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

Washington, DC

January 25, 2016

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Ronald Petersen (Chair), Ronald Petersen (Chair), Gary Epstein-Lubow, Laura Gitlin, Harry Johns, Myriam Marquez, Helen Matheny, Jennifer Mead, Sowande Tichawonna, Angela Taylor, Donna Walberg

- *Federal Members (or representatives) Present*: Marianne Shaughnessy and Susan Cooley (Department of Veterans Affairs [VA]), Linda Elam (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Bruce Finke (Indian Health Service [IHS]), Richard Hodes,(National Institute on Aging, National Institutes of Health [NIA/NIH]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Lisa McGuire (Centers for Disease Control and Prevention [CDC]), William Spector (Agency for Healthcare Research and Quality), Jane Tilly (Administration on Community Living [ACL]), Joan Weiss (Health Resources and Services Administration [HRSA])

- *Quorum present?* Yes

- *Advisory Council Designated Federal Officer*: Rohini Khillan (ASPE)

General Proceedings

At 9:42 a.m. ET, Dr. Ronald Petersen called the meeting to order. Dr. Petersen thanked the participants and ASPE for quickly facilitating a WebEx meeting to allow the Council to meet in spite of weather-related challenges. He also shared that the discussion of Council recommendations will be moved to the April meeting so that discussion can take place during a face-to-face meeting. Dr. Petersen highlighted several considerations related to this timing change:

- APSE's strategic planning efforts will not be negatively impacted by three-month delay in delivery of Council recommendations.

- The NIH bypass budget process will not be compromised by the delay in Council recommendations.

- The development of recommendations may be even better informed by the March 2016 Alzheimer's Disease-Related Dementias Summit.

- The additional time for onboarding the six new Council members will allow for more robust participation in recommendations development by all Council members.

Federal Workgroup Updates

Jane Tilly, Shari Ling, and Richard Hodes shared updates from the federal workgroups.

Long-Term Services and Supports (LTSS)

- In fiscal year 2016 (FY2016), NIH received a $350 million increase in funding for Alzheimer’s disease; these additional funds are inclusive of efforts related to LTSS.

- In December 2015, NIA released the 2014-2015 *Alzheimer’s Disease Progress Report: Advancing Research Toward A Cure*. Research progress in the Care and Caregiver Support category (Category E), as well as promising research opportunities are included in the report.

- The ACL/CDC/NIA-sponsored Webinar series is in its third year and is well-attended, with approximately 800 participants at each Webinar. Continuing Education credits are available for these Webinars, and material is archived online.

- Two sets of LTSS funding opportunity announcements (FOAs) were issued in September 2015. These FOAs included three distinct funding mechanisms, and the earliest application date was December 11, 2015. Applications will be reviewed in March 2016. The areas of research include:
    - Research on basic and translational research on caregiving for individuals with Alzheimer’s disease, at the individual, family, community, and population level. (Research on Informal and Formal Caregiving for Alzheimer's Disease, R01-PAR-15-348 and R21-PAR-15-351).
    - Research on health disparities in Alzheimer’s disease and related dementias (ADRD). (Emerging Directions for Addressing Health Disparities in Alzheimer's Disease R01-PAR-15-349 and R03-PAR-15-350).

- ASPE is examining select models of dementia care, with a focus on understanding implementation challenges for providers. The one-year project was initiated in October 2015 and will include an environmental scan and a case study series.

- In November 2015, HHS and the University of Kansas held a panel on Alzheimer's research and care; Dr. Linda Elam delivered the keynote address.

- IHS and VA reported that the Resources for Enhancing Alzheimer's Caregiver Health Program in Indian Country continues expand its reach and progress with 22 certified service providers in nine Tribal communities.

- The VA provided federal agencies with a report on their innovative models of dementia care, which is now being disseminated by federal partners. This report completes the National Alzheimer's Plan Action 2.E.3.

Clinical Services

- The Banner Alzheimer's Institute sponsored a National Conference on Alzheimer's Disease and Dementias in Native American Communities in October 2015. It was noted that the meeting represented a true public-private partnership between Banner and ACL, and may serve as an important leverage point for future work with a diverse audience (e.g., care providers, policymakers, researchers). Next steps from this meeting are being determined.

- CMS reported substantial progress in work supporting Goals 2 and 3 of the National Plan, specifically:

    - In December 2015, CMS updated its quality strategy, with new emphasis on person-centered care and a focus on assessments across many health care settings. The Council was encouraged to review the strategy online.
    - Also in December 2015, the National Quality Forum released a report on efforts to identify gaps in quality measurement of service provision. There are a number of opportunities for the public to comment on and provide input to this work.
    - CMS released a factsheet in December 2015 to provide guidance on the Home Health benefit. This document highlights opportunities to better meet the needs of persons with ADRD, caregivers and families.
    - CMS has launched a new Medicaid innovation accelerator program, Goals for Community Integration--Long-Term Services and Supports. The aims of this program are to increase tenancy-sustaining services, expand housing development partnership opportunities, and increase strategies that can expand home and community-based services. There are likely opportunities for intersections between this program and work being conducted by ACL.
    - Some of those living with Alzheimer's disease are dual-eligible beneficiaries (persons enrolled in both Medicaid and Medicare) and represent a high-risk and high-need population. Additionally, some of these individuals are also eligible for benefits from the VA or Department of Defense. In November 2015, CMS approved the first Financial Alignment demonstration in New York targeting dual-eligible beneficiaries.

    - In January 2016, the Center for Medicare and Medicaid Innovation announced a new demonstration project, the Accountable Health Communities model, that will focus on social determinants and other factors typically considered outside of the scope of medical care. Acknowledging that these factors contribute to health outcomes is a key aspect to this project.
    - The Partnership to Improve Dementia Care project continues to make progress, with steady improvements observed in antipsychotic use among those with dementia--a nearly 25% reduction since the start of program in 2012. This project, a partnership between CMS, federal and state agencies, nursing homes, and other stakeholders, is demonstrating a move towards a more person-centered approach to care within nursing homes.

Research

- The FY2016 budget and its potential implications were discussed by the Council members. NIH received an additional $32 billion for FY2016, with a $1.6 billion increase allocated for NIA overall. Since 2015, the NIA budget has grown more rapidly than the overall NIH budget, with NIA increasing by 33.4% and NIH increasing 6.6%. This funding will provide much-needed funds to address many issues related to aging research, including Alzheimer’s disease.

- Alzheimer’s disease funding received a fairly unprecedented increase of $350 million, a significant increase compared to funding increases for other conditions, and represents a major contribution to the overall funding increase for NIA. An important outcome of the increased federal funding for Alzheimer’s disease is the opportunity to fund a greater percentage of research programs.

- In October 2015, ten FOAs were released in the event that additional funds were made available in the FY2016 budget. Applications were submitted even in advance of budgetary approval, and approximately 200 applications have been received thus far, totaling over $145 million in single-year costs. With the approved FY2016 budget, NIA now has the opportunity to consider a high volume and broad scope of research grant applications, and ultimately can award more research on ADRD. The FOA titles and funding mechanisms are:
    - PAR-15-349--Health Disparities and Alzheimer’s Disease (R01).
    - PAR-15-350--Emerging Directions for Addressing Health Disparities in Alzheimer’s Disease (R03).
    - PAR-15-348--Research on Informal and Formal Caregiving for Alzheimer’s Disease (R01).
    - PAR-15-351--Research on Informal and Formal Caregiving for Alzheimer’s Disease (R21).
    - PAR-15-356--Major Opportunities for Research in Epidemiology of Alzheimer’s Disease and Cognitive Resilience (R01).
    - PAR-15-357--Understanding Alzheimer’s Disease in the Context of the Aging Brain (R01).

  - PAR-15-358--Capturing Complexity in the Molecular and Cellular Mechanisms Involved in the Etiology of Alzheimer's Disease (R01).
  - PAR- 15-359--Novel Approaches to Diagnosing Alzheimer's Disease and Predicting Progression (R01).
  - PAR-16-365--Pilot Clinical Trials for the Spectrum of Alzheimer's Disease and Age-related Cognitive Decline (R01).
  - PAR-16-364--Phase III Clinical Trials for the Spectrum of Alzheimer's Disease and Age-related Cognitive Decline (R01).

- Several new Alzheimer's disease initiatives were approved during the January 2016 National Advisory Council on Aging. Implementation of these initiatives will be dependent upon FY2017 funding levels. Initiatives include:
  - Impact of Aging in Human Cell Models of Alzheimer's Disease.
  - Alzheimer's Disease Clinical Trials Consortium.
  - Neurodegenerative Disease Biorepository.
  - From Association to Function in the Alzheimer's Disease Post Genomics Era.
  - Technology to Assess Everyday Functions.
  - Mobile Consent (using mobile technology to facilitate clinical trial enrollment).

- The NIH Research Condition and Disease Categorization reporting system is a computerized process that categorizes the amount of funding dedicated to a particular disease, condition, or research area. The system includes separate categories for Alzheimer's disease, frontotemporal degeneration, Lewy body dementia, and vascular cognitive impairment with dementia. A new "roll-up" category that combines all four conditions has been created to serve as a baseline for tracking funding moving forward. The individual categories will remain available for more detailed tracking purposes.

- Exact amounts of future federal funding remains unknown; however, for planning purposes, the current assumption is that the FY2017 allocation will remain flat relative to FY2016.

- The FY2018 bypass budget is expected to be released in summer 2016.

- The International Alzheimer's Disease Research Portfolio (IADRP) is a database of research conducted by public and private organizations (in the United States and abroad), developed by NIH and the Alzheimer's Association. IADRP uses the Common Alzheimer's Disease Research Ontology and facilitates access to organizations and groups advancing Alzheimer's disease research. IADRP was highlighted as a dynamic and useful tool for tracking scientists, funders, and policymakers, as well as for reviewing the overall research status in the field.

- The Alzheimer's Disease-Related Dementias (ADRD) 2016 Summit will be held March 29-30, 2016 at the NIH campus in Bethesda, Maryland. The summit is free and open to the public, and sponsored by the National Institute of Neurological Disorders and Stroke (NINDS) in collaboration with NIA.

- In February 2016, NINDS plans to release five FOAs on Alzheimer's disease-related dementias, with awards expected by September 2016. The funding will originate from NIA but will be managed by NINDS. The FOAs will focus on:
  - Biomarkers for small vessel vascular contributions to cognitive impairment and dementia (VCID) (two FOAs).
  - Basic research on diffuse white matter disease in VCID.
  - Biomarkers for Lewy body dementia.
  - Tau biology and contribution to neurodegeneration.

Discussion

- During the LTSS presentation, it was clarified that the term "long-term services and supports", as used during these meetings, includes institutional care as well as care provided outside of institutions.

- Federal workgroup members will determine if the VA report on innovative models of care can be disseminated outside of the federal partners and relevant groups to which it has already been distributed.

- It was noted that there has been a shift in focus to include home care as an important site of dementia care, in addition to institutions which have typically been prioritized (e.g., nursing homes).

- Council members expressed interest in understanding how facilities are managing patients who may be receiving fewer antipsychotic agents, yet have behavioral issues that benefitted from antipsychotic use. Efforts are underway to examine prescribing practices to determine if other medications are being substituted for antipsychotic agents.

- The Council discussed that while some data have shown that home-based dementia care may be better than care provided within institutions, it remains a challenge to determine if home care is truly "better value care". CMS uses data on quality of care, costs of care, and averted costs to determine best practices. An example of averted costs are the avoidance of preventable issues (e.g., dehydration) that may result in hospital admission and increased care costs. These issues are emerging and will likely be addressed in future work.

- All CMS innovation projects are evaluated to determine if they meet the criteria of better care and/or lower costs prior to being considered for expansion.

- Federal and nonfederal Council members expressed their appreciation for the efforts of NIH, NIA, Congress, and other relevant stakeholders, for the substantial increase in federal funding allocated for ADRD. Additionally, researchers were acknowledged for their hard work and contributions that drives the field of dementia research forward.

- Bypass budget development efforts will be bolstered by the approval of the FY2016 budget. While future funding is never certain, there is optimism that legislators will continue to prioritize dementia-related research, and that NIH will remain assertive in requesting the much-needed budgetary support.

- It was noted that the FY2016 funding was not allocated to any specific research areas (e.g., dementia care and services); however, the IADRP may be an effective tool to track money spent to support specific areas of interest.

Public Input

Rohini Khillan read public comments that were submitted prior to the meeting. Ms. Khillan read for two minutes from each submitted comment and referred participants to review the full comments when made available online by ASPE.

Seven members of the public provided comments to ASPE and they included: people living with dementia, caregivers of people with dementia, and representatives from Mansbach Health Tools LLC and Counter Point Health Services, the LEAD Coalition, the Alliance for Aging Research, and The National Asian Pacific Center on Aging. The public comments provided perspectives on the following:

- Early identification of dementia and expansion of supports are two critically important areas in meeting the needs of persons with dementia and their caregivers. The Advisory Council should expand their work with public and private partners to facilitate early identification of patients.

- The significant increase in funding for NIH dementia research in FY2016 is a tremendous accomplishment by Congress and all those whose collaborative efforts facilitated the funding approval. More work is needed to appropriately fund care and services for those already living with dementia, for whom much of current research may not be helpful. The planned Research Summit on Care and Services for Persons with Dementia and their Families is one step in improving the outcomes for those with dementia and their caregivers.

- Community-based integrated care models, such as the Program of All-Inclusive Care for the Elderly, have demonstrated successful outcomes among elderly persons receiving care in their own homes. CMS has the authority to pilot such a model and potentially impact persons living with Alzheimer’s disease whose needs are not currently met by the health and long-term care systems.

- While the FY2016 funding levels for Alzheimer's disease were impressive, it is important to continue to achieve further increases in FY2017 to maintain momentum in this important research area.

- Infection control in care facilities remains an issue, as health care-associated infections are a major public health problem. These infections also impact Alzheimer's disease patients, as they comprise a majority of Medicare-eligible nursing home residents. Improved practices related to prevention, antibiotic administration, and infection surveillance can help reduce the burden of infections in this vulnerable population.

- The presence of only one person who is living with dementia on the Advisory Council is problematic and discriminatory against those the Council is designed to serve. The Council should ensure that all meetings are conducted with the proper accommodations made as indicated by the Americans with Disabilities Act.

- The development of practical solutions to address the needs of persons living with dementia and their caregivers is needed. The Council is encouraged to expand partnerships that address all aspects of need, including: care, emotional needs, housing, caregiver support, and legal considerations.

- The Asian American and Pacific Islander (AAPI) community represents an important population for this Council, as AAPI women have the highest life expectancy of any ethnic group in the United States. This group experiences several barriers to early diagnosis of dementia and dementia interventions, in part due to language barriers, cultural factors, stigma, and lack of access to care. Increasing awareness among AAPI communities is an important step that should be considered at future Council meetings.

Milestones for Goals 2 and 3 of the National Plan

Matthew Baumgart, Senior Director Public Policy at the Alzheimer's Association presented an overview of his organization's work to develop milestones addressing Goal #2 (enhance care quality and efficiency) and Goal #3 (expand supports for people with Alzheimer's disease and their families) of the National Alzheimer's Plan.

- The Alzheimer's Association consulted with an outside firm, BCG, to coordinate an expert working group and to facilitate development of milestones.

- The expert workgroup was comprised of 14 individuals from various organizations and academic institutions. The workgroup was charged with developing milestones by using research milestones as a guiding principle, and by working within the existing structure of the National Alzheimer's Plan. The workgroup was advised against focusing on process details at this stage.

- In addition to focusing on milestones relative to the National Alzheimer's Plan, the workgroup aimed to ensure consistency with existing federal efforts, such as work conducted by HRSA, CDC, CMS, and ACL.

- The milestone generation process spanned September-December 2016 and included: a review of the evidence, objective creation, review of preliminary milestones, and finalization of milestones. During the milestone review process, the workgroup solicited external feedback to help refine milestones and ensure their relevance.

- Each milestone is associated with specific implementation steps and criteria for success. It was also discussed that developing milestones in this fashion allows for identifying short and longer-term implementation goals. For example, underneath Strategy 2.E milestone section on provision of ADRD care and support interventions (see below), milestones 1-5 can be accomplished in a medium-term timeframe, while milestone 6 is likely to be longer term.

- While the milestones, implementation details, and success criteria identified were too numerous to discuss fully during the meeting, Mr. Baumgart provided insight on a subset of objectives, milestone sections and actual milestones.

Goal #2--Enhance Care Quality and Efficiency

<u>Objective</u>: All persons living with ADRD, regardless of location, race, ethnicity, sexual orientation or socioeconomic class, should receive high-quality person/family-centered care by well-trained practitioners and workers from detection and diagnosis through end-of-life, across all health care and LTSS settings and systems.

Strategy 2.A: Build a workforce with the skills to provide high-quality care.

- <u>Milestone Section</u>: Build and retain a diverse dementia-capable workforce with the skills and capacity to provide high-quality care.
    1. Identify and set targets for dementia-capable workforce needs at the state and county level.
    2. Increase dementia-capable workforce through financial incentives and competitive income.
    3. Increase dementia-specific technical education for direct care roles.
    4. Expand efforts to retain direct care workforce by building career pathways with supervisory and administrative support.
    5. Increase diverse dementia-capable workforce through financial incentives.

- <u>Milestone Section</u>: Ensure health care providers across settings are skilled and credentialed in dementia-specific care.

- <u>Milestone Section</u>: Ensure all direct care workers have proper training to effectively care for persons with ADRD and support their key family and friend caregivers in home, community, and institutional settings.

Strategy 2.B: Ensure timely and accurate diagnosis.

- Milestone Section: Develop consensus on ADRD prevalence measurements and report diagnosis levels.
    1. Develop consensus on ADRD prevalence measurement.
    2. Gather and report ADRD diagnostic data.

- Milestone Section: Raise public awareness of ADRD and encourage detection of cognitive impairment.
    1. Support awareness campaigns to increase understanding and encourage cognitive assessments.
    2. Activate faith-based and community-based organizations to increase awareness and understanding.

- Milestone Section: Raise physician awareness, and equip physicians to detect, diagnosis, and disclose.

Strategy 2.E: Explore the effectiveness of new models of care for people with Alzheimer's disease.

- Milestone Section: Identify state of science and develop a research road map regarding best practices.
    1. Build coalition of cross-disciplinary experts to convene at a research summit on ADRD care and support.
    2. Release public report on ADRD care and support evidence-based interventions.
    3. Convene group annually to review most current ADRD care and support research.
    4. Ensure geriatric research on general medical conditions incorporates persons with ADRD.

- Milestone Section: Provide ADRD Care and Support interventions research funding, informed by Annual Summit.
    1. Identify and evaluate quality outcomes and cost effectiveness of interventions.
    2. Provide funding for community-based pragmatic and adaptive research methods in interventions.
    3. Provide funding to stimulate and support innovative learning for new models of care for persons with ADRD.
    4. Provide funding for ADRD care and support translation studies.
    5. Provide funding for comparative effectiveness studies to identify most effective supportive interventions.
    6. Provide funding to roll out interventions proven effective, and adaptive throughout community settings.

- A manuscript describing the milestones-generating process and reporting on process outcomes was accepted for publication by the journal Alzheimer’s and Dementia in January 2016; members of the Council received copies of the accepted manuscript.

- Council members were offered the opportunity to be briefed more fully on the milestones process and outcomes, upon request. It was acknowledged that more time would be needed to fully discuss the outcomes, and their implications for the Councils work moving forward.

Discussion

- Council members asked about the composition of the milestone expert workgroup, particularly interested in why no federal employees or Council members were included. In an attempt to keep the working group at a reasonable size (under 15 members), federal participants were not included so as not to prioritize any one agency over others. It was also explained that the milestone peer review process was inclusive of federal participants. It was noted that Council members were not included in the workgroup so that the work could be conducted by individuals with new perspectives.

- Several Council members were disappointed by the decision to not include any of them in the process, and considered it to be a missed opportunity for efficient work to be conducted well-informed workgroup members. It was noted that having an opportunity to provide comment on draft milestones is significantly different from an opportunity to provide input from the beginning of the process.

- The Council recommended additional steps be taken to prioritize the many milestones generated, perhaps by creating a list of the top ten items for implementation, to help guide the process moving forward. The workgroup is no longer working on this project; however, the Council agreed that some degree of prioritization would be very useful to reiterate the urgency of the issues and help improve care quickly. Engaging the Council in prioritization work may be an appropriate step.

- The milestones provide an opportunity to foster partnerships among varied stakeholders that can assume different responsibilities. It was also discussed that many types of providers, not just physicians, are engaged in dementia care, and all efforts need to bear this diverse workforce in mind.

Update on Dementia Care and Research Summit

Sarah Lock, Katie Maslow, and Ian Kremer discussed ongoing plans for a research summit on care and services for those with dementia and their caregivers. The summit is aligned with three main NAPA goals, #2-Enhance care quality and efficiency, #3-Expand supports for people with Alzheimer’s and their families, and #5-Improve data to track progress.

- The goal of the research summit is to accelerate the design, testing, translation, and scaling up of effective approaches to increase quality of care and services and improve outcomes, including quality of life and the lived experience of ADRD, for persons with these conditions and their families.

- The summit is being planned to address needs of persons living with dementia, with a realization that this represents a highly varied population that often has limited access to best practices of dementia care.

- The summit is being designed to advance and build upon existing efforts in an attempt to improve the quality of life and care provision for persons with dementia. The summit and subsequent activities <u>will not</u> replace or recreate existing research, pilot and demonstration programs, or existing initiatives.

- Two main topics will be the focus of the research summit:
    1. Evidence-based care practices and services for persons with dementia and family caregivers.
        - What do we know about the effectiveness of existing, evidence-based care practices and services?
        - What additional research is needed to address research gaps and to allow targeting of particular care practices and services to persons with dementia and family caregivers who are most likely to benefit?

    2. Translation studies to test evidence-based care practices and services outside research settings.
        - Which evidence-based care practices and services have been tested in translation studies?
        - What real-world outcomes have been found with respect to effectiveness, acceptability, feasibility, costs, and training and skills needed to deliver the care practices and services?
        - What additional translation studies are needed to support scaling up of effective care practices and services?

- Currently, several topics are under consideration in advance of the summit to be presented as introductory information. For example, an assessment of the true demographics of dementia patients that include more than the “typical” care situation, may be helpful in describing the target population the summit aims to address. Additional questions for consideration before the summit may include:
    - Are there promising care practices and services that cannot be studied with randomized clinical trial methodology? If so, what alternate methodologies can be used to produce findings that will be acknowledged as “evidence based”?
    - How can persons with dementia be routinely engaged (e.g., interviewed) in research on care practices and services?
    - How can persons with dementia and family caregivers be engaged in identifying important research on care practices and services and outcomes that are meaningful to them?

- Summit organizers are engaged in discussions with the LEAD Coalition and other stakeholders to identify the most appropriate outcomes from the meeting. It was noted that outreach to potential partners is ongoing, and an iterative process is in place to hopefully gain sign-on and input from many key stakeholders.

- Council members may provide important guidance on the stakeholders being considered for participation in the summit. Currently, there are 130 signatures signing on to the summit. Stakeholders being prioritized for the summit include:
    - Persons with dementia and family and other key caregivers,
    - Government and private sector organizations that support research on dementia-related issues,
    - Researchers who conduct studies to test and evaluate approaches to improve dementia care and services,
    - Organizations and individuals that advocate for improved dementia care and services, and
    - Government and private sector providers and payers.

- Desired outcomes from the summit were discussed and include:
    - Identification of research gaps,
    - Identification of translation study gaps, including gaps in information needed to support scaling up,
    - Establishment of priorities for research and translation studies,
    - Establishment of priorities considered for funding by government and private sector organizations that support research and translation studies,
    - Establishment of priorities to be considered for inclusion in NAPA plan updates, and
    - Establishment of priorities for scaling considered by government and private sector providers and payers.

- The summit is planned as a public-private partnership, although it remains unclear to what extent the Federal Government will invest in the effort. Even if federal funding support is not possible, the summit will continue and be open to all.

- The format of the summit is still under discussion; however, preliminary thinking was discussed. Information on demographics and research methodology will be prepared and distributed prior to the summit. The actual event will include invited speaker presentations and panel discussions, and will encourage participation from all participants. Summit findings and recommendations for next steps will be developed by summit workgroup(s).

- The summit details discussed are all in the planning stages and the Council was encouraged to provide input and suggestions. Given the high level of interest from the ADRD community, there is pressure to achieve a successful and productive event, although it will be important to recognize that not every goal will be accomplished at this one meeting.

Discussion

- This summit is clearly a very large undertaking that needs to move forward on a fairly aggressive timeline. The LEAD Coalition has invested heavily in the summit and is eager to have federal participation and support. It may be necessary to designate one participating federal agency as a 'lead among equals' in order to move forward efficiently.

- The pre-work approach was deemed an interesting and favorable strategy to promote alignment among participants and make the actual summit as effective as possible.

- ASPE is committed to supporting the summit and continuing to provide thought leadership to the effort. AARP offered to support the logistics and planning aspects of the summit development, and NIA offered to facilitate the planning process along with current partners. Additionally, individual Council members offered their support to the endeavor.

Concluding Remarks

- Ms. Khillan reminded the Council that their recommendations are not restricted by federal activities or budget and should be aspirational. This differs from the National Alzheimer's Plan which is subject to restrictions.

- ASPE will continue to work to make the process of Plan development more transparent to better inform the Council.

- The Council agreed that subcommittees should develop reports and/or presentations in advance of the April 2016 meeting to facilitate group discussion. Subcommittee recommendations will be distributed two weeks in advance of the next Council meeting.

- It was requested that ASPE provide a full-year calendar of Council meetings; however, due to the site scheduling requirements, it is not possible to confirm meeting dates more than 3 months in advance.

- The tentative date for the next Council meeting is Friday April 29, 2016. Council members and the public will be informed of the confirmed meeting information once it is available.

The meeting adjourned at 1:27 p.m.

Minutes submitted by Rohini Khillan (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.