

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

Washington, DC

January 17, 2012

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, Eric Hall, David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, David Hyde Pierce, Laura Trejo, George Vradenburg, Geraldine Woolfolk
- *Federal Members Present:* Lynda Anderson (CDC), Regina Benjamin (Surgeon General), Bruce Finke (IHS), Richard Hodes (NIH), Russell Katz (FDA), Donald Moulds (ASPE), Cindy Padilla (AoA), William Spector (AHRQ), Amber Story (NSF), Joyce Berry (SAMHSA), Joan Weiss (HRSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)
- *Others Federal Officials Present:* Shari Ling (CMS)

Proceedings

- Meeting was called to order at 9:30 a.m. by Chair Ronald Petersen.
- Introductions of Advisory Council members were made.
- Dr. Lamont reported that Anita Albright's position on the Advisory Council is vacant because she has changed position. The position will be posted in the *Federal Register*, and nominations are encouraged.
- Dr. Petersen acknowledged comments to the Advisory Council by the public, reminding them of the gravity of their task and encouraging their efforts to continue.
- An overview of the agenda was provided, and the purpose of the meeting was outlined. At the meeting, the representatives from HHS presented an overview of the draft Framework for the National Plan to Address Alzheimer's Disease.

Following that presentation, the chairs of the three subcommittees (Research, Clinical Care, and Long-Term Services and Supports) summarized the feedback on the draft Framework from their subcommittees and suggested recommendations for discussion by the full Advisory Council. The Advisory Council discussed the draft National Plan to Address Alzheimer's Disease. The meeting also included an open public session for non-Advisory Council attendees to address issues or topics that should be addressed in the National Plan.

- Dr. Moulds described the reasoning behind HHS's decision to submit a draft Framework rather than a full draft of the National Plan to the Advisory Council at this meeting. HHS officials felt that additional time was needed for input from Advisory Council members and other stakeholders.

Presentation and Feedback on Draft Framework

- The Advisory Council heard presentations by the federal working groups related to the draft Framework for the National Plan to Address Alzheimer's Disease. The PowerPoint slides for these presentations are available at <http://aspe.hhs.gov/daltcp/napa/#Jan2012MtgMat>.
- *Draft Framework Overview*, presented by Helen Lamont, ASPE/HHS:
 - The draft Framework is intended to provide broad goals and specific strategies for addressing Alzheimer's disease and related dementias. Dr. Lamont emphasized that the actions outlined include only those that could be achieved by Federal Government agencies with existing resources.
 - In the draft Framework, the term "Alzheimer's disease," or AD, refers to Alzheimer's disease and related dementias, consistent with the approach used by Congress in drafting the authorizing language.
 - The goals, as defined in the draft Framework, are as follows:
 - Prevent and effectively treat Alzheimer's disease and effectively treat Alzheimer's disease by 2025.
 - Optimize care quality and efficiency.
 - Expand patient and family support.
 - Enhance public awareness and engagement.
 - Track progress and drive improvement.
 - During the discussion period, Advisory Council members indicated that the stated goals were appropriate. One member requested that the goals be reframed in a quantifiable manner with metrics to show incremental change over time.

- *Actions Proposed for Goal 4: Enhance Public Awareness and Engagement and Goal 5: Improve Data to Track Progress*, presented by Helen Lamont, ASPE/HHS:
 - Strategy 4.A: Educate the Public about Alzheimer's Disease. The proposed action was the design and implementation of a national education and outreach campaign on Alzheimer's disease. Dr. Lamont requested additional input from Advisory Council members to further define the appropriate audiences, messages, and medium. During the discussion period, Advisory Council members agreed that an inventory of existing educational resources could be collected (e.g., from the Alzheimer's Association, Alzheimer's Foundation, NIA's Alzheimer's Disease Education and Referral Center) and that a campaign would require substantial public and private resources.
 - Strategy 4.B: Work with State and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease Awareness and Readiness Across the Government. The suggested action is to convene local, state, and federal leadership to outline strategies to leverage available resources and programs across multiple levels of government. During the discussion period, Advisory Council members requested that an analysis of existing state plans on Alzheimer's disease be provided to the Advisory Council and suggested a review of Alzheimer's plans in other countries. Advisory Council members also inquired about who would convene the governmental leaders and whether the discussion should include private industry leaders. Dr. Moulds responded that HHS is looking to the Advisory Council for guidance for the Federal Government on ways to convene leaders and ways to reach out to other stakeholders. One Advisory Council member suggested that non-federal stakeholders could convene leaders and bring suggestions back to HHS for consideration. Dr. Moulds reiterated that there is nothing in Federal Advisory Committee Act rules that would prohibit that kind of activity.
- *Actions Proposed for Goal 5: Track Progress and Drive Improvement*, presented by Helen Lamont, ASPE/HHS:
 - Strategy 5.A: Enhance HHS's Ability to Track Progress. Potential policy questions and specific gaps in data, such as a more accurate estimate of the cost of health care for persons with Alzheimer's disease, need to be addressed. During the discussion period, Council members indicated that data gaps could not be filled without significant investment of resources from CMS.
 - Strategy 5.B: Monitor Progress on the National Plan. The National Plan is a document designed to be updated regularly. Dr. Moulds requested the Advisory Council members look closely at the goals, strategies, and actions

presented by the federal subcommittees and recommend ways to measure progress.

- *Actions Proposed for Goal 3: Expand Patient and Family Support*, presented by Cindy Padilla, Principal Deputy Assistant Secretary, AoA:
 - Ms. Padilla presented an overview of the Long-Term Services and Supports (LTSS) working group's scope, process, and topics considered in creating the goal, strategies and action steps. Ms. Padilla provided an in-depth description of the subcommittee's goal and stated that the strategies and actions focus on support for people with Alzheimer's disease, their families, and other informal caregivers.
 - Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials. Actions include identifying culturally sensitive materials and training, distributing materials to caregivers, and utilizing informatics (such as the use of health information technology applications for caregivers).
 - Strategy 3.B: Enable Family Caregivers to Continue to Provide Care While Maintaining Their Own Health and Well-Being. Actions include using existing data sets to identify unmet service needs, reviewing and delivering state-of-the-art evidence-based interventions through community-based organizations, and providing caregivers support in crisis and emergency situations. During the discussion period, members asked who currently monitors the implementation of evidence-based programs. Ms. Padilla responded that currently each agency monitors their programs independently. Designing common metrics to measure the effectiveness of interventions was also mentioned. Ms. Padilla commented that it is the hope of HHS that the National Plan will provide guidance to pull the programs together across agencies.
 - Strategy 3.C: Assist Families in Planning for Future Long-Term Care Needs. Actions include examining awareness of LTSS needs and options to identify barriers to planning and expanding awareness efforts.
 - Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease. Actions include educating legal professionals about working with people with Alzheimer's disease as well as monitoring, reporting, and reducing the use of antipsychotic medications in nursing homes.

- During the discussion period, Advisory Council members asked to what extent programs include end-of-life counseling. Ms. Padilla indicated that some AoA-funded programs are currently providing end-of-life counseling to individuals who request it.
- *Feedback on Actions Proposed for Goal 3: Expand Patient and Family Support*, presented by David Hoffman, Chair, LTSS Subcommittee:
 - The LTSS Subcommittee used four guiding principles in their deliberations:
 - Patients, caregivers, and families are constituencies that must be addressed.
 - LTSS should include services to maintain caregiver health.
 - The National Plan must assure that a robust dementia-capable system of LTSS is available in every state.
 - The National Plan must assure improvements in quality of life and lead to more efficient and effective provision of care.
 - The LTSS Subcommittee was in agreement that Goal 3 was appropriate and the Council Subcommittee appreciated the federal working group's draft. The LTSS subcommittee identified ten additional actions to be incorporated into the National Plan:
 - Ensure use of new diagnostic guidelines for Alzheimer's disease when individuals are admitted or assessed for eligibility for long-term services and supports.
 - Engage patients and families in advanced care planning.
 - Incorporate recommendations for end-of-life into all surveillance and quality improvement systems.
 - Embed practice recommendations for every care setting in surveillance and quality improvement measures.
 - Assess caregiver health/mental health risk regularly.
 - Assure access to a full array of LTSS for persons with younger-onset Alzheimer's disease.
 - Designate state agencies to coordinate all LTSS using federal funds.
 - Include information about Alzheimer's disease in curriculum for any profession/career track affecting LTSS.
 - Provide Alzheimer's disease-specific training for all state agency staff providing LTSS.
 - Include adult day care services as an optional service under Medicaid.
 - During the discussion period, an Advisory Council member asked the subcommittee whether there were any examples of states that are successfully coordinating services and supports for persons with Alzheimer's disease. Mr. Hoffman shared that New York State is working on improving coordination of services with the Department of Health serving the lead role. Additional comments included suggestions for specific metrics to include in the goal and strategies. Mr. Hoffman also suggested that a

state lead agency for LTSS should be designated by the Governor and should require cross-coordination among public health, Medicaid, and aging agencies. Ms. Padilla offered that, in general, state aging and human services agencies could improve partnering within states and with non-governmental organizations. Mr. Hoffman suggested that intermediate metrics related to Goal 3 might include availability of services, number of people accessing services, number of people aware of services, number of health care professionals aware of and referring to services, and the burden absorbed by caregivers in providing long-term services at home. Advisory Council members also discussed the importance of investing in evidenced-based practices that have been proven to maintain quality of life, maintain health and well-being for caregivers, maintain people in their communities, and achieve saving for the system.

- *Actions Proposed for Goal 2: Enhance Care Quality and Efficiency*, presented by Shari Ling (CMS):
 - The proposed strategies and actions touch on all care providers across all settings and are grounded in existing evidence of best practices. It was acknowledged that there is overlap between the strategies in Goal 2 and Goal 3, and that significant public-private partnerships would be required to accomplish these goals. In addition, the Clinical Care Subcommittee was in agreement that quality and efficiency can be measured if data is collected and available, which will require private industry data to complement existing federal data sources.
 - Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care. Actions include creating standardized dementia-specific guidelines and curricula for LTSS professionals, strengthening the direct-care workforce, and supporting state and local policies that reinforce the provision of quality care.
 - Strategy 2.B: Ensure Timely and Accurate Diagnosis. Actions include linking the public to diagnosis and treatment services and identifying and disseminating a toolbox to aid in the identification of cognitive impairments and risks for dementia for use in the Medicare Annual Wellness Visit.
 - Strategy 2.C: Educate and Support Patients and Families upon Diagnosis. Actions include educating physicians and health care providers about accessing LTSS and providing care planning assistance for persons with Alzheimer's disease and their caregivers.
 - Strategy 2.D: Identify and Implement High-Quality Dementia Care Guidelines and Measures Across Care Settings. The main action is exploring existing dementia care guidelines and measures. The measures associated with this strategy would be grounded in evidence and existing

program metrics. Selection of these measures would require public-private partnership.

- Strategy 2.E: Ensure that People with Alzheimer’s Disease Experience Safe and Effective Care Transitions Between Settings and Systems. Actions include implementing and evaluating new care models that support care transitions and developing an Alzheimer’s disease-specific toolkit on care transitions, specifically building on Medicare’s community-based care transitions program and the Office on Disability’s analysis of evidence-based care transitions programs.
- Strategy 2.F: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with Alzheimer’s disease. Actions include reviewing and evaluating the effectiveness of care coordination models.
- Strategy 2.G: Improve Care for Populations Disproportionally Affected by Alzheimer’s Disease. The main action presented was designating a taskforce devoted to improving care for specific populations challenged because of issues with health literacy, increased prevalence, or risk.
- During the discussion period, Advisory Council members reiterated the need for metrics to be defined. Dr. Ling listed several existing and emerging data sources, including the Minimum Data Set (MDS 3.0), Medicare/Medicaid claims data, and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys. HHS’s Healthy People 2020 was highlighted as an existing plan that identifies some baseline quality data. In addition, a request was made for CMS to identify a single cognitive assessment tool for all providers to use during the Medicare Annual Wellness Visit as a way to capture disease-related data that can be tracked through time and perhaps linked to research data.
- *Feedback on Actions Proposed Goal 2: Enhance Care Quality and Efficiency*, presented by Dr. Laurel Coleman, Chair, Clinical Care Subcommittee:
 - In addition to reviewing the draft Framework, the Clinical Care Subcommittee reviewed the literature and spoke with experts in academia, community-based organizations, and industry.
 - The Clinical Care Subcommittee proposed a revised Goal 2 statement: Individuals with Alzheimer’s disease have the disease detected and diagnosed at an early stage, receive care planning, and have access to coordinated and high-quality health care through the course of the disease.

- In addition, the subcommittee presented an additional set of recommended actions to be incorporated into the strategies set forth by the Clinical Care Subcommittee. These actions included the following:
 - Launch a public awareness campaign that promotes awareness and early detection, with special focus on diverse communities and populations (e.g., younger-onset, persons with intellectual disabilities).
 - Launch an additional campaign on early detection targeted at educating health care professionals.
 - Redesign Medicare coverage and physician reimbursement to encourage diagnosis and to provide care planning for diagnosed individuals and their caregivers. In exchange for reimbursement, physicians would be required to record diagnoses in medical records.
 - Develop quality indicators for care and treatment of individuals with Alzheimer's disease.
 - Provide grants, through the CMS Innovation Center, for medical home model pilot projects specifically targeted at improving medical management for individuals with Alzheimer's disease, including managing coexisting conditions. This demonstration could be targeted at dually eligible individuals.
 - Create a blue-ribbon panel to recommend models of palliative care for people with advanced dementia, potentially funded through the CMS Innovation Center.
 - Improve and expand the National Family Caregiver Support Program (NFSCP), in part by incorporating evidence-based caregiver support models into the program. Increase NFSCP funding to support caregiver needs assessment; additional support groups, counseling, respite, and caregiver training; and access to all services for persons with Alzheimer's disease under the age of 60.
 - Develop pilot projects to reduce emergency room visits and hospitalizations for individuals with Alzheimer's disease, potentially funded through the CMS Innovation Center.
 - Expand funding and incentives for inter-professional geriatrics education and training programs for health professionals. This could include increasing funding for students, faculty, practitioners, direct service workers and family caregivers under Title VII and Title VIII of the Public Health Services Act. This could include student loan forgiveness for health professionals who study geriatrics and gerontology and work in underserved communities.

- During the discussion period, Advisory Council members suggested that the subgroup further investigate the following:
 - Whether the financial incentives for Accountable Care Organizations to control expenditures would discourage adaptation of high-cost "breakthrough" treatments for Alzheimer's disease.
 - Indicators of disease burden, such as health care costs related to Alzheimer's disease in the Medicare program, including providing

education to Medicare providers to enable them to provide more detailed coding on claims.

- Supporting service needs of children under the age of 18 who provide in-home care for relatives with Alzheimer's disease.
- Financial relief, such as tax rebates, for families who are paying out-of-pocket for their loved ones' care.
- Hospital emergency room care and in-patient care, specifically addressing staff training and facility design.
- Family-friendly workforce policies to assist caregivers needing flexible time to care for persons with Alzheimer's disease.
- Developing a system of experts available for practitioners that includes access to diagnostic assistance and community resources, and potentially piloting such a system using funding from the CMS Innovation Center.

- *Actions Proposed for Goal 1: Enhance Research to Prevent and Effectively Treat Alzheimer's Disease and Effectively Treat Alzheimer's Disease by 2025*, presented by Richard Hodes, NIH:

- The strategies and actions described focused on defining a process for prioritizing, in a measurable and accountable way, the research efforts to the future.
- Strategy 1.A: Identify Research Priorities and Milestones. The main proposed action is an international Alzheimer's disease-specific research summit with experts from a variety of research areas to identify priorities, milestones, and a timeline.
- Strategy 1.B: Enhance Scientific Research Aimed at Preventing and Treating Alzheimer's Disease. Actions include expanding basic research underlying Alzheimer's disease, identifying risk and protective factors for identification of targets, and improving enrollment in clinical trials by including more diverse populations.
- Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease. Proposed actions include identifying imaging and biomarkers to monitor disease progression and improving public-private collaborations.
- Strategy 1.D: Coordinate Research with International Public and Private Entities. Proposed actions include the creation of a comprehensive national and international inventory of research activities in the public and private sectors. The intent would be to make prioritization of research investments easier by collaboratively tracking investments and identifying gaps and non-

productive duplications. The Alzheimer's Disease Neuroimaging Initiative (ADNI) was highlighted as an example of a successful international research process and project.

- During the discussion period, Advisory Council members suggested setting as a high priority the development of a surrogate biomarker/endpoint that predicts or correlates with Alzheimer's disease. In theory, this would help move new biomedical treatments through clinical development and regulatory processes at a faster rate than current technology allows. In addition, presymptomatic identification of Alzheimer's disease could have implications for clinical and long-term services and supports, including increased demand for early intervention services.
- *Feedback on Actions Proposed for Goal 1: Enhance Research to Prevent and Effectively Treat Alzheimer's Disease and Effectively Treat Alzheimer's Disease by 2025*, presented by Jennifer Manly, Chair, Research Subcommittee:
 - The Research Subcommittee's principles for research-related goals, strategies and actions included that all proposals must be measurable, with an emphasis on accountability; additional resources and partners are needed; and the proposals must be responsive to the needs of those with Alzheimer's disease. The Research Subcommittee defined the scope of research activities to be included in the National Plan as a broad set of activities, including basic and epidemiologic research, development of non-pharmacologic and pharmacologic treatments and interventions, and testing of the efficacy and safety of those interventions. Attention needs to be paid to regulatory requirements and processes, especially related to the FDA approval process.
 - The Research Subcommittee proposed a revised Goal 2 statement: To prevent, effectively treat, and substantially delay the onset or slow the progression of Alzheimer's disease by 2020. The subcommittee's justification for a 2020 target date was guided by the group's belief that the National Plan goals should be bold and aggressive, yet maintain the support of the research community who will be carrying out the work proposed. The subcommittee maintains that the difference of 5 years is meaningful to the millions of people who will be affected by Alzheimer's disease and that, given sufficient resources, the research community is prepared to meet this deadline.
 - In addition, the Research Subcommittee presented an additional set of recommended actions to be incorporated into the strategies set forth by the federal Subcommittee. These actions include the following:
 - Commit resources to Alzheimer's research in an aggressive manner with appropriate accountability that will match the current and growing impact of the disease on society.

- Within 5 years, accelerate public access to new therapeutic interventions, including both pharmacologic interventions and non-pharmacologic interventions by compressing the average time for therapy development and regulatory review by 3 years.
- Provide incentives to private industry to invest in disease-modifying interventions.
- o No comments were made during the discussion period by members of the Advisory Council.
- *Closed Session:* From 12:15 p.m. to 1:15 p.m., a closed session was attended by Advisory Council members.

Subcommittee Breakout Sessions

- Advisory Council members met with their designated subcommittees to discuss the actions proposed by the respective federal subcommittees. Their charge was to develop additional changes and suggestions for the goals, strategies and actions outlined by the federal subcommittees. Members of the public present were invited to listen in on the deliberations.

Public Input

- *Public Comments*, moderated by Chair Ronald Petersen: Sixteen members of the public presented testimony, including family caregivers; a person with early-onset Alzheimer's disease, the National Task Group on Intellectual Disabilities and Dementia, Prevent Alzheimer's Disease 2020, the Alzheimer's Association, the American Health Assistance Foundation, the American Psychological Association, the Eldercare Workforce Alliance, the National Alliance for Caregiving, and the Alliance for Aging Research. Speakers made the following suggestions:
 - o Include additional strategies and actions that address the needs of persons with intellectual and developmental disabilities (IDD) and dementia. This may consist of improving services for people with IDD and dementia, developing workforce standards and training, adopting standardized diagnostic criteria, including persons with IDD and dementia in randomized controlled research trials, providing specialized supports for family caregivers, preparing state developmental disability agencies for the increase in acute and long-term service needs for persons with IDD and dementia, and utilizing funds from the CMS Innovation Center to pilot innovative models of community care.

- Devote federal funds to research on the causes of Alzheimer’s disease.
- Create a national Institutional Review Board for the oversight of multicenter clinical trials involving chronic neurodegenerative diseases.
- Educate Federal Government agencies and state Attorneys General about the components of the Olmstead Act and how they affect persons with dementia. Review relevant federal Medicaid regulations, policies, and previous guidance to assure that they are compatible with the requirements of the Olmstead decision and are focused on the needs of elders with disabilities, especially those with dementia. Medicaid is an important financial resource to assist states in meeting the Olmstead mandate. However, the scope of the Olmstead decision is not limited to Medicaid beneficiaries or to services financed by the Medicaid program. The Olmstead decision applies to all qualified individuals with disabilities, regardless of age.
- Enlist the U.S. Office of Personnel Management to promote federal employee participation in clinical trials.
- Designate a federal agency or quasi-government agency to coordinate public and private Alzheimer’s programs.
- Include mention of the role of psychologists in the diagnostic process.
- Focus public awareness and education campaigns on lifestyle changes in the promotion of prevention of further disability associated with dementia.
- Increase research in cognition as well as basic biology.
- Ensure investment in a sufficient, skilled elder workforce.
- Continue to address high-quality, coordinated interdisciplinary care through a team approach to care that includes persons with Alzheimer’s disease, their caregivers, and their families.
- Increase federal research investment to \$23 billion over the next 10 years. This funding would support investment across the field, from molecular biology to medical systems research.
- Fully fund the Older Americans Act Title III-E program, the National Family Caregiver Support Program.

- Focus on Medicare-funded in-home care, preserve in-home services in Medicare, and require Medicare to develop and reimburse innovative in-home services.
- Expand support for ongoing caregiver assessment to identify unmet caregiver needs and provide education, training, and support.
- Provide recommendations for the FY2013 budget with regards to Alzheimer's disease research, including an increase of \$1.4 billion for NIH and an increase of \$500 million for FDA.

Concluding Remarks for Day 1

- Chair Ronald Petersen thanked the Advisory Council members and the public for their input.
- The meeting adjourned at 4:30 p.m.

January 18, 2012

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, Eric Hall, David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, Laura Trejo, George Vradenburg, Geraldine Woolfolk. *Via Phone:* David Hyde Pierce.
- *Federal Members Present:* Lynda Anderson (CDC), Regina Benjamin (Surgeon General), Bruce Finke (IHS), Richard Hodes (NIH), Russell Katz (FDA), Donald Moulds (ASPE), Cindy Padilla (AoA), William Shrank (CMS), William Spector (AHRQ), Joyce Berry (SAMHSA), Joan Weiss (HRSA). *Via Phone:* Amber Story (NSF).
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)

Proceedings

- Meeting was called to order at 9:15 a.m. by Chair Ronald Petersen.
- An overview of the process, goal, and objectives for the second day of the meeting was outlined. The goal was to provide input to the Secretary of HHS as she develops a draft plan on Alzheimer's disease. One objective for the second day was for the full Advisory Council to hear and participate in constructive discussion about additional feedback from the subcommittees based on the previous day's discussion. Another objective was to document Advisory Council members' consensus around goals, strategies, and actions.
- Dr. Moulds stated that federal members had expressed that they were uncomfortable with the proposition of either voting on or endorsing recommendations that involve the allocation of federal resources. Federal members will abstain from comment on proposals related to the allocation of resources and endorsement of specific legislation.
- Dr. Lamont clarified that public comments on the Framework would be accepted until February 8 via e-mail to napa@hhs.gov. Following the release of the draft plan, a 30-day to 60-day *Federal Register* notice will be posted, asking for comments. Thus, there will be two opportunities for written comments, and input will be shared with the Advisory Council and the Secretary.

- The Advisory Council heard presentations by the three Advisory Council Subcommittees outlining their initial recommendations for expanding the draft Framework for the National Plan to Address Alzheimer's Disease. The PowerPoint slides for these presentations are available at <http://aspe.hhs.gov/daltcp/napa/011712/Mtg2-SubSlides.shtml>.
- *LTSS Subcommittee Proposal for Goal 3: Expand Patient and Family Support*, presented by David Hoffman, Chair, LTSS Subcommittee:
 - The LTSS Subcommittee principles described during the previous day were reiterated, and two additional principles/observations were added:
 - Caregivers are by nature sometimes isolated and reluctant to ask for help or do not know how to ask, even when it is needed. This isolation must be considered when managing programs for their benefit.
 - All services must be culturally appropriate. Outreach needs to include people from diverse communities, and no assumptions should be made that what works for one group will work for all groups.
 - In addition to the ten additional actions identified on day 1, the LTSS subcommittee added the following:
 - Relevant state agencies should provide key information about Alzheimer's disease to all staff working in human service agencies (e.g., social services, area agencies on aging) and first responders.
 - LTSS linkages should be provided to state, local and private housing resources.
 - The Affordable Care Act, including the Prevention and Public Health Fund, is a possible federal funding source for the LTSS Subcommittee's recommendation to support a state lead agency to coordinate all available public and private LTSS in every state.
 - The LTSS Subcommittee added to its professional training recommendation that: (1) rather than generic education, professional should be provided with specific decision-making tools for their profession; and (2) multiple training modalities must be used to provide training to any person in a profession or career track involved with LTSS.
 - During the discussion period, Advisory Council members suggested a number of additional actions:
 - Increase support for LTSS-related research, specifically to look at palliative care as it relates to Alzheimer's disease and caregiver research.
 - Review existing HHS plans to look for crossover strategies to create synergies in activities (e.g., Healthy People 2020, HHS Action Plan to Reduce Health Disparities, National Prevention Strategy).

- Increase support for studying the economics of caregiving, including the economic support of the family, caregivers within the community, and the impact of caregiving on work productivity.
 - Engage community-based organizations when designing and implementing the outreach campaign. Utilize community health workers and other non-traditional community-based workers in the campaign.
 - Develop a systematic way to study the hypothesis that high quality of care and support for families results in lower overall costs. Conduct similar analyses of the cost impact of evidence-based programs.
 - Identify ways to engage the private sector to stimulate business reaction to this population (e.g., explore tax policy or reimbursement policy incentives for private industry to develop new technologies to address care and caregiver needs, such as concerns about isolation and support).
 - Use the National Health and Aging Trend Study data to analyze the status of caregivers of all older adults with functional needs.
 - Identify best practices/model policies that employers may be able to implement to help support caregivers (e.g., AARP model employer policies).
 - Identify evidence-based practice recommendations for every care setting and research them, as necessary, for inclusion in a new care quality surveillance system (e.g., Alzheimer’s Association dementia care practice recommendations for nursing homes, assisted living, home care, and end-of-life care).
- *Clinical Care Subcommittee Proposal Goal 2: Enhance Care Quality and Efficiency*, presented by Dr. Laurel Coleman, Chair, Clinical Care Subcommittee, assisted by Dr. Bruce Finke:
 - The Clinical Care Subcommittee process merged the subcommittee and the subcommittee’s recommendations.
 - The Clinical Care Subcommittee reiterated that it recommended revised wording for Goal 2: Individuals with Alzheimer’s disease have the disease detected and diagnoses at an early stage, receive care planning, and have access to coordinated and high-quality health care throughout the course of the disease.
 - In addition to the actions identified on the previous day, the Clinical Care Subcommittee added the following:
 - Link the public to diagnostic and treatment services.
 - Enhance assistance for people with Alzheimer’s disease and their caregivers to plan for care needs.
 - Educate physicians about accessing long-term services and supports.

- Identify/develop dementia care guidelines/protocols/pathways to anchor quality indicators.
 - Provide medical management for individuals with Alzheimer’s disease, including management of coexisting medical conditions and coordination with family and community care providers in all settings (in-home care, long-term care, and inpatient hospital care) through robust, patient-centered medical home capacity in primary care.
 - Design public-private partnerships to develop and evaluate ways to improve hospital care for people with Alzheimer’s disease and other forms of dementia.
 - Implement interventions specific to populations with disparities (e.g., prevalence, access to services, disease impact).
- A focus is needed on primary care. The medical home could become a model for creating dementia-capable primary care. Dementia-capable care requires care team capabilities, care coordination, and care management, which are capabilities that are central to the concept of medical homes.
 - During the discussion period, Advisory Council members suggested a number of additional actions including the following:
 - Further explore the potential burden that the Clinical Care Subcommittee’s recommendations might place on primary care providers. Potentially create a template for providers that would be tied to new reimbursement structures.
 - Recognize in writing the National Plan that cost avoidance is challenging to measure in the same way as direct cost because it is focused on preventing emergency room visits, falls, and inappropriate hospitalizations.
 - Examine the opportunities provided by the Affordable Care Act (including Accountable Care Organizations) for re-envisioning the provision of care for persons with Alzheimer’s disease. In formulating recommendations, consider how the entirety of a patient’s medical costs is being managed. In addition, as best practices are brought into primary care, consider how to inform providers about how specific interventions may influence quality and the broader cost of care for which they will be accountable.
 - In developing metrics for this goal, examine the availability of services, access to services, and the “take-up rate” of services (i.e., how many people actually take advantage of services).
- *Research Subcommittee Proposal Goal 1: Enhance Research to Prevent and Effectively Treat Alzheimer’s Disease and Effectively Treat Alzheimer’s Disease by 2025*, presented by Jennifer Manly, Chair, Research Subcommittee
 - The Research Subcommittee’s concerns include potentially high-risk, high-reward proposals, enhancing training for Alzheimer’s disease researchers

who are in the early in their careers, and the process of developing priorities for research so that decisions can be made on how to best utilize those funds and maximize benefits.

- The Research Subcommittee reiterated their preference that the statement for Goal 2 be revised to the following: Prevent, effectively treat, and substantially delay the onset and progression of Alzheimer's disease by 2020.
- In addition to the actions identified on the previous day, the Research Subcommittee added the following:
 - Immediately increase annual federal research funding investment to a minimum of \$2 billion in targeted, outcome-oriented Alzheimer's research initiatives spanning basic, translational, and clinical research, and hold recipients of funding accountable for progress toward the overall stated goal.
 - Require HHS to develop, execute, and regularly update a scientific research plan and priorities to accelerate breakthroughs in Alzheimer's disease research. The research plan should include a review of the research infrastructure and provide programmatic recommendations for achieving these targeted research opportunities through sustainable, higher levels of annual funding.
 - Identify a person or office to be responsible and accountable for the execution of and advocacy for the National Plan, including responsibility for issuing reports to Congress and the Advisory Council.
- The Research Subcommittee recommended reduction of the time for moving therapies from target identification and validation through regulatory approval.
- Dr. Petersen presented the Research Subcommittee's case for speeding up the stated target date for Goal 1:
 - 2020 is attractive because it creates a sense of urgency.
 - A shorter timeframe is proactive and adds credibility to the National Plan.
 - The overall goal was modified to include delaying the onset of Alzheimer's disease, thus not guaranteeing a cure/prevention in 10 years (i.e., the development of a very effective, symptom-controlling drug would meet the goal as presented by the subcommittee).
- During the discussion period, Dr. Hodes emphasized the need to proceed in a date selection with caution to avoid unintended consequences that could distort the optimal scientific effort because of a set date.

- During the discussion period, members of the Advisory Council also suggested the following:
 - Involve the scientific community in setting research priorities.
 - Proposing an additional \$2 billion investment in research in this area may not be realistic given that domestic discretionary funding is frozen for the next 2 years.
 - Include language around researching models of care, including the best approaches to take care of persons with Alzheimer's disease outside of the drug development and other prevention-focused efforts.

- Dr. Moulds provided guidance on Subcommittee activity in advance of the release of the draft Framework of the National Plan. All groups were encouraged to continue meeting on a regular basis to discuss recommendations for the National Plan. Dr. Moulds clarified that the subcommittees are constrained by a stipulation that they must report back to the Advisory Council before making formal recommendations, creating some restrictions about the flow of information.

Concluding Remarks for Day 2

- *Concluding Remarks*, provided by Dr. Petersen, Chair:
 - Progress has been made toward the Framework and toward recommendations for the first draft to be released in early February.
 - The subcommittees will continue to convene and focus on collecting more data.
 - Additional stakeholder input needs to be included in developing the draft plan.
 - Timeline:
 - Full Advisory Council conference call in March (date TBD)
 - Next in-person meetings will be on April 17 and July 23.
 - Thanks to Advisory Council members and the public for their input.

- Meeting adjourned at 12:18 p.m.

Minutes submitted by Helen Lamont (ASPE).

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