

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

Washington, DC

July 23, 2012

Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, Eric Hall, David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, David Hyde Pierce, Laura Trejo, George Vradenburg, Geraldine Woolfolk
- *Federal Members Present:* Bruce Finke (IHS), Richard Hodes (NIH), Laura Lawrence (ACL/AoA), Shari Ling (CMS), Anna Marsh (SAMHSA), Donald Moulds (ASPE) (by telephone), Anand Parekh (OASH), William Spector (AHRQ), Amber Story (NSF), Joan Weiss (HRSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Jane Tilly (ASPE)
- *Others Federal Officials Present:* Susan Cooley (VA)

Proceedings

- Meeting was called to order at 9:05 a.m. by Chair Ronald Petersen.
- Introductions of Advisory Council members were made.
- Dr. Petersen provided an overview of the agenda and the purpose of the meeting. The primary purpose of this meeting was to have the Federal Workgroup chairs and private partners report progress to date on the National Plan. In addition, political and media feedback, public-private partnerships and implementation monitoring of plan actions were to be discussed. At the end of the meeting, statements by the public were planned.

Research Subcommittee Report

- Presented by Richard Hodes, MD, Director, National Institute on Aging, National Institutes of Health (NIH).
- Alzheimer's Research Summit May 14-15, 2012.
 - U.S. Department of Health and Human Services (HHS) Secretary Kathleen Sebelius presented the National Plan and NIH Director Dr. Francis Collins announced two Alzheimer's disease clinical trials.
 - Topics discussed included the current understanding of Alzheimer's disease, the need for more basic research into the pathobiology of Alzheimer's disease, existing models and approaches to drug development, and new ideas to speed development of effective interventions for treatment and prevention.
 - Initial recommendations from the Summit led to the creation of a blueprint for an integrated, multidisciplinary research agenda.
 - Recommendations focus on discovery and translational research activities critical to the development of disease-modifying and symptomatic therapies for the cognitive and neuropsychiatric symptoms of Alzheimer's disease. The recommendations identify the types of infrastructures, resources, and new public-private partnerships needed to successfully implement this translational agenda.
 - Specific recommendations can be found at <http://www.nia.nih.gov/newsroom/announcements/2012/05/alzheimers-disease-research-summit-offers-research-recommendations>.
 - Summit webcast is archived at <http://videocast.nih.gov>.
 - Approximately 500 people attended both days; almost 500 people watched nationally and internationally by webcast; and representatives from 38 states and 8 countries attended.
- Common Alzheimer's Disease Research Ontology (CADRO) and database of supported research.
 - A *three-tiered classification system* jointly created by the National Institute on Aging and the Alzheimer's Association to capture the complete range of Alzheimer's disease research and research-related resources.
 - More than 2,000 unique research projects were coded using the CADRO (for 2008 to 2011) across multiple funding organizations, including NIH,

Department of Veterans Affairs (VA), Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, and the Alzheimer's Association.

- Available to the public through a web-based searchable database in July 2012 to allow national and international tracking of ongoing research.
- Suggested uses of CADRO for Alzheimer's disease research portfolio analysis:
 - Quantify and analyze the collective investment in Alzheimer's disease research funding over time across multiple funding organizations (beginning 2008).
 - Baseline to measure future performance and progress including implementation of initiatives in response to National Alzheimer's Project Act (NAPA) and Alzheimer's disease Summit recommendations.
 - Trend analyses of awarded research by CADRO categories, topics, and themes.
 - Areas of overlap, duplication, and potential opportunities for collaboration among funding organizations.
 - Emerging areas of science and opportunities for translation.
 - Potential research gaps and areas that may be underfunded.
- FY2012 initiatives funded by President's \$50 million allocation from within NIH budget.
 - One-year, immediate funding to boost Alzheimer's research in FY2012 in response to President Obama signing NAPA.
 - The following research projects will be funded:
 - Alzheimer's disease genome sequencing by National Human Genome Research Institute Genome Centers.
 - Use of new induced pluripotent stem cell methods to obtain insights into the cellular processes of Alzheimer's disease.
 - Small Business Alzheimer's Disease Research (STTR) R41/R42-Phase I, Phase II, and Fast-Track/Small Business Innovation Research (SBIR) R43/R44 Grant-Phase I, Phase II, and Fast-Track.

- Two Alzheimer's disease clinical trials--one treatment and one prevention.
 1. Pilot Trial of Intranasal Insulin for Alzheimer's and Mild Cognitive Impairment (treatment).
 2. Amyloid PET Scans in Presymptomatic Early-Onset Alzheimer's Disease (prevention).
- FY2013 planning for initiatives supported by President's designated \$80 million additional NIH funding.
 - June 2012--NIH Planning process to identify FY2013 initiatives.
 - August 2012--Preparation of Funding Opportunity Announcements (FOAs).
 - September 2012--Review of proposed initiatives by National Advisory Council on Aging.
 - October 2012--Announcement of FOAs and schedule for applications, review, and funding in FY13, contingent on availability of funds.
- Public-private-international partnerships.
 - During the May 2012 Alzheimer's Summit, NIH and partners established a working group to look at accelerating ways to collaborate and maximize efficiency in public, private, and international efforts.
 - In July 2012, the Alzheimer's Association and the National Institute on Aging convened a meeting of international Alzheimer's research funders.
 - In July 2012, a meeting of the International Consortium of Alzheimer's Disease Genetics was convened.
 - In the area of biomarkers, the worldwide Alzheimer's Disease Neuroimaging Initiative (ADNI) continues to lead efforts to identify early biomarkers and the science of the disease.
- Dr. Petersen opened the floor for further discussion around the National Plan goal to *Prevent and Effectively Treat Alzheimer's Disease by 2025*. Issues discussed included the following:
 - Is there a specific schedule of translational drug development that would lead to FDA approval of a drug for treatment or prevention of Alzheimer's disease by 2025?

- Dr. Hodes responded that although prevention and treatment initiatives are underway, it is unknown if those will be successful. In preparing an improved, next generation of clinical trials, new translational activities, animal models, and potent stem cells translated into neurons need to be initiated to find new targets. Finally, if the right targets remain unknown, basic research must continue, which is a multiyear process.
- A follow-up request was made that NIH create a written timeline for the Advisory Council.
- In FY2013, will any NIH FOAs address the balance between basic and translational work and drug development, prevention trials with drugs versus prevention trials with lifestyle or behavioral interventions? In addition, will upcoming FOAs address the balance between the previously discussed research and caregiver research?
 - Dr. Hodes responded that NIH will solicit research applications on nonpharmacological and pharmacological interventions.
- A follow-up comment expressed a concern that behavioral interventions competing within the same FOA with drug interventions could be disadvantaged by reviewers that only have expertise in pharmacological interventions.
- A follow-up response requested clarification on the process of deciding on proposed initiatives. Dr. Hodes responded that the process of reviewing proposed initiatives is predecisional and is not open to the public. NIH engages in activities to gather expert and public input to the decision process, such as that from the Advisory Council and Summit participants.
- Who is responsible for assessing the results of the CADRO and matching the results to NIH funding priorities?
 - Dr. Hodes responded that NIH intends to track the categories of research in the CADRO and map them to recommendations that arise from the Summit and the Advisory Council's activities. This may result in funding priority changes over time.
- What potential sources of funding (global, industry, or otherwise) are available to enhance current and proposed NIH Alzheimer's-specific funding?
 - Dr. Hodes responded that federal and public/private investment currently dominates funding for basic research. Translational research remains predominantly in private and public sectors and clinical trials funding comes from the pharmaceutical and other parts of the private

sector. Developing and using biomarkers may be one way to leverage private sector investment. Cerebrospinal fluid diagnostics is an emerging area that may have potential for commercialization. NIH will continue to fuel private sector funding by providing basic discoveries that will enhance the drug discovery pipeline.

Clinical Care Subcommittee Report

- Presented by Shari Ling, MD, Centers for Medicare & Medicaid Services (CMS) and Joan Weiss, PhD, Health Resources and Services Administration.
- Dr. Ling opened with a statement that the National Plan implementation has opened the door for productive conversations across federal agencies including those among CMS, VA, and the Department of Defense. Dr. Ling commented positively on the research advancements to date.
- The Clinical Care Subcommittee report was divided into two presentations--CMS-led activities and Health Resources and Services Administration (HRSA)-led activities.
 - CMS-led Activities.
 - Cognitive assessment for Medicare Annual Wellness Visit.
 1. CMS is working with partners to identify appropriate assessment tools that can be used in a variety of outpatient settings, including the wellness visit.
 2. Additional work is underway to look at the utilization of this visit and as a possible quality measure.
 - Care transition models.
 1. The CMS Innovation Center has funded a Health Care Innovation Award for a 3-year project at the University of California, Los Angeles, to evaluate a new care model to support effective care transitions for people with Alzheimer's disease.
 2. The program will provide comprehensive care to persons with Alzheimer's disease and their caregivers and help them navigate the service delivery system. The program has three main components: a dementia registry, a needs assessment of patients listed in the registry, and individualized dementia-care plans based on those assessments.
 3. The model extends beyond the confines of physician's offices into the community setting with intensive dementia care monitoring and care coordination by advanced practice nurses and other health professionals.

- Nursing home workforce training materials.
 1. CMS has developed *Hand in Hand*, a training series for nursing homes that emphasizes person-centered care, prevention of abuse, and high-quality care for residents. The training is to be distributed to all nursing homes in August 2012.
 2. CMS is also producing a mandatory training for state and federal surveyors focused on behavioral health, available in September 2012.

- Dementia care guidelines and measures.
 1. Dementia quality measures were put forward and recommended for implementation in the Physician Quality Reporting System.
 2. CMS held a Technical Expert Panel (TEP) to review evidence to support the development of quality measures to improve the behavioral health of nursing home residents, focused on antipsychotic agents. Two measures from that effort are soon to be included on the Nursing Home Compare website.
 3. In September 2012, the measure development contractor will convene a TEP to solicit input regarding two quality measures as the measures move toward National Quality Forum endorsement.

- CMS Partnership to Improve Dementia Care.
 1. The Partnership was created to improve behavioral health among nursing home residents with dementia and to protect them from unnecessary drug use.
 2. The first year goal is to reduce prevalence rate of antipsychotic drug use in long-stay nursing home residents by 15% by end of 2012.
 3. CMS has held several state implementation calls, including Quality Improvement Organizations, state-based agencies, the Learning in Action Network, and a variety of other participants, to create and enhance coalitions focusing on improving behavioral health, training for providers, and behavioral management techniques.

- o HRSA-led activities, presented by Joan Weiss, PhD, RN, CRNP, Chief, Geriatrics and Allied Health Branch, Bureau of Health Professions, HRSA.
 - Geriatric Education Centers (GEC).
 1. Dr. Weiss stated that HRSA received \$2 million through the Prevention Public Health Fund and is focusing the funding on geriatric continuing education to healthcare providers.
 2. A total of \$43,000 was provided to each GEC to partner with other entities to revise and update existing evidence-based practice curricula related to Alzheimer's disease and use the curricula to train multiprofessional teams of health care practitioners.

3. Training must include cognitive assessment (to be updated when the CMS Annual Wellness Visit tools are released); clinical guidelines on how to work with persons with the disease and their families; managing the disease in the context of other health conditions; referrals to appropriate clinical trials and long-term services and supports in the community; and recognizing and treating signs of caregiver burden and depression.
 4. GECs are to provide trainings free of charge as continuing education to providers.
 5. An overview of programs in West Virginia, Pennsylvania, and New Jersey was provided.
- Comments on the Clinical Care Subcommittee Report during discussion periods included the following:
 - When will the tools for cognitive assessment for use during the Annual Wellness Visit be available?
 - Dr. Hodes explained that a process was in place to complete the activity this summer. However, the process has been extended an additional 6 months to work with experts to examine which instruments would have the best predictive value with the fewest false negatives and false positives. It is likely that a small number of instruments might be recommended to practitioners for use, rather than a single instrument.
 - Dr. Ling added that the process of selecting these tools will also be used to support other HHS efforts on multiple chronic conditions.
 - A follow-up response reiterated an urgency to select the tools, disseminate them, and build awareness of the problem among providers.
 - Will the training for nursing home staff will be translated into home and community-based settings?
 - Dr. Ling responded that it is possible that the newly developed materials could be modified to use in non-nursing home settings. The nursing home setting was selected as a starting point to reduce the unnecessary use of antipsychotics. The nursing home setting provided CMS an initial setting with available data to track progress.
 - Have any states submitted Medicaid waivers associated with dementia services and has CMS has engaged state Medicaid directors on this issue?

- Dr. Ling responded that several states are engaged in the CMS Partnership to Improve Dementia Care but that she was not aware of any states submitting waivers associated with the issue.
- How does the use of a new cognitive assessment tool relate to reimbursement? How will CMS ensure that the tool recommended is actually adopted?
 - Dr. Ling responded that, at this time, CMS does not have the granularity in its data sources to identify which elements of the Annual Wellness visit have been completed. There is no current data capability to track specifically how many assessments have been conducted or their results.
 - Related to this data issue, CMS is currently working to acquire the data elements through electronic health records.
- Will the GECs' trainings address the needs of the medically underserved populations, including racial and ethnic minorities and individuals with intellectual disabilities?
 - Dr. Weiss stated that HRSA could not require it, but highly recommended that GECs try to translate educational materials to other languages to meet the needs of their communities.
 - A follow-up response noted that another option for addressing issues of linguistic translation would be for GECs to partner with other organizations.
- Why were the GEC training funds not used to create a standardized curriculum rather than giving a small amount of money to a large number of organizations to develop the same type of training?
 - Dr. Weiss responded that HRSA has already begun conversations related to standardized training. This limited funding was used to augment peer-reviewed training curricula already in place, not to create new curricula programs. GECs were provided training materials developed by the Alzheimer's Disease Education and Referral Center as a model. In addition, The Bureau of Health Professionals is creating performance measures to track the impact of the training.

Long-Term Services and Supports (LTSS) Subcommittee Report

- Presented by Jane Tilly, DrPH, HHS Office of the Assistant for Planning and Evaluation.

- Dr. Tilly introduced the report presentation with a brief mention of the creation of the Administration for Community Living (ACL) by combining the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities.
- The LTSS Subcommittee report was segmented into two presentations--the Alzheimer's Awareness Campaign and the Community-Based Programs Meeting.
 - Alzheimer's Awareness Campaign, presented by Hunter McKay, Administration for Community Living.
 - Awareness Campaign activities are associated with National Plan Actions 4.A.1 and 3.C.2. The FY2012 budget for the Campaign is \$4 million. To meet budgetary constraints, all elements of the campaign must be printed and appear before September 28, 2012.
 - Mr. McKay stated that the purpose of the Campaign is to connect caregivers with existing resources. The approach implemented was to use plain language coaching messages. The two key message points of the Campaign are:
 1. Acknowledge caregivers.
 2. You don't have to go it alone.
 - The target audience is:
 1. Caregivers, especially spouses.
 2. Ages 60-75.
 3. Spanish-speaking.
 - Alzheimers.gov.
 1. The new website is an online consumer resource, organized by topic and disease stage, written in plain language and accompanied by a full Spanish-language site.
 2. It includes testimonials by real caregivers who have "been there," using language that is authentic and speaks to the target audience. The testimonials provide a sense of help available in each website section.
 3. The website will evolve over time with assistance from a working group of subject matter experts providing periodic updates. There are currently new topics in development and future development of content will be based on consumer preferences. Suggestions from the public for improvements are accepted through the website. The work includes coordination among governmental and nongovernmental organizations.

- Marketing Plan.
 1. Marketing approach uses many forms of media (television, radio, banner ads, print/outdoor) using a similar theme. The selection of media is designed for targeted segments.
 2. Television (\$2 million investment) and print ads will begin August 2012.
 3. Response to initial media buy will provide data to improve future media efforts.

- Cosponsors.
 1. ACL is not permitted to solicit contributions. Several private interests have expressed interest including associations, foundations, and private corporations.
 2. No explicit co-branding can be mentioned in Campaign materials.

- Evaluation.
 1. The website is designed to allow consumer preference and behavior to dictate website design updates by identifying what information consumers really want. Data sources will include Google analytics, YouTube analytics, and website-based survey.

- Next Steps.
 1. Efforts will include expansion into social media, improving use of earned media, and identifying networks/partners with an interest in this information.

- o Community-Based Programs Meeting, presented by Laura Lawrence, Administration for Community Living.
 - This activity is associated with National Plan Action 3.B.3: Review the state of the art of evidence-based interventions that can be delivered by community-based organizations.

 - Ms. Lawrence stated that there are a number of evidence-based nonpharmacological programs for individuals with Alzheimer’s disease and their caregivers, some shown to be effective a decade or more ago, yet none are widely available across the country. In addition, although programs are available to help with some of the most difficult symptoms/situations of Alzheimer’s disease, widely available programs for other difficult symptoms/situations have not been developed and evaluated.

 - On June 28, 2012, the Alliance for Aging Research, with funding from the MetLife Foundation and in partnership with the Administration on Aging, hosted a meeting of researchers and community-based

implementers of evidence-based interventions to support people with Alzheimer's and their caregivers at home and in the community.

- The objectives of the meeting were to:
 1. Highlight programs that have been brought to scale.
 2. Discuss programs that did not translate well into the community.
 3. Identify gaps in the research.
 - The event was a working meeting to help gather information for a white paper that will be used to stimulate discussion from the larger Alzheimer's community. The white paper, with recommendations, will be released to the public in September 2012.
- Comments on the LTSS Subcommittee Report during discussion periods included the following:
 - A lot of media is planned that is outside of the website but the ultimate measure is based on the website only; is that correct?
 - Mr. McKay responded that website metrics are the primary metrics. He said that they are still struggling with how to come up with valid metrics. Given the small investment in the Campaign, it would be unlikely that even a large-scale survey would show a large change in public awareness in a short period of time.
 - A focus mainly on a website misses people with lower socioeconomic status who do not use the Internet as much. Ultimately the Campaign's focus on accessing a website may not be useful to this population. How does that change awareness and behavior among people who actually need this information most?
 - Mr. McKay responded that this issue is something the Campaign struggled to address. Given the limited timeframe and funding, it was determined to focus on the biggest bang for the dollar.
 - What does the budget look like moving forward in the next year?
 - Mr. McKay responded that the Secretary's FY2013 budget included an additional \$4.2 million.
 - There are a number of resource that may be able to be leveraged--nonprofits, other interested entities. Is the Campaign able to coordinate and collaborate to explore opportunities and ideas?
 - Mr. McKay responded that the Campaign is open to partnering with others inside and outside of government. Others can help identify what

is best for consumers to know and what resources really work for consumers.

Feedback on the National Plan

- Presented by Don Moulds, PhD, Acting Assistant Secretary for Planning and Evaluation, HHS Office of the Assistant Secretary for Planning and Evaluation.
- Dr. Moulds reported that the release of the plan garnered significant media coverage from television, science magazines, and other print media. Particular interest by the media focused on NIH clinical trials.
- Feedback by Congress was directed to the HHS Secretary and was positive in nature. Questions that have arisen have focused on the methodology for prioritization and funding specific to Alzheimer's research.
- Dr. Moulds addressed a concern voiced by a few members of the Advisory Council regarding the role of the Secretary in making final decisions on the National Plan's actions. Dr. Moulds assured the Advisory Council that the Secretary took the recommendations of the Advisory Council subcommittees seriously. He reiterated that while not all of the recommendations submitted by the Advisory Council subcommittees made it into the final plan, there is potential for some of them to be added to the next plan.
- Four specific recommendations of the Advisory Council subcommittees not adopted in the final plan were discussed in depth.
 - Recommendation for states to identify a specific lead agency to hold responsibility for coordinating across the various entities within the state and in a position to communicate with the Federal Government on behalf of the state on Alzheimer's disease initiatives.
 - Dr. Moulds stated that the final plan contained activities that coordinated efforts with state agencies and their related networks.
 - Recommendation for the creation of a White House Office of Alzheimer's Disease and a corresponding HHS office.
 - Dr. Mould stated that the decision not to include this recommendation was based on the decision that the infrastructure to implement and monitor the Plan initiatives is already in place.

- Recommendation for a significant increase in research funding.
 - The White House and HHS felt that the funding priorities already established for FY2012 and FY2013 were significant.
- Recommendations for activities that focused on end-of-life care.
 - Dr. Moulds noted the highly politicized nature of the issue.
- Comments on National Plan Feedback during discussion periods included the following:
 - Is a breakdown of media coverage by audience demographics available?
 - Dr. Moulds responded that the Assistant Secretary for Public Affairs (ASPA) will be tasked with providing an analysis of the coverage.
 - Media attention around the release of the plan itself tended to be mostly on the clinical trials. Is it possible that the lack of focus on the significance of the plan was because the final draft was not much different from the second draft and thus it was not new news in the media?
 - Dr. Moulds responded that his perspective was that the clinical trials highlighted were unique and may have had a stronger human interest angle than the full National Plan.

Priorities for Public-Private Partnerships

- Presented by Don Moulds, PhD, Acting Assistant Secretary for Planning and Evaluation, HHS Office of the Assistant Secretary for Planning and Evaluation.
- International Coordination Efforts.
 - Dr. Moulds outlined three objectives for working with international partners:
 - Share/compare best practices across countries that have or are developing government plans.
 - Facilitate the sharing of crucial information that can potentially head off paths that are not as fruitful as other paths or build on information that exists in “precompetitive space.”
 - Leverage work across the world to bring attention to the challenges of Alzheimer’s disease and bring international focus to the disease.

- Dr. Moulds mentioned interest in convening government officials responsible for their country's plans to meet about the first two objectives listed above. Conversations are ongoing with Alzheimer's Disease International and the DHHS Office of Global Affairs to set up an official meeting.
- The Alzheimer's Disease and Dementia Leadership Council (ADDLC).
 - The ADDLC, a joint collaboration of the New York Academy of Sciences and One Mind for Research, has formed four working groups focused on basic research, early development and translational research, prevention trials, and policy for public-private partnerships.
 - Dr. Petersen read from a letter from the ADDLC outlining the group's recommendations to improve the productivity of biomedical research and development and accelerate progress toward new diagnostics, treatments, and prevention.
 - Next steps and potential interaction with the national plan outlined by ADDLC included the following:
 - Organize an international Alzheimer's disease research summit with cross-sector participation to showcase work on basic/preclinical research plan, early development/translational tools, and models for public private partnerships to be held at the New York Academy of Sciences in May 2013.
 - Conduct an economic assessment of the Alzheimer's disease environment (discussion pending regarding vendor support) to establish a business case for companies and public-private entities to come together and co-invest.
 - Other partnerships, Existing and Potential.
- Global CEO Initiative on Alzheimer's, presented by George Vradenburg.
 - The initiative is a specific industry response to the invitation extended in the National Plan to actively engage private stakeholders and to encourage focused collaboration.
 - The membership includes drug development companies, payers, providers, financial services, and IT companies.

- Goals include:
 - Prevent and treat Alzheimer's by 2025.
 - Detect and diagnose the disease as soon as possible.
 - Enhance the ability of families to care for persons with dementia.
- Would like to partner with HHS in a collaborative effort to set milestones, metrics, and timelines for activities contained in the National Plan and to increase public awareness.
- Researchers Against Alzheimer's Disease, presented by George Vradenburg.
 - Mr. Vradenburg described this group as an advocacy group aimed at pulling together 1,000 researchers around three main propositions: (1) the importance of Alzheimer's disease; (2) 2025 is an important mobilizing goal; and (3) resources are needed to cure the disease.
 - It is an effort try and pool together government, industry, and the research community.
- Alzheimer's Association efforts, presented by Harry Johns.
 - Mr. Johns outlined existing and new efforts of the Alzheimer's Association that support the actions outlined in the National Plan.
 - Recent efforts include the convening of research funders at the Alzheimer's Association International Conference in July 2012 and the hosting of a scientific meeting on Alzheimer's disease and Down syndrome in September 2012.
- Alzheimer's Foundation of America (AFA), presented by Eric Hall.
 - Mr. Hall reported that the AFA is engaging professional associations of all types and all backgrounds and trades to come together and to voice their opinions about how the professional associations can participate in the plan.
 - AFA is also engaging health economists to help put together what funding is necessary to fully fund implementation of the long-term support services and the clinical care activities.

Timing and Process for Developing Next FACA Recommendations

- Presented by Dr. Ron Petersen and Dr. Don Moulds.
- The charge to the Advisory Council is to put forth recommendations to the Secretary for consideration. However, during the development of the first National Plan, both the National strategy and the Advisory Council recommendations were developed in tandem. The Advisory Council's recommendations needed to be developed early enough for the Secretary to consider integrating the recommendations into the National Plan.
 - A timeline to develop Advisory Council recommendations was established.
 - Each of the three Advisory Council subcommittees will meet via phone between July and October to evaluate each of the National Plan recommendations and revisit any Advisory Council-proposed actions that did not make it into the final plan.
 - Advisory Council subcommittees will formally suggest revisions at the January meeting.

Implementation Monitoring

- Presented by Dr. Don Moulds and Sara Potter.
- Standard Monitoring Tool.
 - HHS is developing a web-based resource for strategic planning that will be pilot tested with the National Alzheimer's Plan. Its utility is to strengthen agency capacity to develop interconnected strategic and implementation plans and to be able to report on progress. It will also assist staff in connecting plans to each other, to leverage resources, reduce duplication of effort, and ensure coordination when appropriate.
 - The tool enables federal staff to sort and organize the materials, filter terms any number of ways, and create charts and graphs that typically take a very long time.
 - The tool is being built now and agencies will have the opportunity to test the tool in advance of an October launch.
 - The tool will not be accessible to entities outside of HHS.

Public Input

- *Public Comments*, moderated by Dr. Tilly: Eight members of the public presented testimony, including a person with younger-onset Alzheimer's disease; family caregivers; a reporter; the Alliance for Aging Research; the Alzheimer's Association; Leaders Engaged on Alzheimer's Disease; and the National Task Group on Intellectual Disabilities and Dementia Practices. Speakers made the following recommendations and observations:
 - Encourage engagement of other federal agencies (e.g., Departments of Treasury, Labor, and Commerce) on a regular basis and engage them to work on broad issues. For example, work force issues include both provider impact (training professional caregivers) and an impact on the business sector (productivity of the work force).
 - Catalog dementia-related efforts that are ongoing throughout all federal agencies and disseminate to the public.
 - Provide clear, measurable goals for improving care and support for persons with Alzheimer's disease and their families.
 - Improve access to adult day services or residential programs for people with frontotemporal dementia (FTD), typically a younger-onset form of dementia.
 - Identifying diagnostics to differentiate between FTD and Alzheimer's could reduce variability in clinical trial design.
 - Examine the role of microglia in the development or prevention of Alzheimer's.
 - Examine whether veterans registered in the Department of Defense's radiation registry for veterans also have dementia.
 - Educate and train caregivers and facility staff to care appropriately for individuals living with Alzheimer's disease and develop new interventions to better support nonprofessional caregivers.
 - Articulate how the 2025 goal will be achieved.
 - New university-based investigators interested in the field of Alzheimer's research have reported that their deans and their department chairs are encouraging them to look at other diseases with better funding.
 - Implement the Plan as quickly as possible.

- Provide the general public with information about the specific process being used to select the cognitive assessment tools to be used in the Medicare Annual Wellness Visit.
- Include in Nursing Home Compare both the percentages of antipsychotics and of individuals who have dementia. The number of people in a facility who have dementia will affect the percentages of antipsychotics used.
- Encourage CMS to strictly enforce current regulatory and legal requirements regarding antipsychotics.
- Reinterpret Medicare statute for dementia-specific training to extend to nursing supervisors, potentially using nursing home civil monetary penalty funds.
- Examine nursing home staff ratios and their association with the percentage use of antipsychotics in nursing homes.
- Create specific protocols to improve the dementia capability of hospitals.
- Encourage development of 911 emergency registries for persons with dementia.
- Develop a consumer guide to wandering-related technologies.
- Provide consumer information to protect citizens against “cure hoaxes.”
- Encourage the use of living wills by persons with Alzheimer’s disease.
- Convene the Special Populations Task Force as indicated in Action 2.H.2 of the National Plan.
- Provide dedicated funding to the National Institute on Aging to study Down syndrome and early onset Alzheimer’s.

Concluding Remarks

- *Concluding Remarks*, provided by Dr. Petersen, Chair:
 - Acknowledged the hard work it has taken to complete the activities to date.
 - Advisory Council subcommittees will meet via phone over the next months to begin the process of updating and creating recommendations for the second National Plan.

- The next Advisory Council meeting will be October 15, 2012.
- Meeting adjourned at 4:00 p.m.

Minutes submitted by Jane Tilly (ASPE).

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