

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

Washington, DC

January 27, 2015

Advisory Council Members in Attendance

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

General Proceedings

At 9:08 a.m., Chair Dr. Ronald Petersen called the meeting to order.

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

National Alzheimer's Project Act (NAPA) Review

Ms. Sheila Burke presented suggestions, main points, and next steps to be considered when developing the final set of recommendations.

- Two major points were highlighted:
 - Goal-setting and streamlining
 - Increasing exposure of committee recommendations--to become more well-known and engage people more directly

- Next steps to be considered by Federal Advisory Committee Act (FACA) include the following:
 - Have subcommittees review the goals and action items prepared to date and determine rank, priority, and whether the current goals ought to be edited, deleted, or adjusted to meet new challenges.
 - Discuss with respective subcommittee chairs the pros and cons of increasing efforts of coordination and cooperation in achieving Goals 2 and 3.
 - Ask each subcommittee to “cross-walk” recommendations with National Plan goals, strategies, and actions. Recommendations should be at the same “altitude” and scope of existing Plan components.
 - Convene subcommittee leaders to determine how to structure and orient work.
 - Given the importance of the recommendations, perhaps consider moving the time frame back so that the full FACA is given additional time to discuss the items each subcommittee proposes before voting. A change to the agenda, which has the subcommittees provide an overview at the October meeting, would provide the opportunity for subcommittees to learn the direction of their colleagues’ work and possibly modify and coordinate their recommendations before a January vote.

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

- Both federal and nonfederal members of the subcommittees provide the recommendations. If the subcommittee members are to recommend goals and metrics, there appears to be a gap in the process if not everything is included in the National Plan.

- An effort should be made to discuss and expose the recommendations more widely. One way of doing that is to have an audience look at the full breadth of what is being considered. Although it may not ultimately translate to the final Plan adjustments and may not become part of the Secretary’s plan, it could quickly become part of a consideration by Congress. There are two products to be considered: a product of the Advisory Council and the National Plan.

- An annual wellness visit was highly recommended for the previous update to the National Plan, but currently, because of the billing code used by providers, there is no mechanism to tell whether the cognitive assessment was done, what type

of tool was used, whether care planning was done, or whether a referral was provided.

- A variety of steps need to be taken to incentivize people to have the wellness visit and to make the availability of wellness visits better known.
- Even if not all recommendations are included in the Plan, applying metrics and goals to each of the recommendations ought to be part of the consideration at the subcommittee level. This will allow for identification of data necessary for the evaluation on whether progress is made.
- Consultation with federal agencies is important, but they may not have authority to make a change. Seeking change by taking the recommendations to Congress is advised.
- Changes in the recommendation development schedule, or at least modifications to the schedule, should be seriously considered.
- Annual wellness visits should consider the wellness of the caregivers, the majority of whom are women, in an effort to better understand the health impact of long-term caregiving.
- In terms of budgetary process, the Plan comes out in the spring. At that point, it is too late to have an impact on the budget discussions. The President's budget has its own cycle, is the product of work that occurred during the previous year, and is essentially completed at the end of the summer for review by the Office of Management and Budget (OMB), with a few opportunities for radical changes as it goes into the fall. The Congress, on the other hand, begins its process with the President's budget. Therefore, final recommendations could have an impact on what Congress is considering in the context of the appropriations bill and possibly a budget process that plays out through the summer. The recommendations will not have an impact on the President's budget this year but will potentially have an impact next year.
- The current timing for submitting the recommendation works well and should not be moved to late summer. Because the recommendations and the Plan are coming out in the spring, these two products could inform the agencies in time to be seriously considered before their recommendations are submitted to OMB at the end of the summer.
- Press releases would provide great exposure; however, press releases would not fall under the work of the agency. The advisory committees, which reside in a certain area, are independent.

- ASPE can send the report and recommendations to their constituents on behalf of the Council via Listserv and by publishing a notice in the *Federal Register*.
- There is a thin line between informing and lobbying Congress. Council members are considered federal employees as part of the Hatch Act of 1939 and cannot lobby Congress. Congress will come to its own conclusions on what steps might need to be taken to achieve the results.
- Creating a short-term working group would allow Council members to identify better exposure opportunities and coordinate with advocacy organizations.

Long-Term Services and Supports (LTSS) Subcommittee Recommendations

David Hoffman presented five recommendations from the LTSS Subcommittee:

- **Recommendation 1: Dementia-Capable LTSS**

The U.S. Department of Health and Humans Services (HHS) should support state initiatives to provide robust, dementia capable LTSS systems through:

- Providing coordinated Alzheimer's disease related activities across state agencies through an identified state lead entity with adequate funding from Congress.
- Supporting Alzheimer's Advisory Council partnerships with national partners to engage state governments in LTSS efforts.
- Partnering with state lead entities to assure full access to LTSS for populations at high-risk for Alzheimer's disease.

- **Recommendation 2: LTSS Research and Evaluation**

HHS should encourage federal agencies to include research on LTSS that addresses dementia capability in their research agendas. Topics needing further research include:

- Interventions that are: Culturally appropriate, for people in the early stages of dementia, for people with Down syndrome and other intellectual disabilities, and for people in the end stages of dementia.
- Impact of caregiving on health and quality of life of caregivers.
- Adequate training for paraprofessional caregivers in every venue to address cultural and dementia competence.

- **Recommendation 3: Coverage**

CMS should redesign Medicare coverage and health care providers' reimbursement to encourage diagnosis, support care planning, and active referral to LTSS:

- Include care planning with a family caregiver in Medicare coverage even if the individual with Alzheimer's disease is not present.
- Incorporate recommendations for palliative care into CMS surveillance and quality improvement systems.
- Provide reimbursement for providers to discuss palliative care early in the disease process.
- The Office of Civil Rights, HRSA and CMS should clarify and disseminate information to providers about the procedures under HIPAA with regard to sharing medical information with caregivers related to cognitive impairment, prognosis, and care planning in FFY 2015. This information should clarify that health professionals may evaluate decision-making capacity and that when patients lack decisional capacity, professionals may share appropriate information in the patient's best interest with caregivers. This guidance will be useful to professionals dealing with patients with any of the wide variety of diseases that may lead to a lack of decision-making capabilities.

- **Recommendation 4: Caregiver Support**

HHS, state lead entities, and providers should assure that caregiver behavioral health risk is assessed and addressed regularly through:

- Engaging individuals and families in advance care planning (health, legal, estate, and financial).
- Assuring that health and related systems funded with federal resources improve chronic disease treatment and related services for people with Alzheimer's disease as well as family caregivers.

- **Recommendation 5: Funding for LTSS**

Congress should assure adequate funding for the following:

- Activities listed in the Public Health Roadmap, the Alzheimer's Disease Supportive Services Program (ADSSP) and the National Family Caregiver Support Program.
- The Older Americans Act Title III to expand services to people with younger-onset dementia.
- The cost of federal support for state lead entities is estimated at \$80 million. Cost of other recommendations should be calculated by public and private entities with resources to establish estimates.
- An HHS panel to recommend innovative means of financing LTSS.

Discussion after the presentation included the following comments and clarifications:

- There is a tremendous amount of overlap in recommendations from the LTSS Subcommittee and the Clinical Care Subcommittee, which can also be seen as synergy.
- Except for specific recommendations about Congress providing funding and the dollar amount that supports state-led entities on which the federal members were silent, Federal and public members of the Committee agreed on the recommendations.
- The low-cost or no-cost recommendations are expected to be the subject of conversation shortly after the meeting.
- No actual costs associated with Goals 2 and 3 have been established yet. This task is currently in progress.
- Developing performance metrics might be difficult for some of the LTSS recommendations. The Council will ask for technical assistance from federal partners and others in developing the metrics and cost estimates.

After the discussion, committee members voted, and all of the previously listed recommendations from the LTSS Subcommittee carried. Federal members abstained from the vote.

Presentation on the Third Institute of Medicine (IOM) Advanced Dementia Panel

Drs. Susan Mitchell and Laurel Coleman reported on the IOM Advanced Dementia Panel proceedings.

- The objectives were to convene experts to review current research, innovative practices, and health policy pertinent to the care of people with advanced dementia and their families, and to make recommendations to HHS and the NAPA Advisory Council about priority initiatives to improve that care.
- With approximately 1,000,000 Americans with advanced dementia, there is a pressing need to provide high-quality care for these people and their families. Special considerations for the advanced dementia population include: (1) this is a vulnerable population with unique needs and severe functional and cognitive impairment; and (2) this population relies on surrogate decision-making and cannot live alone. In addition, family/caregiver burden is of high importance.

- Organization:
 - Co-chairs: Drs. Mitchell and Coleman.
 - Facilitator: Katie Maslow (IOM).
 - Core Group: Attend all meetings and formulate final recommendations.
 - Experts: Attend specific meetings.
 - Observers: Public, professional, and provider organizations; advocates; and staff from many federal agencies (Administration on Aging [AoA]/ACL, AHRQ, ASPE, the Centers for Disease Control and Prevention [CDC], CMS, HRSA, the National Institute on Aging [NIA], the National Institute of Nursing Research, the Substance Abuse and Mental Health Services Administration, and VA).

- Core Group, along with the following individuals: Co-chairs: Drs. Coleman and Mitchell; Dr. Alice Bonner: Northeastern University, *policy*; Dr. Sharon Brangman: the State University of New York, *care delivery, education*; Mary Ersek, RN: the University of Pennsylvania, *nursing, research and care delivery*; Dr. Laura Hanson: University of North Carolina, *clinical research*; and Dr. R. Sean Morrison: Mount Sinai, *research and policy*. The following individuals also participated in drafting final recommendations: Dr. Diane Meier: Center to Advance Palliative Care (CAPC), *policy*; Dr. Maribeth Gallagher: Hospice of the Valley, *care delivery*; Dr. Greg Sachs: Indiana University, *clinical research*; Dr. Joan Teno: Brown University, *clinical and policy research*; and David Hoffman: New York State Health Department, *public policy*.

- The first meeting, Research Panel, was held on January 28, 2014, and included the following experts in addition to the Core Group: Dr. Marilyn Albert, Dr. Ken Covinsky, Dr. Joan Teno, Dr. Richard Schultz, Dr. Constantine Lyketsos, and Dr. Greg Sachs.
 - The agenda items included Advanced Dementia Research Overview (Dr. Mitchell), Patient Experience (Dr. Hanson), Family Experience (Dr. Ersek), Health Services Utilization (Dr. Teno), and Infrastructure and Funding (Dr. Morrison).

- The Research Panel reached the following conclusions:
 - 25 years of research in nursing home, hospitals and community focused on feeding tubes, infections, hospice, decision-making, prognosis, family and costs.
 - Knowledge: delineated problems and main targets to improve care of patients with dementia and their families.
 - Clinical course: terminal condition and difficult prognostication.

- Sources of distress: treatable symptoms, measurement challenges.
 - Treatment of clinical complications:
 - Feeding and infections are most common.
 - Tube-feeding has no benefit, and antibiotics are overused.
 - Health services:
 - Hospice helps but is underused.
 - Hospital: common, costly, burdensome, avoidable.
 - Misuse of skilled nursing facility (SNF) (post-acute care).
 - Disparities.
 - Strategies to improve care: mostly observational: advance care planning, hospice; two randomized controlled trials: decision support tools.
 - Clearly delineated opportunities to improve care.
 - Current research priority: determine how to address opportunities: design and test clinical interventions and models of care to improve advanced dementia care and to design and evaluate health policy initiatives that incentivize high-quality, goal-directed care.
- The second meeting, Clinical Practice Panel, was held on September 28, 2014, and included the following experts in addition to those in the Core Group: Dr. Margaret Noel, MemoryCare; Dr. Jody Comart, Hebrew SeniorLife; Jed Levine, New York Chapter of the Alzheimer's Association; Dr. Ashley Shreves, Mount Sinai Hospital; Dr. Maribeth Gallagher, Hospice of the Valley; Dayna Cooper, MSN, VA Geriatrics and Extended Care; Dr. Greg Sachs, Indiana University; Ann Wyatt, MSW, Alzheimer's Association consultant; and Tena Alonzo, MA, Beatitudes.
 - The agenda items included innovative practices in care for people with advanced dementia in nursing homes, home and the community, hospice, and hospitals and emergency departments, as well as support and training for families and other caregivers.
 - The Clinical Practice Panel reached the following conclusions:
 - Nursing home program: Beatitudes:
 - High family and staff satisfaction.
 - Low medication use and reduced hospital and emergency department use.
 - Community programs:
 - Focus on palliative care and support for family/caregivers.
 - Advance care planning is a common theme.

- People with dementia (PwD) are less likely to die in the hospital and more likely to have lower levels of pain and distress.
- Hospice program:
 - Published results with lower use of restraints and feeding tubes and lower rates of hospitalizations.
 - Works cooperatively with long-term care facilities.
 - Excellent symptom management and family satisfaction.
- New strategies and programs:
 - All show promising results: training family caregivers, emergency department consultations, and printed guides for advance care planning/education.
- Very positive and encouraging day for all.
- Challenges:
 - Promising programs are slow to “scale up” and replicate.
 - Programs merit broader evaluation.
 - Successful programs need good leaders and culture change.
 - Are there policy incentives and regulatory “levers” that could hasten implementation of these models?
- The third meeting, Policy Panel, was held on January 21, 2015. The participants included the Core Group, along with David Hoffman and the following experts: Dr. Diane Meier, Mount Sinai Hospital, CAPC; Dr. Joan Teno, Brown University; Dr. Susan Miller, Brown University; Dr. David Grabowski, Harvard University; and Dr. Greg Sachs, Indiana University.
 - The agenda items included transforming care for people with advanced dementia: What will it take? How do we measure quality for this population? Agenda items also included policy barriers and opportunities for providing good care in various settings: home and community, nursing home, hospice, and hospital, as well as care transitions.
- The Policy Panel reached the following conclusions:
 - Very complex policy issues with high risk for unintended consequences.
 - Lack of access to palliative care.
 - Long-term care: Complex fiscal and regulatory policies create misaligned incentives that promote poor care.
 - Hospice: problems with access for PwD, documentation of dementia diagnosis, and coordination with the Medicare SNF benefit.
 - Home and community care: A large number of people have advanced dementia but have little information about specific needs.

- Acute and sub-acute care settings and services are used often, but care is often not beneficial.
- Quality metrics: many unique issues for advanced dementia.
- The Core Group formulated final recommendations based on the feedback from all three meetings and focused on advanced dementia, building on the existing National Plan and federal initiatives, priorities, and feasibility.
- Over-Arching Goal: To ensure the quality of life and quality of care for people with advanced dementia and their families across care settings.

- **Strategy 1:**

To ensure access to high-quality palliative care for people with advanced dementia and their families across all settings.

- Primary palliative care.
- Palliative care consultation.
- Hospice--beneficial but there are major access concerns.

What is palliative care?

- Palliative care is specialized medical care for people with serious illnesses.
- Provides relief from the symptoms, pain, and stress of a serious illness regardless of the diagnosis.
- Improves quality of life for the person and family.
- A team of doctors, nurses, and other specialists work with a person's other doctors to provide an extra layer of support.
- Appropriate at any age and at any stage in a serious illness and can be provided together with curative treatments.

- **Strategy 2:**

Prepare a workforce that is competent to deliver care to people with advanced dementia and their families.

- Health care workers (e.g., nurses, physicians, direct care workers, social workers) and LTSS (e.g., transportation, meals).
- Culturally competent--disparities across cultures.
- Across all settings--hospice that provides care for cancer patients but may not have adequately trained staff to provide care for patients with advanced dementia.
- New and existing workers.

- **Strategy 3:**

Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia.

- Harmonize documentation across settings.
- Critical to care, research, program evaluation, and policy.

- **Strategy 4:**

Support research, evaluation and dissemination of models of care to meet the needs of people with advanced dementia and their families.

- Across care settings.
- Align payment and delivery.
- Unique considerations that merit focus on advanced dementia.

- **Strategy 5:**

Leverage existing mechanisms to ensure access to high quality care for people with advanced dementia and their families.

- Examples: payment, regulatory, and public reporting:
 - Consider existing infrastructure (e.g., state coalitions to improve dementia care, quality improvement organizations, HHS Partnership for Patients).

- **Strategy 6:**

Support quality metrics that ensure transparency and accountability for the care of people with advanced dementia and their families.

- Must include proxy reporting (e.g., family, nurse).
- Examples of unique metrics:
 - Effective symptom assessment and management.
 - Burdensome, non-beneficial treatments (e.g., tube feeding, transitions).
 - Care concordant with values and preferences.
- Critical for clinical care accountability and research and policy evaluation

Discussion after the presentation included the following comments and clarifications:

- The recommendations from the Clinical Care Subcommittee are consonant with the LTSS Subcommittee's discussions.

- With a lot of movement and changes happening right now with health care, policy changes need to be considered, and the implications of those transformations need to be carefully thought out.
- Pointing at the evidence to see where gaps still exist is an opportunity for future research.
- There is disconnect in that some of the opportunities applicable to people with advanced dementia have to be seized early on. It is worth emphasizing that not all palliative care has to be just at the end of life. Two important aspects that transcend all different care settings, silos, and time and space are the care plan and the goals of care.
- Accountable care organizations (ACOs) are trying to change incentives by looking comprehensively at improved health outcomes and lower costs.
- ACOs are new, and the outcomes of that system change are yet to be seen. The high cost of the dementia patient population largely comes from a lack of care coordination and management over time, so ACOs should be more in the business of managing care and providing education and resources early than they would be in the current system, which is fragmented by silos.
- The dementia patient population provides a tremendous opportunity for bundled payment initiatives and capitated systems to work really well, but access to care needs to be balanced on both sides.
- Palliative care is an important access point for the services.
- There is a reasonable amount of evidence to show that programs such as Evercare, which bundles Medicare and Medicaid payments and hospice, delivers better care to patients with fewer health care transitions, with no differences in patient survival, and other measures. However, it is important to remember that quality elements or metrics are not known, even in a great program like Evercare, and these programs are not replicated throughout the United States. The billing codes recorded are not necessarily the diagnosis codes or the stage or the function of the patient, making understanding the characteristics of the population they cared for challenging.

Clinical Care Subcommittee Recommendations

Dr. Laurel Coleman presented recommendations from the Clinical Care subcommittee.

- **Recommendations 1: Dementia Friendly Communities (DFCs)**

HHS should encourage efforts to foster DFCs.

- Dementia Friendly Communities
 - A DFC resource currently exists on a state basis in Minnesota (Act on Alzheimer's), which has enabled 33 communities to start local efforts to better support people living with dementia and their care partners (CPs).
 - Early results from this effort has shown increased awareness of dementia throughout all sectors of the community (law enforcement, businesses, transportation, faith communities, etc.) as well as increased options for CP support and engagement with the community.
 - There may be DFC efforts in other states on a smaller scale that have additional strategies that should be investigated and evaluated as well.
 - HHS should support a piloting process of 10-15 communities or states funded by a request for proposal (RFP) process that would help seed community efforts and evaluate results. The communities chosen should reflect differences in cultural groups, size of community, and rural/urban locales.
 - Should the evaluation of the pilot programs justify replication, then the goal would be widespread adoption of DFCs by 2020.
 - Specific short and longer term success metrics of DFCs might include: increased access to support services for PwD and their CPs; new and/or more accessible services in multiple community sectors (e.g., faith, legal, financial, clinical services); increased rates of detection/diagnosis and participation in clinical trials due to normalization and greater awareness of the disease; increased rates of advance planning; increased rates of "living well" for PwDs and CPs via agreed upon indicators.

- **Recommendation 2: Improving Clinical Care for Persons Living with Dementia**

Evaluate feasibility of measuring care quality and effectiveness by using patient-centered goals.

- Improving Clinical Care for Persons Living with Dementia
 - Identify currently available measures that would reflect patient perspectives on care satisfaction in various settings.
 - Initiate regular measurement and reporting with those that are feasible now.

- Develop a specific plan to improve measurement capability over the next 3 years so that the perspectives and goals of people with Alzheimer's and their families are known. Subsequently, the metrics or goals relating to satisfaction with care and timely diagnosis can be developed and measured.
 - For reference, in 2014, the Clinical Care Subcommittee suggested the following measures based on the model in Great Britain: (1) I was diagnosed in a timely way; (2) I know what I can do to help myself, and I know who else can help me; (3) Those helping to look after me feel well supported; and (4) My wishes for my care are respected.
- In addition to the two recommendations, six goals were presented and are to be included with recommendations:
 - **Goal 1:** To ensure access to high quality palliative care for persons with advanced dementia and their families across all settings.
 - **Goal 2:** Prepare a workforce that is competent to deliver care to persons with advanced dementia and their families.
 - **Goal 3:** Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia.
 - **Goal 4:** Support research, evaluation and dissemination of models of care to meet the needs of persons with advanced dementia and their families.
 - **Goal 5:** Leverage existing mechanisms to ensure access to high quality care for persons with advanced dementia and their families.
 - **Goal 6:** Support quality metrics that ensure transparency and accountability for the care of persons with advanced dementia and their families.

Discussion after the presentation included the following comments and clarifications:

- The recommendations were jointly developed and supported by the Clinical Care and LTSS subcommittees. Because there is overlap on some recommendations, they will be streamlined and reorganized.
- The concept of DFCs is broader than the concept of dementia capability, which refers to clinical care and LTSS and includes more traditional services that people call upon to help manage care. In this concept, the community itself is able to handle the needs of PwD.
- DFCs are very consistent with the concept of “age-friendly” communities. The name might have changed, but the concept is the same.
- The National Quality Forum (NQF) is making efforts to assess the gaps and create a framework for measuring the quality of home and community-based services (HCBS). This is an HHS effort, but independent of that, there are other efforts to examine what can be done using electronic methods. Work on standardizing the important and critical data elements of what constitutes a good

care plan that is responsive to care goals is under way, but the work is not specific to dementia. The challenge of how to make it relevant and meaningful for PwD and their caregivers remains.

- Developing a compendium covering what states are doing, what models exist, and how states' activities differ should be considered.
- The final presentation of recommendations to the HHS Secretary and Congress would be more easily comprehensible if the altitude is increased and fewer goals that take more into consideration are considered.
- Every research recommendation will have four or five bullets under it, although there will be only four goals. This is a matter of packaging a presentation, and because all of the goals have been approved, this may be simply a matter of how best to make the presentation; 17 recommendations might be too many.
- Palliative care was thought to be the most important recommendation.
- All 17 recommendations will be included, but the presentation of the final recommendations will be discussed and decided later, keeping in mind the implications for preparing an executive summary.

After the discussion, committee members voted, and all of the recommendations from the Clinical Care Subcommittee carried. The goals, however, may be presented as a subgroup rather than as standalone recommendations to limit the number of final recommendations. Federal members abstained from the vote.

Research Subcommittee Recommendations

Dr. Jennifer Manly presented the recommendations from the Research Subcommittee.

- **Recommendation 1**

The 2015 National Plan must provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing and effectively treating Alzheimer's Disease by 2025.

- Roadmap should invite broad and inclusive input from experts.
- Priorities and interim milestones should be evaluated and updated each year.
- Include specific research milestones to:
 - Reduce racial/ethnic/socioeconomic disparities in Alzheimer's disease.

- Increase access to early diagnosis, diagnostic procedures, and potential disease modifying treatments among diverse groups.
- Make significant improvements in research recruitment rates and outreach among diverse populations.
- Include and prioritize specific milestones for Alzheimer's disease and related disorders.
- Include and prioritize specific milestones for populations at high risk for Alzheimer's disease (e.g., people with Down syndrome).

- **Recommendation 2**

The urgent need for increased annual federal research funding sufficient to meet the 2025 goal remains a top priority. Initial estimates of that level are \$2 billion per year but may be more. That investment would be applied to Alzheimer's research initiatives spanning basic, translational and clinical research.

- **Recommendation 3**

In developing their professional judgment budget, the NIH should identify the total science-driven funding needs for the budget year and also address the scale of needs anticipated through 2025.

- **Recommendation 4**

The 2015 National Plan should outline specific contributions being made by the United States government to the international initiatives needed to fulfill the commitments made by the United States government at the 2013 Dementia Summit in London, including how the United States government intends to raise the level of engagement, and seniority of governmental officials, engaged in those efforts.

In support of Recommendations 3 and 4, Harry Johns and George Vradenburg presented the following updates:

- The Alzheimer's Accountability Act
 - The Alzheimer's Association has worked with leaders in Congress to get the Alzheimer's Accountability Act first introduced into Congress in the past session with the intent that NIH would be enabled as they are at the National Cancer Institute to directly tell Congress and the Presidential Administration what, in their professional judgment as scientists, is the real amount of money that should be budgeted for Alzheimer's research. The legislation says that this is the NIH director's responsibility, but the likely person to assume this responsibility moving forward is Dr. Richard Hodes. The intent here is to create that opportunity, so it is not mitigated by politics

and other budgetary constraints that could be in place. In addition, the legislation has a responsibility to this Council to make a comment on the budget that scientists at NIH have submitted. The process will likely be addressed in the July meeting of the Council because the budget process starts in May-June. This will be an opportunity for Dr. Hodes and his colleagues to tell Congress, the Presidential Administration, and the Council the cost of the research element.

- International Update
 - At the Dementia Summit in London in December 2013, all of the Group of 8 countries made a number of commitments, which included the commitment to preventing and treating Alzheimer's by 2025 and a number of commitments in terms of significantly and collectively increasing international research efforts against the disease.
 - Another event was held in France on how to better move products from academic laboratories and commercial marketplaces and increasing the rate of public and private partnerships to accomplish that. During this event, the Minister of Health of Canada committed significant additional dollars to research budgets and committed to becoming a dementia friendly country, following Japan and the United Kingdom.
 - In fall 2014, legacy event was held in Japan during which three national funding agencies integrated, and dementia was identified as the major priority of their national research funding. Their National Plan is being reorganized to focus on perspectives of PwD and how the system responds to integrate the social care systems, so those systems are seamless for a person with dementia. In addition to the 2025 research goal, Japan has a 2025 care and support goal.
 - In spring 2015 there will be a meeting at the World Health Organization (WHO) with 62 health ministers invited. So far there is no indication whether the HHS Secretary is planning on attending.
 - Recommendation 4 speaks to the extent to which the United States government is taking steps internationally when combined with other governments' efforts.

Discussion after the presentation included the following comments and clarifications:

- The LTSS Subcommittee and the Clinical Care Subcommittee have made some important research and program evaluation recommendations. Perhaps all of these recommendations should be combined as part of our Research and Program Evaluation Subcommittee.
- In response to Down syndrome as a predisposing factor in Alzheimer's disease, it is important to remember that CDC, AHRQ, the Department of Defense, VA, and CMS are conducting program evaluations and may be interested in this area as a part of traumatic brain injury work.

- In Recommendation 2, the investment would be applied to research initiatives, meaning basic translation and clinical research. Community care or LTSS were not included in this recommendation, but research is needed in those areas as well.
- The National Institute on Disability and Rehabilitation Research will be a part of ACL and does a fair amount of work on traumatic brain injury.
- It was suggested that language be added to Recommendation 2 to include LTSS, because research is surely needed in that area also.

After the discussion, committee members voted, and all of the recommendations from the Research Subcommittee carried. Federal members abstained from the vote.

Public Input

Rohini Khillan moderated the public comments portion of the meeting.

Eleven members of the public presented testimony either in person or by email and included people living in the early stages of Alzheimer's, family members and caregivers of PwD, and representatives from the National Certification Board for Alzheimer Care, Alzheimer's Foundation of America (AFA), Dementia Action Alliance, Association for Frontotemporal Degeneration (AFTD), Alliance for Aging Research, Eldercare Workforce Alliance (EWA), and National Task Group on Intellectual Disabilities and Dementia Practices (NTG).

- In 2015, the stakes are high; if you are a daughter of aging parents, the likelihood that you will be caring for your children and parents at the same time is increasing. The likelihood that one more of your parents will have dementia is growing exponentially. As a daughter, I want to emphasize how desperately we need to create an infrastructure to support our family caregivers. A large portion of the National Plan is directed to this theme. We need to step up efforts to make this a reality. I believe we are at a critical juncture when we are going to lose a generation of daughters to the perils of caring for a parent or parents with dementia.
- It was recommended that the nonfederal members of the Council consider sending letters to Secretary Burwell, encouraging her to be the United States representative at the ministerial meeting and to take the opportunity to learn firsthand from her international counterparts about what could be done even better at home.
- Nonfederal members of the Council were encouraged to conduct their own Capitol Hill briefing about the 2015 recommendations--not necessarily to take

positions in front of members of Congress and their staff, but show up on the Hill and walk through the report that is submitted to the Secretary.

- It is important that people get early detection and diagnosis that are timely, accurate, and conveyed compassionately. Give families and people with Alzheimer's disease all the opportunities to know what they are facing and what they can do about it.
- Connections should be drawn from the annual wellness visit, to the HOPE for Alzheimer's Act that we are all familiar with, to forthcoming legislation. There is an expectation to see cures initiated in the 21st century in an effort to have a global clinical trials platform. There is an intention to do that for pediatric diseases, and there is no reason not to do the same for central nervous system diseases, particularly for Alzheimer's-related disorders.
- From the global clinical trials platform, if there is an effort to translate into research cohorts, families and people with Alzheimer's disease are given the power to do something beyond their own families or their communities and country and for people around the world, and to help advance the day when there is prevention, a better means of treatment, and eventually a cure.
- Japan and Sweden are examples of countries that currently adopted provision of dementia care and small settings as national policy.
- Partnerships between the National Plan and the states were recommended. States should be encouraged to adopt state plans.
- The Plan should be used to encourage the implementation in state governor's offices and to commit resources to dementia care at the state level for people with intellectual disabilities.
- In addition to the national focus of the Plan and commitment among federal agencies, the states are involved as well, creating opportunities for partnerships among the 51 entities (the states and Washington, DC) and other territories.
- NTG developed a national curriculum on dementia care and intellectual disabilities, which is now available. The curriculum has gone through a pilot testing phase and will be available to entities around the country.
- AFA recommends that CMS develop and execute a timeline to nationally adopt innovative care models and caregiver supports. Soon, the data from Round 1 from the Center for Medicare and Medicaid Innovation demonstration projects will be available and provide the evidence-based data that CMS needs to make these innovative dementia caregiving programs national.

- AFA recommends having the NAPA board ask the National Governor's Association to establish a forum for states to get together to share best practices and failures and to discuss gaps in coverage.
- Another recommendation is to promote and encourage opportunities for memory screening. Specifically, AFA is asking the NAPA board for further research on cognitive screening and its impact on people with Alzheimer's disease and their families. With early diagnosis of Alzheimer's disease, much can be done for the person with Alzheimer's disease and the caregiver to prepare them for the challenges associated with the disease.
- Another recommendation is to increase United States commitment to international efforts.
- The last recommendation calls for resources and calls on Congress to double funding in FY 2016 for Alzheimer's disease research and to set us on a pathway toward \$2 billion in funding by 2020.
- Most of these recommendations are not costly, can be quickly implemented, and will have an immediate and positive impact.
- Currently, there has been a worldwide effort against Ebola. This year, the United States will spend \$5.2 billion in combating Ebola, developing a cure, preparing hospitals, and training caregivers and other first responders. That type of commitment is needed to fight Alzheimer's disease and provide support and services for their family caregivers.
- Care and services should be included in the recommendations. The likelihood of finding a cure or a treatment that will address the symptoms that affect one's life if he or she was to develop the disease, and his or her quality of family life, is extremely unlikely to be solved within the next 10 years, given the complexities of neurodegenerative conditions. The same level of the Council's engagement used to develop research recommendations is needed to develop recommendations for care.
- There needs to be a financial commitment to find out what is out there, what is working, what is not working, and how to make that part of the National Plan.
- There needs to be a common word instead of using "dementia" and "Alzheimer's disease" interchangeably. Language matters, and the rights and the responsibilities of the individual in this nation matter. We have to be dementia competent and dementia confident, not dementia friendly.

- AFTD recommended a related dementia expert to be included as an additional Council member. This person could be a caregiver, a staff member or board member of a rare disease advocacy organization, or a researcher.
- AFTD is releasing an RFP for an economic burden study (the first of its kind) in caregiving for frontotemporal dementia (FTD). That study would specifically inform the introduced recommendation.
- NIH announced the largest-ever round of grants in FTD research. The research community and AFTD are incredibly excited about these opportunities.
- Experts consider Alzheimer's disease to be the most expensive disease known to man, and addressing this issue is an urgent matter. An adequate workforce is critically important. The Council could provide core competencies for dementia training. The eight domains of dementia training include knowledge of the disease, communication, patient rights, behavior, activity, help, caregiver needs, and safety. This would be helpful in developing a model for state plans.
- Most of the information and metrics, especially funding and dollar amounts, are based on the federal funding. It is important to remember that the public pays out of pocket, and huge amounts of that are for private-pay home care.
- EWA is a coalition of 31 national organizations joined to address the immediate future of the care workforce in the crisis states. Access to quality health care for older adults with cognitive impairments is vital to healthy aging. It is important to determine how many dementia-capable geriatric and gerontological health specialists are needed to address the needs of the population, both in the short term and long term, as well as to target strategies and milestones for meeting the need and ensuring competency. EWA looks forward to seeing the report, hopes that this will remain a priority of the Advisory Council, and would like to offer support for this effort. EWA strongly supports the recommendations from the Council for adequate training and compensation for the direct care workforce, as well as increased emphasis on funding supports and resources for family caregivers.
- EWA would like to stress the importance of Advisory Council support for geriatrics and gerontology education and training programs responsible for preparing the health care workforce. This responsibility falls primarily to HRSA, specifically administering the Titles VII and VIII programs of the Public Health Service Act. In recent years, the funding for these programs has remained leveled, but additional funding is essential if these programs' activities are to be expanded to address the needs of the growing number of older adults with Alzheimer's and dementia.
- In December 2014, HRSA announced that it would be consolidating the four existing Titles VII and VIII programs into one grant called the Geriatrics

Workforce Enhancement Program. Applicants for the new program will have the opportunity to apply for funding through the Alzheimer's Disease Prevention Education and Outreach program, which supports continuing education for health care professionals, including direct care workers and community caregivers. The new program is designed to provide greater flexibility for grantees to meet the needs of specific communities. HRSA estimates that with the current funding levels, only 40 awards will be made.

- EWA urges the public members of the Council to call for increased funding to these training programs.
- Additionally, EWA would like the public members of the Council to include the 2013 recommendation: Congress passed legislation to provide loan repayment for those in disciplines specializing in geriatrics and elder care. Ensuring that everyone is competent to care for older adults is imperative to meeting the needs of people with Alzheimer's and family caregivers.
- Because the Advisory Committee has the power to go directly to Congress, the Committee could ask them for follow-up. There may be a reason that the Committee cannot say that Congress is not moving fast enough, and the dollars are not forthcoming. Please think outside the box because you have no limitations.
- The Alzheimer's Accountability Act (H.R. 4351/S. 2192) was signed into law, and the bill is to ensure that Congress has necessary information to set funding based on what NIH believes is required to best research Alzheimer's. It is my hope that the Council will work with NIH and submit recommendations that will accurately reflect the needs of the community and in turn have those needs funded in the FY 2016 HHS appropriations bill to help lead us toward the goal of effectively treating and preventing Alzheimer's.
- Abington Health has introduced the first step of its dementia-friendly training program.
- A few months ago, an article by Dr. David Satcher, "Alzheimer's Is Greater Public Health Crisis than Ebola," was published. I was appalled to hear that the United States government requested \$6 billion in funding to address Ebola. Although I understand the importance of action, why doesn't someone see dementia as an even greater need? People who get Ebola in the United States still have hope for a cure and survive. Those with Alzheimer's disease are not so fortunate. About 5 people have been affected by Ebola in the United States compared with more than 5 million who have been affected by dementia.
- AARP has spoken out against the injustices being done to PwD in the latest edition of its bulletin, called "Where's the War On Alzheimer's?"

- More than 500,000 people die from Alzheimer's disease each year.
 - The average monthly death rate is 41,666.
 - The average weekly death rate is 9,615.
 - The average daily death rate is 1,369.
 - The average hourly death rate is 57.

This is equivalent to three 747 airplanes crashing every day. Who in this room does not see the urgency that we must do something now?

- Posterior cortical atrophy (PCA) is a progressive degenerative condition involving the loss and dysfunction of brain cells, particularly at the back of the brain, where visual processing takes place. In the vast majority of cases, this loss of brain cells is associated with the same pathological brain changes seen in typical Alzheimer's disease, but in addition to memory issues, PCA affects how the brain interprets what the eye sees. It also affects the ability to access the right words from the brain, making speech difficult.
- Of major concern is the financial component of continuing care. I was appalled to learn of Congress's recent plans to cut Medicare disability benefits, apparently as a response to significant fraud in the system. Why not address the fraud issue separately, and allow those who really need the benefits to continue receiving them? I have some ideas about how this could be accomplished, such as requiring that the recipient has a disease that is incurable and/or terminal and require validation from at least three physicians. I believe that this alone would eliminate much of the fraud. I would gladly work with your committees on this subject as appropriate.
- Moving the time frame for National Plan recommendations back to October would give more time to the process. Although HHS works hard to develop the slides, seeing them only 2 days before they are presented hardly provides enough time for thoughtful deliberation, let alone for Council members to vote on recommendations that will potentially affect millions of Americans.
- The LTSS recommendations are way too general and provide no benchmarks for which agency should specifically execute which task, what the timing of each task should be, or how much federal and/or private funding may be needed. For example, one of the recommendations states that HHS should support state initiatives for dementia-capable systems by "providing coordinated Alzheimer's disease-related activities across state agencies through an identified state-led entity with adequate funding from Congress." What activities should they coordinate? Through which agencies? What would "adequate funding from Congress" mean? The CMS recommendations in particular have tremendous potential but are not properly mapped out. For example, what needs to happen for CMS to allow for care planning when the patients are not there--do we need a

new code for providers to have time to counsel or train family members, or is there an existing code that could be expanded?

- Member of the public supported LTSS Recommendation 5 that calls on Congress for funding and even mentions a specific amount. Additionally it was recommended to add CDC's Lifespan Respite Care Program to calls for funding ADSSP and NFCSP. Estimates for these programs can be found in the authorizing language and/or with caregiving groups.
- The work on advanced dementia is very impressive and so important. This community, knowing what we know about Alzheimer's disease and related dementias, has something very important to say to policymakers about the value of giving people with serious illness the freedom to make more informed choices about their care and the power to have those choices honored. So, whether we might support the Care Planning Act of 2013, introduced by Senators Isakson and Warner, and/or the Advanced Planning and Compassionate Care Act of 2014, introduced by Senators Collins and Rockefeller, advanced care planning needs to start sooner, along with the support of the patient's health care professionals, and it should be covered by Medicare and Medicaid. A lot of complications of care mentioned here could be avoided if more people had a plan. Bigger-picture policy recommendations to help support all of the other great recommendations suggested should be considered.
- It would be great to see something in the 2015 Plan about engaging CMS and CDC in a campaign to encourage providers to use the utilize wellness visit. The wellness visit benefit has been in place for 4 years now, and little to nothing has been done to take advantage of it and get more people identified.
- Policymakers want to know how much the dementia cost for research, clinical care, and long-term care. The professional judgment budget happened because federal staff from NIH would not provide members of Congress with a straight answer about how much was needed.

LTSS Subcommittee Report

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:
 - NIA funded a new study: Consequences of Reduced Antipsychotic Prescribing in Nursing Homes.
 - The project will follow a group of nursing home residents, many with dementia and disabling chronic conditions, enrolled in the Medicare prescription drug benefit (Part D).

- The purpose is to examine drug coverage in the nursing home setting, identify the factors that influence Part D enrollment, and estimate how drug coverage influences the use of medications.
- The findings could inform the Medicare program of the experience of nursing home residents under Part D.
- Activities related to Goal 3, Expand Supports for People with Alzheimer's Disease and Their Families, included the following:
 - ACL is facilitating the Chicago Volunteer Representative Payee Pilot Program in coordination with the Social Security Administration.
 - The Chicago AAA is recruiting and training volunteers to serve as representative payees for older adults with dementia and other conditions who lack the capacity to manage their finances.
 - The program is designed to help people stay in their own homes and maximize their independence.
 - Client service was implemented in late January 2015.
 - Funding from the Corporation for National and Community Service.
 - ACL, with IHS, developed and distributed the "Dementia and Indian Country" fact sheet to tribal leaders at the December 2014 meeting of the Secretary's Tribal Advisory Committee and on <http://www.olderindians.acl.gov>.
 - The Rx Foundation is funding expansion of Resources for Enhancing Alzheimer's Caregiver Health (REACH) to 50 tribal communities through the University of Tennessee.
 - This is a joint venture of IHS and ACL.
 - Caregiving challenges for PwD in Indian country are amplified by the relative lack of formal LTSS and by the rural and frontier setting of many tribal communities.
 - The program provides a strategy and framework for health and social support professionals from IHS and tribal public health nursing programs and the AoA/ACL Native American Caregiver Support program to help family caregivers with the behavioral symptoms of elders with dementia and their own stress and coping.
- Activities related to Goal 4, Enhance Public Awareness and Engagement, included the following:
 - ACL and the Banner Alzheimer's Institute are planning the 3rd Annual Alzheimer's in Indian Country Conference, which is scheduled for September 2015 in the Gila River Indian Community in Arizona.

- Activities related to Goal 5, Improve Data to Track Progress, included the following:
 - An ASPE report, Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study, which uses the National Health and Aging Trends Study, to describe late-life disability and care needs of older adults with dementia. The report is available at <http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DS.cfm>.
 - An ASPE report, Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study, examines the role and experiences of unpaid caregivers for the older population, including those with dementia, using the new National Study of Caregiving. The report is available at <http://aspe.hhs.gov/daltcp/reports/2014/NHATS-IC.cfm>.
 - In 2014, CDC released Behavioral Risk Factor Surveillance System (BRFSS) data focused on self-reported increased confusion or memory loss (i.e., cognitive impairment). The data were reported in the following documents:
 - 2011 BRFSS data on cognitive impairment and co-occurring conditions among adults aged 60 or older (<http://www.cdc.gov/aging/pdf/2011-brfss-state-summary.pdf>).
 - 2012 BRFSS data examining cognitive impairment and discussions with health care providers among adults aged 45 or older (<http://www.cdc.gov/aging/pdf/2012-BRFSS-state-summary.pdf>).
 - Data brief shared with states (<http://www.cdc.gov/aging/pdf/2012-BRFSS-state-summary.pdf>).

Discussion after the presentation included the following comments and clarifications:

- University of Tennessee Health Science Center with REACH in the VA is moving forward with the project to train tribal providers. The Aging Network and Tribal Health Program are directly involved in this project. More on this project will be reported in the future.
- Subjective cognitive impairment is an important factor and a piece of information that many sites are trying to gather because it can be useful in predicting who will become impaired in the future.

Clinical Care Subcommittee Report

Drs. Joan Weiss and Shari Ling reported on activities of CMS and HRSA.

- HRSA activities included the following:
 - A new Geriatrics Workforce Enhancement Program funding opportunity was released. Its deadline is March 5, 2015, and it is a \$4 million grant for Alzheimer's disease and related dementia education and training.
 - HRSA is working on a unified Alzheimer's disease training curriculum.
 - HRSA is in the process of aggregating data from the Geriatric Education Center Alzheimer's disease and related dementia education and training.
- The Gerontology Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis published a Report and Recommendations, available at <https://www.geron.org/images/gsa/documents/gsaciworkgroup2015report.pdf>.
- The Physician Quality Reporting System Dementia Measures Group includes the following quality measures:
 - 280 -- Dementia: Staging of Dementia -- Percentage of patients, regardless of age, with a diagnosis of dementia whose severity of dementia was classified as mild, moderate or severe at least once within a 12 month period.
 - 281 -- Dementia: Cognitive Assessment -- Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least within a 12 month period.
 - 282 -- Dementia: Functional Status Assessment -- Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results reviewed at least once within a 12 month period.
 - 283 -- Dementia: Neuropsychiatric Symptom Assessment -- Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and results reviewed at least once in a 12 month period.
 - 284 -- Dementia: Management of Neuropsychiatric Symptoms -- Percentage of patients, regardless of age, with a diagnosis of dementia who have one or more neuropsychiatric symptoms who received or were recommended to receive an intervention for neuropsychiatric symptoms within a 12 month.
 - 285 -- Dementia: Screening for Depressive Symptoms -- Percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12 month period.
 - 286 -- Dementia: Counseling Regarding Safety Concerns -- Percentage of patients, regardless of age, with a diagnosis of dementia or their

- caregiver(s) who were counseled or referred for counseling regarding safety concerns within in a 12 month period.
- 287 -- Dementia: Counseling Regarding Risks of Driving -- Percentage of patients, regardless of age, with a diagnosis of dementia or their caregiver(s) who were counseled regarding the risks of driving and the alternatives to driving at least once within a 12 month period.
 - 288 -- Dementia: Caregiver Education and Support -- Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND referred to additional resources for support within a 12 month period.
- The NQF published its final report, titled “Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer’s Disease.”
 - Comprehensive diagnostic evaluation and needs assessment characteristics include the following:
 - Establish an accurate diagnosis of dementia.
 - Determine functional status, living arrangements, and impact on family.
 - Assess needs of the person with dementia.
 - Assess resources of the person with dementia.
 - Evaluate driving status and other safety concerns.
 - Identify a proxy or spokesperson for decisions that the person with dementia cannot or will not be able to make in the future.
 - Facilitate use of advance directives.
 - Identify caregiver needs (at baseline).
 - The NQF Measure Application Partnership recommended to move forward with the development of the electronic Clinical Quality Measures. The measures included the following:
 - The percentage of patients aged 80 or older at the start of the measurement period with documentation in the electronic health record at least once during the measurement period of: (1) results from a standardized cognitive impairment assessment tool; or (2) a patient or informant interview.
 - The percentage of patients with a diagnosis of dementia or a positive result on a standardized tool for assessment of cognitive impairment, with documentation of a designated health care proxy during the measurement period.
 - More information on HCBS quality measures can be accessed at http://www.qualityforum.org/Measuring_HCBS_Quality.aspx.

Discussion after the presentation included the following comments and clarifications:

- Medicare-participating physicians and physician group practices receive an incentive for reporting and participation in this quality reporting program. The program has evolved from the incentive for participation to an adjustment of payment. The providers are permitted to report using any of the quality measures that are available for this purpose to avoid the adjustment. Providers can choose from the dementia-specific quality measures currently in use because there is no requirement to report any specific quality measure.
- The annual wellness visit is a built-in benefit for Medicare beneficiaries but continues to be underutilized.

Research Subcommittee Report

Dr. Richard Hodes reported on the following research activities:

- FY 2015 Appropriations Update:
 - H.R. 83: On December 16, 2014, President Obama signed into law the Consolidated and Further Continuing Appropriations Act, 2015, which provides funding through September 30, 2015, as P.L. 113-235.
 - NIA received an additional \$25 million in its budget for FY 2015.
 - Total NIA appropriation increased from \$1.172 billion in FY 2014 to \$1.198 billion in FY 2015.
- NIA Budget Increase Report Language:
 - Alzheimer's disease: The agreement includes an increase of \$25,000,000 for NIA. In keeping with longstanding practice, the agreement does not recommend a specific amount of NIH funding for this purpose or for any other individual disease. Doing so would establish a dangerous precedent that could politicize the NIH peer review system. *Nevertheless, in recognition that Alzheimer's disease poses a serious threat to the Nation's long-term health and economic stability, the agreement expects that a significant portion of the recommended increase for NIA should be directed to research on Alzheimer's disease.* The exact amount should be determined by scientific opportunity of additional research on this disease and the quality of grant applications that are submitted for Alzheimer's disease relative to those submitted for other diseases.
 - The report language acknowledged the \$25 million increase in NIA's budget.
 - No specific earmarks for Alzheimer's disease were mandated, but the language states that "a significant portion of the recommended increase for NIA should be directed to research on Alzheimer's."

- Decisions about funding allocations should be determined by scientific opportunity and the quality of grant applications that are submitted for Alzheimer's disease relative to those submitted for other diseases.
- Alzheimer's Disease Bypass Budget Language:
 - SEC. 230: Hereafter, for each fiscal year through FY 2025, the Director of the NIH shall prepare and submit directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the HHS Secretary and the Advisory Council on Alzheimer's Research, Care, and Services, an annual budget estimate (including an estimate of the number and type of personnel needs for the Institutes) for the initiatives of the NIH pursuant to the National Plan, as required under section 2(d)(2) of Public Law 111-375.
 - Language in SEC. 230 of the FY 2015 Appropriations Act requires a bypass budget for NIH Alzheimer's disease research to be submitted to the President.
 - The HHS Secretary may review and comment, but not alter, the NIH budget submission.
 - The budget will be estimated based on the NIH components of the National Plan.
 - NIH is in discussion regarding how the development of the budget will proceed.
- The 2015 Alzheimer's Disease Research Summit will be held on February 9-10, 2015, and national and international participation is anticipated. Five hundred attendees already registered. For those not able to attend, a live videocast will be available.
- Group of 7 wrap-up will be held from March 16-17, 2015, in Geneva, Switzerland. The meeting is organized by the WHO.
- International Alzheimer's Disease Research Portfolio (IADRP) Update:
 - The Canadian Institutes of Health Research is now officially part of the IADRP. Its portfolio has been uploaded, and it is listed as a member. Its data now comprise almost 10% of the current IADRP records.
 - Common Alzheimer's Disease Research Ontology has been adopted by the WHO for its upcoming portfolio analysis.
 - IADRP by the numbers:
 - Alzheimer's disease project data from across 27 NIH Institutes and Centers.
 - Data from 32 public, private, and international funding organizations representing 8 countries.

- Approximately 6,000 unique projects.
 - An estimated 3,800 principal investigators working at approximately 1,000 institutions in 31 countries.
- The Advances in Amyotrophic Lateral Sclerosis (ALS) and FTD Genetics Workshop was held on November 14, 2014. Progress on ongoing efforts in FTD and ALS human genetics research, with particular focus on genes that cause both FTD and ALS, was shared. Discussions included strategies to improve clinical assessments, enable meta-analyses across genetic data sets, and validate candidate disease alleles. The workshop was co-hosted by National Institute of Neurological Disorders and Stroke (NINDS), AFTD, and the ALS Association.
 - The Alzheimer's disease-related dementias 2016 meeting organized by NINDS will be held from March 29-30, 2016, at the Natcher Conference Center, NIH Main Campus, Bethesda, Maryland. The goals of the meeting are to assess progress and to revise and update the Alzheimer's disease-related dementias 2013 recommendations.

Discussion after the presentation included the following comments and clarifications:

- The target timeline for submission of the bypass budget is June 2015. It is necessary to link the most recent priorities from the National Plan to submit the bypass budget. The National Plan is expected to be available in May. In the meantime, NIH will continue to review scientific input from previous iterations, and those will be updated again after the February 2015 Summit. The estimates of research cost requirements will be ready as the Plan comes out in May.
- To identify any gaps in the National Plan, NIA will examine the inputs from the 2015 Summit, 2012 Summit, and Related Dementia Summit and coordinate and integrate all of the information.
- The Plan facilitates the professional judgment budget. Therefore, the publication time of the Plan is important.
- The bypass budget will go to the President and Congress. It will include comments from the HHS Secretary but will not be altered. The President's budget will come out in February 2016.
- Based on the legislation, the bypass budget will be a single-year estimate. The language associated with the budget may include comments on anticipated needs through 2025.
- It was recommended for NIH to look at lessons learned from the National Cancer Institute and the NIH Office of AIDS Research about the process of preparing the bypass budget.

- In addition to cost estimates for cure and treatment research, the research activities brought up in the LTSS Recommendations should be included in the bypass budget.

Concluding Remarks

- Dr. Ron Petersen requested that the subcommittee chairs address any relevant topics and provide input for the preamble.
- Subcommittees are encouraged to start thinking about how to move from prioritizing to developing metrics.
- The Council is to consider the process of sending letters to Secretary Burwell and Congress to inform them of developed recommendations.
- Rohini Khillan will follow up with more details on the process of including additional Council members.
- Dr. Laura Trejo resigned from the Council because of work commitments.
- Senator Susan Collins, Majority Chair of the U.S. Senate Special Committee on Aging, has been considered a champion for Alzheimer's disease.

The next Advisory Council meeting will take place on April 27, 2015.

The meeting adjourned at 2:48 p.m.

Minutes submitted by Rohini Khillan (ASPE).

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