

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

National Guard Association of the United States
1 Massachusetts Avenue, N.W.
Washington, DC 20001
September 27, 2011
9:30a.m. - 4:00p.m.

Advisory Council Members

- *Non-Federal Members Present:* Ronald Peterson (Chair), Anita Albright, Laurel Coleman, Eric Hall, David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, David Hyde Pierce, Laura Trejo, George Vradenburg, Geraldine Woolfolk
- *Federal Members Present:* Regina Benjamin (Surgeon General), James Burris (VA), Bruce Finke (IHS), Victor Freeman (HRSA), Richard Hodes (NIH), Russell Katz (FDA), Donald Moulds (ASPE), Cindy Padilla (AoA), Anand Parekh (OASH), William Shrank (CMS), William Spector (AHRQ), Amber Story (NSF), Col. Brian Unwin (DoD), Janet Collins representing Linda Anderson (CDC), Marian Scheinholtz representing Kathryn Power (SAMHSA)
- *Quorum present?* Yes.
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)
- *Others Federal Officials Present:* Joseph Chin (CMS), Shari Ling (CMS), Marjory Cannon (CMS), Jane Tilly (AoA)

Proceedings

- Meeting called to order at 9:30 a.m. by Chair Ronald Peterson.
- Introductions of Advisory Council members were made.
- The National Alzheimer's Project Act (NAPA) and the role of the Advisory Council were described by Donald Moulds. The law requires that the Secretary of Health and Human Services (HHS) develop a national strategy to combat Alzheimer's disease. The Advisory Council will provide input and comment on the draft plan. Mr. Moulds reported that a draft plan, written by federal staff, will be completed by December 2011. Unlike other advisory councils, NAPA does not appear to

preclude Federal Representatives from voting on Advisory Council recommendations. Bi-laws may need to be established.

- Shortly after the legislation was passed, the Secretary of HHS established a federal interagency group to develop an inventory of federal programs related to Alzheimer's disease and conduct gaps and opportunities analyses related to these programs. The interagency groups divided into subgroups that cover three broad categories: Research, Clinical Care and Long-Term Services and Supports. Advisory Council members will be provided with these analyses in December. This information will inform the work of the Advisory Council. The Advisory Council heard several presentations related to the findings of the workgroups. The PowerPoint slides for these presentations are available at <http://aspe.hhs.gov/daltcp/napa/Mtg1-Slides1.shtml>.
- *Research Inventory*, presented by Richard Hodes, M.D., Director, National Institute on Aging, National Institutes of Health (NIH):
 - An overview of the federal research continuum and federal research funding by category and agency was presented. The main agencies funding research related to Alzheimer's disease are the National Institutes of Health, the Department of Veterans Affairs, the Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality. Dr. Hodes reported that the Federal Government spent approximately \$502 million on research on Alzheimer's disease in FY 2010.
 - The success of the Alzheimer's Disease Neuroimaging Initiative (ADNI), which began with funding through NIH and is currently an international public/private partnership, was highlighted. Successes in social and behavioral research were also mentioned.
 - During the discussion period, members inquired as to where additional funding, if available, could be profitably spent. Dr. Hodes responded that only 10-15% of meritorious applications to NIH are currently funded, with most funding provided for basic science rather than translational research. Current funding for Alzheimer's disease-related research at NIH is \$450 million, accounting for the bulk of the federal research investment.
- *Clinical Care Inventory*, presented provided by Shari Ling, M.D., Medical Officer, Office of Clinical Standards and Quality, Centers for Medicare and Medicaid Services (CMS):
 - The subgroup's scope and assumptions, process and topics considered in creating the inventory was described. The subgroup separated its topics by clinical focus (e.g., diagnosis, treatment) and system focus (e.g., social/legal issues). Existing services include: ambulatory care; geriatric primary care; hospice; and geriatric research and clinical centers.

- The Affordable Care Act included new program funding, such as the Medicare Annual Wellness Visit, and training awards and opportunities.
- During the discussion period, Advisory Council members inquired as to the cost of clinical care services for persons with Alzheimer's disease. Dr. Ling responded that additional research using Medicare, Medicaid, and private insurance claims data is needed to provide accurate cost estimates. Mr. Johns added that the national Alzheimer's Association has sponsored research using Medicare claims data to estimate expenditures by people with Alzheimer's disease.
- Additional comments included suggestions that the subgroup examine: health information technology, health disparities, and other available data (e.g., CMS's nursing home Minimum Data Set).
- *Long-Term Services and Supports Inventory*, presented by Cindy Padilla, Principal Deputy Assistant Secretary, Administration on Aging (AoA):
 - An overview of the subgroup's scope, process and topics considered in creating the inventory was presented. The subgroup separated its topics into five categories: planning for long-term services and supports, long-term services and supports, residential care settings, workforce, and quality and safety. Services and programs highlighted included: the Alzheimer's Disease Supportive Services Program, the Medicaid nursing home benefit, Medicaid home and community-based services, and Veterans Affairs' employee education system.
 - During the discussion period, Advisory Council members suggested that the subgroup further investigate: state agencies partnering to serve persons with dementia and their caregivers (e.g., Mental Health/Substance Abuse agencies partnering with Aging agencies), the role of adult day services, the scale/availability of existing programs, the lack of dementia-specific personnel in state health departments, program participation by members of various socio-economic groups, and various model programs.
- *Clinical Care Gaps and Opportunities Analysis*, presented by Shari Ling, M.D., Centers for Medicare and Medicaid Services (CMS):
 - An overview of the criteria that informed the subgroup's analysis was presented. The subgroup separated its suggested actions into three areas: direct clinical services, home and community-based services, and education and outreach for patients, families and providers.
 - The subgroup identified direct clinical services opportunities related to early diagnosis and appropriate clinical management of dementia. Possible

opportunities regarding home and community-based services included case management, identifying and mitigating unsafe behaviors, and mobilizing health care benefits. Health care provider training on dementia is needed as is training for patients and families.

- Comments during the discussion period included requests for the subgroup to address gaps in: the supply of dementia-capable workers, reimbursement-related barriers, models of care (e.g., medical homes), and the adoption of evidence-based practices in clinical settings.
- *Closed Session:* From 11:45 a.m. to 1:20 p.m., a closed session was attended by Advisory Council members to receive Federal Advisory Committee Act (FACA) training.
- *Research Gaps and Opportunities Analysis*, presented by Richard Hodes, M.D., National Institute on Aging (NIA):
 - The Medicare Annual Wellness Visit requirements in the Affordable Care Act were presented as an example of a new opportunity to improve identification of people with dementia.
 - Three gaps in current scientific knowledge about Alzheimer’s disease and related dementias were identified: (1) Despite extensive research, firm conclusions cannot be drawn about the association of any modifiable risk factor and cognitive decline. (2) Evidence is insufficient to support the use of pharmaceuticals or supplements to prevent cognitive decline. (3) There are no “highly reliable consensus-based diagnostic criteria” for Alzheimer’s disease.
 - There have been successful attempts by the international scientific community to address gaps in the past, such as ADNI, the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) intervention aimed at improving the state and well-being of caregivers, and the Dominantly Inherited Alzheimer’s Disease Network (DIAN) registry of families with early onset Alzheimer’s disease.
 - Lack of knowledge about which clinical pathways might prevent or cure Alzheimer’s disease and about which intervention strategies are the most promising way to serve people with dementia and their caregivers are the most challenging research gaps.
 - Comments during the discussion period included: a request for confirmation that NIA/NIH is emphasizing research into early stages of dementia, the challenge of recruiting participants for clinical trials (especially minority populations), and the long lag time in implementing evidence-based behavioral interventions in community settings.

- *Long-Term Services and Supports Gaps and Opportunities Analysis*, presented by Cindy Padilla, Administration on Aging (AoA):
 - An overview of the criteria used by the subgroup to identify gaps and opportunities was presented. The workgroup presented examples of gaps in the five areas presented in the inventory presentation: information about use of services, limited dementia-capable service systems, services meeting the needs of special populations, dementia-specific training, and outreach to individuals with dementia and their caregivers.
 - Comments during the discussion period included: a request to add access to services as a gap, a suggestion to identify existing data sets that can be used to measure service usage, an announcement of the upcoming availability of the American Medical Association's systematic evidence-based guidelines for quality measures for dementia care, and a question whether expansion of home and community-based care would reduce expenditures.

- *Priorities for the National Plan on Alzheimer's Disease*, open Advisory Council discussion led by Donald Moulds, Office of the Assistant Secretary for Planning and Evaluation (ASPE)/Department of Health and Human Services (HHS):
 - Several issues were discussed: the process to develop recommendations to the Secretary of HHS; what recommendations the plan should include; and whether the final plan should be a multi-year strategy or an annual plan. The legislation specifies that there is an initial plan due to Congress and an annual report on progress in implementing the plan.
 - Council member suggestions: focus on actions that are transformative, achievable, and measurable; use patient-centered care as a defining principle for all actions; consider use of a public health framework; and draw on existing state dementia plans and public input.
 - Council members requested the opportunity provide input prior to the initial draft by HHS.
 - A motion to create subcommittees of the Advisory Council was debated. The decision on next steps on establishing subcommittees was delegated by the Advisory Council to Chair Ronald Peterson.

Future Meetings

- *Discussion of Future Meetings*, led by Helen Lamont, Designated Federal Officer, Office of the Assistant Secretary for Planning and Evaluation (ASPE)/Department of Health and Human Services (HHS):
 - The January meeting will focus on the draft National Plan.
 - Council members should reserve January 2 and 3 and January 17 for possible next in-person meetings. A two-day meeting is a possibility.
 - Clarification on allowable member-to-member communications will be provided to Council members via email.
 - Council members will be provided links to the Secretary of HHS's strategic action plan for reference.

Public Input

- *Public Comments*, moderated by Chair Ronald Peterson:
 - Twelve members of the public presented testimony, including: a family caregiver; the Alzheimer's Association, the National Alliance for Caregiving, the National Task Group on Intellectual Disabilities and Dementia, and Prevent Alzheimer's Disease 2020.
 - Speakers made the following points:
 - Funding for Alzheimer's disease research, including the discovery of effective pharmacological treatments, should be increased.
 - Public awareness to educate the public about the difference between normal aging and Alzheimer's disease should be supported.
 - Diagnoses should be communicated to people with dementia in a way that encourages planning for the future.
 - Support, including financial compensation and services through programs such as the National Family Caregiver Support Program and Lifespan Respite, should be provided to caregivers. Caregiver assessment should be provided at the same time of patient assessment and should ensure referrals to community services. Understanding and use of the hospice benefit and patient-centered, medical, emotional and spiritual support for persons with dementia and their caregivers should be promoted.

- CMS should be encouraged to develop innovative models of care to improve early diagnosis, treatment and coordination of care through the new Center for Medicare and Medicaid Innovation.
- Adults with intellectual disabilities should have access to the same diagnostic services and community-based support as do other adults. Screening for dementia should be encouraged beginning at age 50 for adults with intellectual disabilities and at age 40 for adults with Down syndrome.
- Information should be obtained from employers about the impact of Alzheimer's disease on their employees and its impact on productivity.
- The Advisory Council should lay out a vision that will unify research, care, and services.

Concluding Remarks

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

Minutes submitted by Helen Lamont (ASPE).