

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

Teleconference

**March 14, 2012**

## Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, Eric Hall, David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, David Hyde Pierce, Laura Trejo, George Vradenburg, Geraldine Woolfolk
- *Federal Members Present:* Lynda Anderson (CDC), James Burris (VA), Regina Benjamin (Surgeon General), Bruce Finke (IHS), Richard Hodes (NIH), Russell Katz (FDA), Laura Lawrence (AoA), Anna Marsh (SAMHSA), Donald Moulds (ASPE), Joan Weiss (HRSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)
- *Others Federal Officials Present:* Joyce Berry (SAMHSA), Joe Chin (CMS), Jane Tilly (ASPE)

## Proceedings

- Meeting called to order at 1:00 p.m. by Chair Ronald Petersen.
- Introductions of Advisory Council members were made.
- Dr. Lamont reported that Anita Albright's position on the Advisory Council is vacant. The position will be posted in the ***Federal Register*** and nominations are encouraged.
- An overview of the agenda was provided and the purpose of the meeting was outlined. The first draft of the National Plan was released on February 22, 2012, and the three subcommittees of the Advisory Council (Long-Term Services and Supports, Clinical Care, and Research) have met to discuss the draft plan and to propose a set of recommendations. The primary purpose of this call was to have

the subcommittee chairs report their subcommittee's recommendations to the full Advisory Council and to allow for open dialogue about the recommendations.

- Dr. Moulds described next steps for the adoption of the National Plan. In early April, the second draft of the plan will be published. The Advisory Council will have the opportunity to make formal recommendations to the Secretary of Health and Human Services in mid-April. The three subcommittees of the Advisory Council were directed to continue to meet via telephone to discuss the day's proceedings, review the second draft of the plan, and develop final recommendations for the Secretary. Dr. Moulds clarified that the subcommittees of the Advisory Council were not constrained to provide recommendations to the Secretary based solely on what is contained in the draft plan. The subcommittees may present any recommendations they feel strongly should be addressed. Not all recommendations will be included in the first plan. However, they may be carried forward into the next planning cycle.

## **Presentation and Feedback on Draft Plan**

- The Advisory Council heard the recommendations of three subcommittees of the Advisory Council related to the Draft National Plan to Address Alzheimer's Disease. The Advisory Council members were charged with providing feedback on the recommendations.
- *Long-Term Services and Supports (LTSS) Recommendations*, presented by David Hoffman, Chair, LTSS Subcommittee:
  - The LTSS subcommittee presented 13 items for consideration:
    - Provide federal funds to support a state lead entity in every state and territory to coordinate all public and private long-term services and supports.
    - Provide \$10.5 million in federal funding for grants to states to develop state action plans to address Alzheimer's disease.
    - Ensure that a robust, dementia-capable system of long-term services and supports is available in every state.
    - Ensure that states mandate adequate training and compensation for paraprofessional caregivers in all care settings.
    - Use the 2011 Guidelines for Diagnosis when an individual is admitted or assessed for eligibility for long-term services and supports.
    - Engage patients and families in advance care planning during the diagnostic process.
    - Incorporate practice recommendations for end-of-life and palliative care into federal and state surveillance and quality improvement systems.
    - Embed practice recommendations for every care setting in surveillance and quality improvement measures.

- Ensure that health and related systems funded with federal resources improve chronic disease treatment and related services for people with Alzheimer’s disease.
  - Assess caregiver health/mental health risk regularly.
  - Ensure access to a full array of LTSS for special and emerging populations, including persons with younger-onset Alzheimer’s disease and persons with developmental disabilities.
  - Include information about Alzheimer’s disease in curriculum for any profession/career track affecting LTSS.
  - Ensure that the development of health information technologies includes tools for caregivers caring for persons with Alzheimer’s disease.
- During the discussion period, Dr. Moulds requested further details on the recommendation for federal funding to support state lead entities for LTSS. The LTSS subcommittee provided further detail of the recommendation:
- Federal funding would not be used to offset any existing resources.
  - Proposed funding would be leveraged with state and private funding.
  - Lead entities would be designated at the state level by governors, with the hope that positions would be high level and secure buy-in from state leaders.
  - Lead entities could include any state agency and should include partnerships with community organizations.

Dr. Moulds also led a conversation about the subcommittee’s vision for the proposed \$10.5 million in federal grant funding to states. The subcommittee clarified that they envisioned a program of planning grants and the creation of state models of lead entities coordinating public and private long-term services and supports.

Advisory Council members acknowledged agreement that activities aimed at training and compensation for paraprofessional caregivers should include program evaluation measures. They asserted that measures should be designed to provide indication that the investments in training added value and systems improvements.

Advisory Council members debated the merits of financial accountability measures that focus on demonstrating that the increased costs of long-term services and supports investments are offset by reducing hospital visits or doctor visits, by reducing rehospitalizations, by delaying institutionalization, and other methods. Consensus on this topic was not reached.

- *Clinical Care Recommendations*, presented by Laurel Coleman, Chair, Clinical Care Subcommittee:

- The Clinical Care subcommittee presented their overall impressions of the draft plan, provided actions for deliberation, and requested that the final plan include additional clarifications and modifications of specific strategies.

The subcommittee recommended that the final plan include more timeframes and deadlines to implement strategies as policy. They noted that the plan should recognize that family caregivers are under personal and financial stress and need more tangible assistance such as respite care support, tax credits for caregiving, or income support for caregiving.

The additional items presented by the subcommittee included:

- Expand education of health care providers through the Health Resources and Service Administration’s Geriatric Education Centers and the Medicare annual wellness visits. Other professionals such as nurse practitioners, nurses, and physician’s assistants should also receive training.
- Create an awareness campaign targeting health professionals focusing on prevalence and detection of Alzheimer’s disease at the annual Medicare wellness visits.
- Adjusting Medicare reimbursement rates to pay for providing the time and expertise needed to evaluate, disclose diagnosis, and begin care planning with patients and their families. Reimbursement should be provided for time spent with the patient’s caregivers when the patient is not present.
- Mandate documentation of dementia or an Alzheimer’s diagnosis in patient charts.
- Designate a blue ribbon panel of experts on palliative care for advanced dementia to discuss models of palliative care in various settings, including skilled nursing facilities, hospice, palliative care, home care, and acute care hospitals. In addition, the panel should look at the “drivers” of transfers between settings (e.g., nursing homes and hospitals) of patients with advanced dementia.
- Develop a new grant program in the Centers for Medicare & Medicaid Innovation to study new models to prevent hospitalizations and rehospitalizations.
- Provide financial supports for caregivers, including tax credits and payment to informal caregivers.
- Make adult day services a state optional benefit under Medicaid.
- Fully fund Administration on Aging caregiver programs until services are replaced or expanded through a more comprehensive program.
- Revise eligibility rules for all caregiver support programs to include persons with younger-onset dementia and persons with intellectual disabilities.
- Broaden efforts to train professionals on the maintenance of dignity, safety, and rights to include accountants, estate planners, and others who provide services to older and Alzheimer’s disease populations.

The subcommittee requested existing strategies be adjusted in the following areas:

- Improve definition of the terms *detection* and *diagnosis*.
  - Support the use of informatics by persons with Alzheimer’s disease and caregivers that are low or no cost to families. Recognize that lower income individuals may not have the resources to utilize tools, which may not be covered if they do not qualify for Medicaid.
  - Recognize that care coordination strategies and models have already been extensively studied. Proven models should be funded, perhaps as demonstration projects, with the hope of broader adoption.
  - Be specific about “certain intellectual disabilities,” perhaps focusing only on people with Down syndrome.
  - In addressing aging in place, acknowledge that people require additional supports over time. These changing needs necessitate periodic reevaluation of eligibility for services, such as hospice.
- During the discussion period, the following areas were covered:
- A LTSS subcommittee member identified consensus between the subcommittees on the importance of educating the legal community about Alzheimer’s disease. Local programs funded under the Older Americans Act currently support an infrastructure that helps with legal services.
  - Education and awareness levels of primary care physicians and other professionals were discussed. A suggestion was made to add working through professional societies (such as the American Medical Association and the American Academy of Family Physicians) to involve the primary care specialties in developing training and other outreach activities. A two-pronged approach to the training of health professionals was suggested. The first prong would be to integrate Alzheimer’s disease education into the curricula of the health professions. The second prong would focus on currently practicing health care providers in private practice (primary care and specialty practices). Another, more targeted campaign-style education around key high-priority issues (such as recognition and advance care planning) was also suggested. This approach would focus on a few specific practice changes. It would start with a definition of the practice change that was needed, how to measure progress, and would package the message in a way that could be conveyed through multiple mechanisms. Lastly, opportunities to use existing formats and resources to educate primary care physicians were discussed (e.g., annual meetings of physician state associations).
  - Dr. Moulds acknowledged the subcommittee’s point that providing appropriate dementia care takes time and payment systems do not adequately reflect the amount of time that best practices call for. He suggested that the subcommittee draft suggestions for a

demonstration that resulted in concrete evidence that providers spending more time with patients results in better outcomes and ultimately in cost savings. These data would result in the Advisory Council being in a better position to advocate for payment systems that adequately compensate for appropriate dementia care.

- *Research Recommendations*, presented by Jennifer Manly, Chair, Research Subcommittee:
  - The Research subcommittee presented several ideas for deliberation:
    - Restate Goal 1 to read: Substantially delay the onset or slow the progression of Alzheimer’s Disease by 2020, and prevent and effectively treat Alzheimer’s Disease by 2025.
    - Develop a clear plan and roadmap of specific research and drug discovery priorities and milestones for achieving the goal of preventing and effectively treating Alzheimer’s by 2025 and its interim 2020 targets. These targets should be informed by a large number of stakeholders.
    - Commit aggressive levels of resources, with appropriate accountability, to Alzheimer’s disease research to match the current and growing impact of the disease on society.
      - Increase annual federal research funding up to a minimum of \$2 billion in targeted, outcome-oriented Alzheimer’s disease research initiatives spanning basic, translational, and clinical research.
      - Require a scientific research plan and priorities to accelerate breakthroughs in Alzheimer’s disease research, a review of research infrastructure including public/private partnerships, and provide programmatic recommendations for achieving these targeted research opportunities through sustainable higher levels of annual funding.
    - Accelerate development of effective treatments. Accelerate public access to new therapeutic interventions by compressing the current average time in the process of identification of therapeutic targets, validation of those targets, development of behavioral and pharmacologic interventions, testing of efficacy and safety, and regulatory review.
      - Develop behavioral and biological markers for potential therapeutic targets or surrogate endpoints.
      - Develop action steps needed to reduce the time for moving therapies from target identification and validation through regulatory approval.
      - Develop a process by which research priorities aimed at accelerating the delivery of effective treatments would be set, including input from scientific experts.
    - Maximize private investment to develop treatments and improve disease monitoring technology. Explore policies that would encourage private industry to invest aggressively in disease-modifying

interventions, to invest in technologies that improve our ability to detect the disease as early as possible, and to monitor the disease accurately so that the effectiveness of interventions can be tested.

- Expand and enhance coordination with global partners and move forward to establish a global Alzheimer’s disease plan to respond to the worldwide scope of the problem.

The subcommittee emphasized that the change in the Goal statement should not be interpreted as favoring drug development over basic discovery.

- During the discussion period, the following areas were covered:
  - The subcommittee reported that the international Alzheimer’s disease community is interested in these recommendations.
  - A member of the Advisory Council asked if the subcommittee had discussed an alternate focus on caregiver research or research on caregiver interventions for Goal 1. It was pointed out that the research summit in May does not include caregiver issues. A recommendation was made that similar efforts toward assessing research needs and promoting research in nonbiomedical domains should be included in other goal areas of the plan.
  - The Administration on Aging, the National Institutes of Health, and private partners will be hosting a research meeting on evidence-based community-based translation studies of caregiver interventions in Summer 2012. The purpose of the meeting is to set priorities and define action steps to implement specific interventions.
- *Public Awareness and Engagement Recommendations*, presented by Helen Lamont and Don Moulds, ASPE:
  - Investments have been made in both in FY2012 and in the President’s FY2013 budget for an awareness campaign. The combined investment is over \$8 million, with \$4 million available in FY2012.
  - This investment is in addition to the physician and outreach piece that will be administered by the Health Resources and Services Administration.
  - The Administration on Aging will serve as the HHS lead in the awareness campaign and is exploring redirecting some resources for existing awareness campaigns funds.
  - HHS has started reaching out to potential private sector partners, including nonprofit organizations and provider associations to try to leverage this investment.
  - Current activities focus on defining the top tier messages, by learning from others who have launched Alzheimer’s disease-awareness campaigns

backed by rigorous research. No decisions have been made on the target audience.

- Advisory Council members offered several suggestions for campaign development, messaging, and target audience.
- *Improve Data to Track Progress Recommendations*, presented by Helen Lamont and Don Moulds, ASPE:
  - HHS has established funding for this Goal at \$1.3 million for FY2013.
  - The primary focus of this recommendation is to enhance the data available to track plan implementation progress.
  - The initial step will be to identify what the data needs are for rigorous policy research. Potential policy research includes exploring the impact of Alzheimer's disease on Medicare and Medicaid.
  - A major challenge is finding data that identify people with Alzheimer's disease or their caregivers in sufficient numbers to do detailed analyses to track progress over time.
  - HHS will develop an implementation plan for the National Plan with measurable milestones, timelines, and accountability going forward.
  - Additional actions include monitoring progress on the plan, reports to Congress, and delivering messages and recommendations from the Advisory Council to the Secretary.
  - An Advisory Council member suggested that HHS create a small working group to draw in experts from other fields or outside the government to assist in thinking through the systems that might be able to address both the metrics and the lack of data.

## **Public Input**

- *Public Comments*, moderated by Helen Lamont: Sixteen members of the public presented testimony, including a Member of Congress, persons with early-onset Alzheimer's disease, family caregivers, health care providers, the Alzheimer's Association, Alzheimer's Community Care, the American Psychological Association, the Assisted Living Federation of America, GE Healthcare, the National Academy of Neuropsychology, the National Coalition on Mental Health and Aging, and the National Down Syndrome Congress.



- Speakers made the following recommendations:
  - Accelerate the proposed target date to prevent and effectively treat Alzheimer’s disease to 2020.
  - Increase Alzheimer research funding. Urge the National Institute on Aging and its funding partners to support additional research in the area of understanding more fully how biomarkers relate to cognition.
  - Support a patient’s “right to die” with physician assistance.
  - Support the development, dissemination, and implementation of innovative advance care planning tools that are easy, effective, and acceptable to both patients and physicians. Unlike most diseases, patients who have dementia typically lose mental capacity to make medical decisions early in the course of the disease. Once that window of opportunity to make decisions closes, they will not be able to participate in their own end-of-life planning.
  - Support a national Silver Alert program and other national-level programs that enhance the security of people with Alzheimer’s disease.
  - Mandate licensure for all service settings claiming to provide specialty-type services, such as dementia adult daycare and dementia units in residential care facilities, and set minimum levels of staff training.
  - Educate medical professionals to recognize that Alzheimer’s disease needs to be treated along with other comorbid illnesses that a patient may present if he or she is admitted to a hospital or visit an emergency room. Often hospitals and emergency rooms do not know how to treat people with Alzheimer’s disease. Clinicians do not know how to cope with the behaviors associated with advanced dementia.
  - Include assisted living as an option when educating families, physicians, and healthcare providers about living options and examine assisted living facilities for best practices in dementia care.
  - Provide support for caregivers.
  - Provide diagnostic training for primary care physicians.
  - Engage the public health community at the federal, state, and local levels. In this regard, the plan could build on leading states where the public health network has begun to address the burdens of Alzheimer’s disease. CDC should be more fully engaged in the plan.

- Monitor the plan in a timely, transparent way to ensure accountability regarding both the implementation of action steps and the meaningfulness of the outcomes.
- Support actions that will accelerate the development and adoption of important diagnostic tools. Encourage the inclusion of action items that stress the need for Medicare to provide access to imaging technologies.
- Include a research focus on Down syndrome and make direct mention of Down syndrome and other intellectual disabilities under Goal 1 concerning prevention and treatment. Include researchers in the area of Down syndrome in the Alzheimer's Disease Research Summit in May. The special problems faced by adults with Down syndrome deserve continued focus by NIH. Include special challenges faced by people with intellectual disabilities under Goal 3, with a particular focus on helping lifelong caregiving, and Goal 4, with a greater awareness of dementia among people with intellectual disabilities in the public education campaign.
- Acknowledge the field of clinical neuropsychology in the assessment, diagnosis, treatment, and support of culturally diverse patients suffering neurological, medical, neurodevelopmental, and psychiatric conditions.
- Recognize the mental and behavioral health issues for which there are effective interventions and supports. The research agenda should include behavioral and social aspects of Alzheimer's disease, which would be immediately useful to families and caregivers, in addition to genetic research. Mental and behavioral health services must be included in the wide array of services available to individuals with Alzheimer's disease. Workforce initiatives should include mental health and behavioral health professionals.
- Acknowledge the critical role of neuropsychological testing and assessment to measure changes in cognitive performance.
- Expand the focus of the public education initiative to include education on modifiable risk factors for Alzheimer's disease, including diabetes, hypertension, obesity, smoking, depression, cognitive inactivity, and physical inactivity.

## Concluding Remarks

- *Concluding Remarks*, provided by Ronald Petersen, Chair, and Don Moulds, ASPE:
  - The subcommittees will reconvene again and provide additional information to the drafters of the next version of the National Plan. The next draft will be released in early April with time for the Advisory Council members to review it before the April 17 in-person meeting in Washington. The April 17 meeting will be focused on implementation strategies, metrics, and evaluation.
  - The Advisory Council may generate a list of recommendations that have not been included in the first two drafts of the Plan. The Advisory Council may have independent recommendations to be submitted to the Secretary. Any recommendations of the Advisory Council to the Secretary would need to be approved by a majority of the Advisory Council or a consensus of the Advisory Council.
  - FACA recommendations not addressed in the first plan may be addressed in future revisions of the plan.
  - Meeting adjourned at 5:15 p.m.

Minutes submitted by Helen Lamont (ASPE).

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