreds of officers, countless man hours, and thousands of dollars. More importantly, because time is of the essence, every minute lost increases the risk of a tragic outcome.
- Currently, taxpayer dollars are used to pay for the bands to track prisoners under house arrest. This technology needs to be made available to those with dementia at no cost to keep them safe.
- Information reported by the drug manufacturers, physicians, and patient education portals on the use of cholinesterase inhibitors stating that the drugs may work for 50% of the people and work for only 6-18 months is misleading and needs to be corrected. This time frame is reported only because that is the longest length of time that the drugs have been clinically studied. Recent information circulated by many experts suggests, however, that these drugs can continue to be effective for longer periods; therefore, the language concerning use of these medications must be changed.
- The Purple Angel Project is a symbol for people with dementia that can be recognized around the world. It is trademarked in the United States and the United Kingdom for use without permission if the guidelines are met. Please adopt this symbol as part of your continued support for dementia.

- The Alzheimer's Association convened a working group of 40 research experts, who represented a broad range of research interests and experiences. The group was charged with reviewing all National Institute on Aging (NIA) milestones, made recommendations, and suggested additional recommendations for consideration in order to fully support success by 2025. The conclusions have been published in the October 2014 issue of *Alzheimer's and Dementia*, freely available on the journal's web page at <http://www.alzheimersanddementia.com>.
- NIA intends to draw on input from scientific sources, such as working groups, together with the deliberations to be held at the upcoming 2015 NIH Alzheimer's Disease Research Summit to update the milestones.
- The fact remains that the amounts requested for Alzheimer's research by the administration over the past several years will not allow for the implementation of milestones required to achieve the 2025 goals. It is recommended that the administration allows for the implementation of milestones in its upcoming budget.

## Update on White House Conference on Aging

Nora Super, Executive Director at the White House Conference on Aging, updated the Council on the 2015 conference.

- The White House has held a conference on aging every decade since 1961, and the next one will be in 2015. It will focus on the issues that are most important to older Americans.
- In the past, White House Conferences on Aging had a statutory requirement in the OAA that establishes the time of the conference. This act, however, has not been reauthorized, and there is no requirement to hold the conference, but the White House is very excited about the opportunity to look at these important issues.
- Recommend the documentary film *I'll Be Me*, which shows both the beauty and pain of Alzheimer's from the perspective of the family and caregivers and helps bring humanity to the issue in a very powerful way.
- The four issues for the 2015 White House Conference on Aging:
  - Making people more aware of the costs of long-term care and their health care costs and what that means for their retirement security. This includes caregivers who often have to take time off from work or leave the workforce altogether. Making the work environment more flexible and more accepting to the needs of caregivers is an important topic.
  - Healthy aging initiatives and how to change the environment so people have the ability to remain independent as long as possible. Of particular interest

is use of technology to improve the care that people with dementia or Alzheimer's receive to help them remain independent and to help caregivers take care of them.

- LTSS.
- Elder justice--the Elder Justice Act was part of the ACA. The Coordinating Council provided the following recommendations: bring awareness to abuse, neglect, and exploitation of elders, especially of those who have dementia; provide workforce training, including health care workforce, law enforcement workforce, and the banking industry; and make the promise of the Elder Justice Act a reality.

Discussion after the presentation included the following comments and clarifications:

- The date has not been set yet for the conference. The plan is for the conference to be held in the SUMMER in celebration of important anniversaries of Medicare and Medicaid, the OAA, and the Social Security Act. Before the conference, beginning in January 2015, there will be a series of regional forums and webinars on specific issues that people can provide feedback on. More information on these events can be found on the website <http://www.whitehouseconferenceonaging.gov>.
- Many of the federal partners who are on the council also served on work groups contributing to this process.
- Across the population, not all of the issues of the dementia population are necessarily falling automatically in the four topic categories mentioned in the presentation, therefore moving the focus to the dementia population and other issues that this population is facing will be important. The National Coalition on Mental Health and Aging had made a similar request about mental health.
- One session of the conference will focus solely on healthy aging, and input on which area might be the most appropriate to highlight regarding Alzheimer's is welcomed.
- In the past, the conferences have not been disease specific.
- The RAND article published in 2013 recognized Alzheimer's/dementia as one of the most costly conditions: three times more costly for someone on Medicare than for an average person and the plan. For Medicaid beneficiaries, it costs 19 times more.
- The impact of Alzheimer's and dementia is so great because people with dementia cannot follow protocols for diabetes and heart disease, which causes increased hospitalizations as a result. This calls for a real consideration of perhaps a fifth topic category focusing on Alzheimer's and dementia.

## Developing Recommendations

Chair Dr. Ronald Petersen moderated discussion regarding the development of recommendations for the 2015 version of the plan. The following comments and recommendations were received:

- The recommendations have been lengthy in the past, which may continue to serve the purpose. However, a concern has been raised that there may be too many (more than 30), and because of that, they do not receive adequate attention. The reduction of the number of recommendations should be considered.
- The Council needs to consider all audiences when preparing recommendations. The audiences include the Secretary and Congress but also the public, advocacy organizations, associations, and foundations, as all these groups use the recommendations to talk to members of Congress.
- Committees should prioritize the needs and work, make decisions, and advocate for them.
- Processes are important because they lay a good foundation to be able to move to the next steps.
- The LTSS system needs to be transformed because the resources are inadequate. The cost estimates associated with that change should be provided. More funding is needed for direct services so that the consumers and their families can really be supported.
- Some existing programs are working successfully and need to be implemented on bigger scale.
- The concern was raised about the fact that the OAA has not been reauthorized.
- The Council needs to clearly communicate the necessity for immediate action and more funding in order to provide some level of security to the communities that rely on direct services.
- The goals need to be reconsidered to try to operationalize meaningful outcomes and drive the system towards them.
- When thinking about the needs, resources, and implementation of good ideas, it is important to keep in mind that the agency or agencies may not have the authority to implement them. This is where nonfederal partners play an important part.

- In addition to the three standing committees, there might be recommendations coming from the ad hoc ethics committee that met a few times in 2014. It was suggested that this group should reconvene.
- The cost estimates need to accompany the recommendations to show the size of the issue and resources needed to address it.
- The Council should be presenting a smaller number of goals (one or two goals maximum for each area) to be accomplished by 2025.
- LTSS requires state and federal involvement, and so far there is very little input from the states.
- NIH should consider providing the cost estimates, annually or by segment, on each of the recommendations showing what it would take to reach the 2025 goal. This exercise will provide a view about the adequacy of the implementation plan on the research side and whether it is inadequate and/or whether it is adequate but not adequately funded, or both.
- Baseline and annual diagnosis rates will drive the development of care plans and treatment plans and will potentially drive participation in clinical trials by looking at the percentage of existing estimated populations diagnosed and what the metric of improving that year over year is.
- The recommendations to Congress need to be explicit and stated with conviction and a sense of urgency.
- Governors or the National Governors Association should be involved on a higher level and become advocates for more effective delivery of LTSS. They have not been engaged adequately so far.
- Cost estimates for LTSS show a lot of variability among the states, and there are data to show that states have developed robust programs that save a lot of money in terms of long-term care costs and, in particular, nursing home placement.
- The goals should be more precise and have a target action toward reaching them, with a small number of clear, overarching goals to keep moving forward and a second level of goals that would start directing the short-term programs.
- By creating and driving the conversation, the investment in research will get accomplished, followed by the outcomes. Along the way, the care and support for people are crucial. Otherwise, 20 million people will be left out: 5 million people with the disease and 15 million caregivers.

- The plan should reflect the idea of providing care and support in the interim, and ultimately treating the disease, so the care and support are no longer needed.
- Recommendations ought to be narrow to get to the really high-level goals. The way the recommendations are communicated to Congress needs to change. This process should be very transparent and loud so that the people recognize their importance, and if the plan does not change enough, that the gap is clear. The members of the Council should be kept informed when the recommendations are submitted and throughout the process.
- The Council should identify potential organizations that care about the dementia issue deeply: the caregiving organizations, the patient associations, the clinical communities, and the medical associations, as well as those providers in the long-term support office, to provide them with a more explicit and easy-to-use avenue by which they participate. The subcommittees should not be cabined around six people; they should be much larger and involve a lot more people.
- Recommendations issued in January should contain a retrospective comment about the previous year's plan and include recommendations as a result of that comment for the upcoming plan.
- In addition to sharing with the Secretary and Congress, the recommendations should be released to state lead agencies and governors across the country because it is really important to bring their attention to the fiscal impact to their states. Providing state-by-state data will further enhance this process. The awareness needs to be heightened at the state level, and states should be included and embrace you as partners in this effort.
- The structure of the Council is perhaps providing constraints on what can and cannot be done. This relates to budgetary recommendations.
- The hope is that the recommendations really affect the plan and the plan really reflects the recommendations. There is a potential to have a better plan.
- The annual update to the plan is a requirement mandated by law.
- Revision to the upcoming recommendations and the Plan should have the element of urgency.
- There was a suggestion to develop an “elevator speech” that will serve as a tool for all the panel members as ambassadors of this work to be able to spread the message.
- The Council cannot ask Congress for money. Under the Hatch Act, even nonfederal Council members act as federal employees and are not allowed to advocate to Congress.

- The experience of developing recommendations that cannot be implemented is discouraging.
- It is important to keep in mind that recommendations are not to be resource bound.
- The Office of Management and Budget plays a key role in achieving the goals and should be invited to join the Council meeting in January.
- The process of providing recommendations to update the national plan should mirror federal budget development timelines in order to make an impact.
- Workforce training remains problematic and needs to be included in recommendations and goals. If children were not able to get access to pediatricians, the nation would be appalled, but there is not a similar degree of concern about older adults with special chronic problems such as Alzheimer's disease who cannot access physicians and other health care professionals with competencies in these particular areas. The current system prevents the providers from actually practicing care in a way that anyone would want for their loved ones and for themselves.
- VA is working to develop models that would provide an example for the nation in terms of excellence in care for geriatric patients but is also facing the challenge of a shortage of geriatricians.
- With many recommendations on workforce development made, one of the major ones adopted in the plan, on increasing the numbers of the geriatric workforce, was to offer loan forgiveness for anyone receiving medical training in geriatrics.

## Subcommittee Updates

Dr. Richard Hodes reported on research activities.

- New Alzheimer's-related initiatives include the following:
  - Biomarkers of Alzheimer's Disease in Down Syndrome (R01), <http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-15-011.html>, NIA and the National Institute of Child Health and Human Development.
  - Interdisciplinary Research to Understand the Vascular Contributions to Alzheimer's Disease (R01), <http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-15-010.html>, NIA and the National Institute of Neurological Disorders and Stroke (NINDS).
  - Immune and Inflammatory Mechanisms in Alzheimer's Disease (R01), <http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-15-018.html>, NIA.

- The 2015 Summit will be held on February 9-10, 2015. National and international participation is anticipated. Summit registration is now open and available at <http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015>. G7 wrap-up, planned by the World Health Organization (WHO) will be held on March 3-4, 2015, in Geneva.
- 2013 Alzheimer's Disease-Related Dementias Summit, primarily sponsored by NIA, provided recommendations that were published in *Neurology* on August 26, 2014. The news studies of FTD included the following:
  - FTD clinical research consortium to support the development of FTD therapies (NINDS and the National Center for Advancing Translational Sciences/Office of Rare Diseases Research)
  - Longitudinal natural history study of familial FTD (NIA and NINDS)
  - A large program project to understand the cellular disease processes that lead to amyotrophic lateral sclerosis and FTD (NINDS)
  - Small Blood Vessels: Big Health Problems? Workshop, held September 18-19, 2014, focused on integration of research findings across organ systems, including the brain, and identifying research gaps. This event was sponsored by NINDS, the National Heart, Lung, and Blood Institute, the National Eye Institute, the Office of Disease Prevention, and the Office of Research on Women's Health.

Ms. Charlene Liggins provided an updated International Alzheimer's Disease Research Portfolio 2.0 (IADRP), an online database that can be accessed at <http://iadrp.nia.nih.gov/>. Current members include research that is funded by essentially all the United States government agencies, federal agencies as well as states and private foundations, and a growing number of international organizations recently added to the first partners (Canada and the United States): Australia, Poland, Italy, Brazil, the United Kingdom, and the Czech Republic. This database tracks and intergrades Alzheimer's research funding in a coordinated way that helps to inform investigators and funders on what has been done, what is being done, and what needs to be done next.

- IADRP 2.0 offers greater functionality and allows for sorting through portfolios to identify opportunities for collaboration and cooperation.
- Tracking progress or funding initiatives can be performed by using milestones that were developed as part of the 2012 Alzheimer's Disease-Related Dementias Summit recommendations. Each milestone is mapped to a particular code, and there are more than 200 codes.
- IADRP 2.0 provides the ability to filter by specific targets.
- In the process of updating the IADRP with 2014 real-time partners.
- Looking into collaboration with <https://clinicaltrials.gov/> data to be able to map pharmaceutical companies' trials in terms of addressing some of the milestones.

Discussion after the presentation included the following comments and clarifications:

- It is likely that this tool will become the standard; whether it will lead to international efforts and milestones tied to priorities or at least categorization, it would be a positive move.
- G7 adopted the 2025 goal with a slightly different characterization.
- WHO is soliciting information about research primers and accomplishments, and IADRP 2.0 could be a good start.
- In terms of frequency of use and tracking, there are usually around 30-50 visitors every month, with increased activity around the time of G7.
- Since the migration to the new site, the monthly report is not available yet.
- The team is currently looking into employing Google Analytics to see which countries are visiting the site and whether they represent other governments or educational institutions.

Dr. Shari Ling, Dr. Joan Weiss, and D.E.B. Potter reported on activities of CMS, HRSA, and the National Quality Forum (NQF).

- HRSA's geriatric programs are continuing activities to train the geriatric workforce through interprofessional education and preparing geriatric specialists.
- During the FY 2012-2013 cycle, Geriatric Education Centers trained approximately 81,500 health care providers and received \$4 million in FY 2014.
- As of September 26, 2013, more than 42,800 health care providers have participated in the Medscape training on "case challenges in early Alzheimer's disease." Medscape has extended the continuing education trainings for another year.
- HRSA awarded a contract in September 2014 to develop a unified Alzheimer's disease curriculum, and the activities are under way, with the first Technical Expert Panel meeting scheduled for mid-November.
- CMS sponsored a Medscape event titled "Patient Goal-Directed Care," targeting those persons with multiple chronic conditions, such as dementia. Presenters included Dr. David Rubin and as Dr. Mary Tinetti.
- The Patient and Family Engagement Campaign through the Quality Improvement Organizations focuses on increasing patient and family involvement in decisions

regarding health and health care and promoting taking action for their own health care in an effort to improve the quality of life.

- A project from New York called Self-Management and Empowerment Program for Caregivers/Medicare Beneficiaries with Dementia/Alzheimer's Disease had a goal to develop a 6-week workshop to teach caregivers about how to cope with five major stressors of caring for a family member with dementia. This project targeted family caregivers and the Hispanic and African American community.
- Missouri's Primaris project called Partners for Dementia Care had a goal to decrease problems that dementia patients face in the acute care settings by directly engaging family and consumers' involvement in health care decision making. The target population was individuals with diagnosed early dementias and their families, acute care staff, and physicians treating persons at risk for dementia.
- The NQF Dementia Including Alzheimer's Disease project released a final report on October 15, 2014. As part of the final report process, public input was received from more than 30 commenters. The final report and recommendations are available at [http://www.qualityforum.org/Prioritizing\\_Measure\\_Gaps\\_-\\_Alzheimers\\_Disease\\_and\\_Related\\_Dementias.aspx](http://www.qualityforum.org/Prioritizing_Measure_Gaps_-_Alzheimers_Disease_and_Related_Dementias.aspx).
- One of the action items was to identify high-quality care guidelines and measures. Across settings and as a result of this project, 85 care guidelines and 125 quality measures currently in use were identified. Of those quality measures, 52% were from international communities. Recommendations centered on several overarching themes: importance of connection to community-based services, need for accountability at the community level, person- and family-centeredness, diagnostic accuracy, and safety.
  - Recommendations for future measure development included the following:
    - Comprehensive diagnostic evaluation and needs assessment.
    - Composite measure of caregiver support.
    - Measures to reflect a dementia-capable health care and community care system.
  - Additional priority areas for measure development were early detection of signs and symptoms of dementia, shared decision making, and care transitions.
  - Additional recommendations were related to performance measurement, dementia research, and policy.
- The CMS Innovation Center's second round of Health Care Innovation Awards was announced in May 2013, and the awards were distributed in summer 2014. A list of awardees is available at <http://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/Round-2.html>.
- Although hospitalization and rehospitalizations within 30 days data show that the rates are declining, for people diagnosed with Alzheimer's disease or dementia,

rehospitalization rates are lagging. This shows a need for additional tools and interventions to help patients and their families manage care transitions safely. More studies are needed to help support the development of such tools and resources.

- The national goal for reduction in use of antipsychotic drugs in dementia care was met with a 15.1% reduction by quarter 4 of 2014.
- The target goal was refined to further reduce the national prevalence of antipsychotic medication use in long-stay nursing home residents by 25% by the end of 2015 and by 30% by the end of 2016 from the initial 2010 levels. In addition, antipsychotic measures will be included in the calculations for each nursing home's rating on the Five-Star Quality Rating System, both for long stay and short stay.
- Hand-in-Hand dementia staff training materials have been disseminated to VA Community Living Centers as well. A series of presentations on the content of training modules, training implementation, alignment with performance indicators, and the evaluation process will be held at VA Medical Centers.

Dr. Jane Tilly provided an update on LTSS activities.

- Activities related to Goal 1--Prevent and Effectively Treat Alzheimer's Disease by 2025 included the following:
  - The 2014 Webinar Series on Alzheimer's Disease Research and Resources included three webinars with more than 700 registrants each and covered the following topics: resources update, research update, and successful community collaborations. The materials are available at [http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/index.aspx#resources](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx#resources).
  - Recruiting Older Adults into Research developed and tested a toolkit, which is now available at <http://www.nia.nih.gov/health/publication/roar-toolkit>.
  - Translation of a 4-month intervention called Care of Persons with Dementia in their Environments that uses occupational therapists and nurse practitioners with home visits. It is taking place in one of Connecticut's home waivers with Medicaid. This might infuse itself into Medicaid programs across the country.
  - A 2-year test of an intervention to find out whether a caregiver support program has an impact on family caregiver distress and biomarkers of cardiovascular disease risk.
  - NIA funded a Center on Improving Healthcare for Cognitively Impaired Elders and Their Caregivers.

- Activities related to Goal 3--Expand Supports for People with Alzheimer's Disease and Their Families included the following:
  - Update a 2011 dementia capability issue brief targeted to state policy makers, around how to develop dementia capability HCBS systems. It also mentioned actions for localities, brain health awareness, and the concept of dementia-friendly communities.
  - The Alzheimer's Disease Supportive Services Program funded six new states in September 2014 as part of the statutory requirements to build dementia-capable systems. The awards were approximately \$450,000 each.
  - Alzheimer's Disease Initiative - Specialized Support Services: ACL awarded 10 grants through Prevention and Public Health Funds to enable states and localities to better serve individuals living alone, those with intellectual disabilities, and those experiencing difficult behaviors. The awards were approximately \$900,000 each.
  - The ACL Legal Assistance Model Grant Program is organizing training on dementia capability in Hawaii for lawyers in 2015; Oregon will target outreach to people with dementia who are in need of legal assistance, and Maine is developing cross-discipline training for the legal and aging networks on dealing with clients with possible dementia and their families.
  - ACL has developed a new brochure, "Respite for Family Caregivers of Persons with Dementia, Including Alzheimer's Disease," which offers background for respite providers and will also help Lifespan Respite grantees create strategies to improve respite access and quality. It can also be a useful resource for family caregivers.
  - Continuing expansion of the Resources for Enhancing Alzheimer's Caregiver Health program to veterans living in tribal communities. The goal is to expand reach into 50 tribal communities over the next 3 years and then eventually across the Tribal Aging Network.
  
- Activities related to Goal 4--Engaging Public Awareness and Engagement included the following:
  - As part of the Campaign on Cognitive Health Awareness, a contract has been signed with Ogilvy Public Relations, and a work plan is being developed.
  
- Activities related to Goal 5--Improve Data to Track Progress included the following:
  - CDC has updated the Behavioral Risk Factor Surveillance System's optional Caregiver Module based on input from the experts and feedback from system's coordinators. It now includes a question on forecasting to help states better understand the potential prevalence of future caregivers.
  - CDC's Healthy Brain Initiative is supporting implementation of the Caregiver Model at the state level through a partnership and award to the Alzheimer's Association.

Discussion after the presentation included the following comments and clarifications:

- ACL is partnering with the Alzheimer's Association TrialMatch and Arizona's prevention initiative registry and research match registry to see if there is an increase in the number of people registered.
- New York, as a result of the 2014 update to the plan, invested an additional \$1 million this year in the Alzheimer's Community Assistance Program in the Alzheimer's Disease Assistance Centers. Two demonstration projects were funded on preventing falls in people with Alzheimer's disease and are already under way. A call for applications on a demonstration project on reducing disparities in Alzheimer's disease will be released soon. Additional initiatives have been funded in Ohio, California, Florida, and Texas.

## **International Work Update**

The G8 meeting in December 2013 in London focused on dementia, with several legacy meetings planned in 2014. Two meetings have taken place, one in London in June 2014 and one in Ottawa in September 2014.

Dr. Linda Elam provided the following comments:

- The meeting in Canada was titled "Harnessing the Power of Discoveries: Maximizing Academia - Industry Synergies."
- The third legacy meeting will be held in Tokyo in the first week of November 2014. The United States will be represented by an employee who is stationed in East Asia.

George Vradenburg provided the following updates and comments:

- The World Dementia Council has four priorities: One is integrated development, which is the pipeline process of getting discoveries out of the laboratory and through regulatory agencies and reimbursement agencies, not just clinical trials.
- Conversations are currently happening on integrating and emerging platforms in Europe and North America and on accelerating clinical trials. An upcoming meeting with regulators from the major regions of the world will focus on how to fit current regulatory standards.
- The second priority is focused around finances and trying to find other funding mechanisms to bring more resources into the early-stage startup company space.

- The third priority is focused around open science and big data, which OECD is leading.
- The fourth priority is focused around care and technology.
- Some efforts that started in Scotland moved into the United States through the AARP Global CEO Initiative, which then moved to Japan. Working on a global stage allows for comparing performance. For example, if the national goal for the diagnosis rate in the United Kingdom is 60%, then 70%, then 80%, and if the country does not have a diagnosis rate standard, the highlights of the differential performance of those countries become quickly apparent.
- The fifth potential priority would be addressing prevention and public health measures.

Harry Johns provided additional comments:

- A paper on behalf of the Alzheimer's Association looking at the idea of modifiable risk factors reinforces the fifth priority. The council is likely to adopt it as yet another objective with a few modifications, given the state of the science.
- The Council needs to present a strong statement to Congress for more research and resources at the government level because without it, the work will not be done by 2025.

## **Concluding Remarks**

The next Advisory Council meeting will take place on January 26, 2015.

The meeting adjourned at 4:53 p.m.

Minutes submitted by Rohini Khillan (ASPE).

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