Policy Update: Alzheimer’s Advisory Council Prepares Recommendations to HHS, Hears Updates on Current Efforts

Lewis-Burke Associates LLC – January 18, 2013

On January 14, the Advisory Council on Alzheimer’s Research, Care and Services (http://aspe.hhs.gov/daltcp/napa/#Council) held its semiannual meeting to hear from federal officials about progress made to date on the implementation of the National Plan to Address Alzheimer’s Disease (http://aspe.hhs.gov/daltcp/napa/#Plan) and to finalize recommendations to the U.S. Department of Health and Human Services (HHS) for the revision of the National Plan, which is expected to be released in April.

The Advisory Council was created to assist HHS with the implementation of the National Alzheimer’s Project Act (NAPA), which was signed into law in January 2011. The goal of NAPA is to develop and implement a national plan to overcome Alzheimer’s disease, calling for new investments in biomedical research; acceleration of new treatments to prevent, halt, or reverse the course of Alzheimer’s disease; and professional preparation of the workforce that serves Alzheimer’s patients and their caregivers. HHS released its first National Plan to Address Alzheimer’s Disease in May 2012. The plan, which identifies and coordinates goals and actions for agencies across HHS, addresses Alzheimer’s disease through research, long-term services and supports, and clinical care.

As required by law, the National Plan will be updated annually to reflect progress as well as to address new goals and priorities.

Highlights from the meeting include:

- Similar to an initial workshop held in 2012, a second research workshop is planned at the National Institutes of Health (NIH) for May 1-2, 2013 to address research needs for “other dementias.” The purpose of the workshop will be to develop specific research priorities and it will be open to the public. Similarly, the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD) have begun planning for a research workshop specific to Down Syndrome and Alzheimer’s disease. These events provide excellent opportunities for interested researchers to be involved in the shaping of future NIH research investment areas. Additional details are below.
- The Advisory Council discussed the recommendations they plan to submit to HHS for the next iteration of the National Plan due out in the spring. While these recommendations are not guaranteed to be included in the next plan, they provide helpful insight into some of the major unresolved issues and areas of concern that remain in the Alzheimer’s research and care communities.
- Notable recommendations include a call for at least $2 billion per year in Alzheimer’s research investments; development of a “unified curriculum” for primary care practitioners; increased funding incentives (such as loan forgiveness) to attract more individuals to geriatrics careers; and creation of a White House and/or HHS office to coordinate Alzheimer’s disease activities. More details on specific recommendations are outlined below.
HHS plans to release its next version of the National Plan in the spring, tentatively in time for the spring Advisory Council meeting scheduled for April 29. Opportunities still exist to provide input into the plan. Comments, suggestions, or recommendations can be submitted at anytime to HHS by emailing napa@hhs.gov.

**Status Reports on National Plan Implementation**

The first half of the meeting included updates from the three subcommittees responsible for implementing the National Plan: Research, Clinical Care, and Long-Term Services and Supports.

**Research Subcommittee**

Dr. Richard Hodes, Director of the National Institute on Aging (NIA) at the National Institutes of Health (NIH), chairs the Research Subcommittee and provided an update on the research-related goals and actions included in the National Plan. The work of the Research Subcommittee is guided by the plan’s goal to “Prevent and Effectively Treat Alzheimer’s Disease by 2025.” The main strategy for implementing this goal is to identify research priorities, which, according to Dr. Hodes, was initiated through a summit in May 2012 at NIH, “Alzheimer’s Disease Research Summit 2012: Path to Treatment and Prevention.” A second workshop is planned for May 1-2, 2013 at NIH to address “other dementias.” Similar to last year’s workshop, the purpose of the 2013 summit will be to develop priorities for research. It will be sponsored by the National Institute of Neurological Disorders and Stroke (NINDS) and NIA, and will be open to the public. Registration is available at http://www.ninds.nih.gov/ADRelatedDementias2013.

Similarly, NIA and the National Institute of Child Health and Human Development (NICHD) have begun planning for a research workshop specifically on Down Syndrome and Alzheimer’s disease, which will take place sometime in 2013; details are not yet available. These research workshops provide excellent opportunities for interested researchers to help shape program investments at NIH for future years.

In addition, given the focus of the National Plan on the use of public-private partnerships (PPPs) to effectively address the goals of the plan, NIA plans to hold a PPP meeting in April 2013 to include representatives from academia, NIH, the pharmaceutical industry, etc. for the purpose of potentially developing partnerships to share preclinical data, drug targets, and animal models in the pre-competitive space to facilitate new therapies for Alzheimer’s disease. To be included in that activity, interested parties are asked to contact Dr. Suzana Petanceska (petancestas@mail.nih.gov).

Finally, Dr. Hodes mentioned the release of a new report, *National Institutes of Health 2011-2012 Alzheimer’s Disease Report: Intensifying the Research Effort* (www.nia.nih.gov/alzheimers/publication/2011-2012-alzheimers-disease-progress-report), which is a report to Congress summarizing research findings from over the last few years.

**Clinical Care Subcommittee**

Dr. Shari Ling, Deputy Chief Medical Officer at the Centers for Medicare and Medicaid Services (CMS), chairs the Clinical Care Subcommittee and provided a status report of their work to implement the National Plan. This particular subcommittee is responsible for a broad range of goals and activities within the plan, including addressing Medicare coverage issues, measuring improvement, training of health professions, care models, improving engagement with patients and caregivers, among others.
According to Dr. Ling, the subcommittee has seen initial success with activities such as implementing and evaluating new care models to support care transitions for people with Alzheimer’s disease, working to strengthen the direct care workforce, collecting and disseminating dementia-specific guidelines and curricula, and identifying and disseminating assessment tools. Still to come are activities such as the initiation of a Patient and Family Engagement Campaign in February 2013, implementation and evaluation of new care models to support care transitions for people with Alzheimer’s disease (due by September 2014), evaluation of the effectiveness of medical home models for people with Alzheimer’s disease (by July 2015), evaluation of the effectiveness of the Independence at Home Demonstration (by July 2015), and examination of the effects of new payment models on care and costs for Alzheimer’s disease treatment (by July 2015).

Dr. Ling also noted that the Community-based Care Transitions Program (CCTP) (http://innovation.cms.gov/initiatives/CCTP/index.html), which was created and funded in the Affordable Care Act (ACA), is continuing to accept applications on a rolling basis.

**Long-Term Services and Supports (LTSS) Subcommittee**

The LTSS Subcommittee is chaired by Dr. Jane Tilly from the Office of Supportive and Caregiver Services at the Administration on Aging (AOA). The LTSS Subcommittee focuses primarily on actions states can take (with support from the federal government) to improve services and supports for those suffering from Alzheimer’s disease, and efforts to improve caregiver support (including family caregivers).

Among notable progress made to date is the collection and dissemination of dementia-specific guidelines and curricula for all provider groups, accomplished through supplemental funding in fiscal year (FY) 2012 to grantees of the Geriatric Education Centers (GEC) program administered by the Health Resources and Services Administration (HRSA); completion of a webinar series for lawyers and caregivers about legal issues for those suffering from Alzheimer’s disease; and initiation of an Alzheimer’s awareness campaign. Available shortly will be a website to include links and contact information for organizations providing dementia-specific guidelines and curricula.

**Advisory Council Recommendations for the Next National Plan**

The second half of the meeting was used to discuss the recommendations each subcommittee has prepared to submit to HHS for the next iteration of the National Plan due out in the spring. While these recommendations are not guaranteed to be included in the next plan, they provide insight into some of the major unresolved issues and areas of concern that remain in the Alzheimer’s research and care communities. The Advisory Council voted to accept the recommendations and proceed with forwarding them to the HHS Secretary after some minor modifications.

Below is a snapshot of notable recommendations made by the Advisory Council.

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<th>Research</th>
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<td>• The Plan should state explicit interim, mid-term and longer term research milestones to achieve the 2025 goal by developing specific research priorities and timelines (a criticism of the original plan has been the lack of timelines for action/completion of goals).</td>
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<td>• Calls for an investment of at least $2 billion per year for Alzheimer’s disease basic, translational, and clinical research.</td>
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- A comprehensive “strategic research plan” is needed to accelerate research breakthroughs.
- Address disparities in Alzheimer’s disease by including specific populations in clinical studies, with special attention to race/ethnicity, sex, and socioeconomic status.
- Calls on the Administration to establish a Global Alzheimer’s Action Plan with international partners.
- Create an office within the White House and/or HHS to serve as the central contact point for the National Plan, as opposed to the current piecemeal structure facilitated through the HHS Secretary’s office.

**Clinical Care**

- Launch a national public awareness campaign to promote early Alzheimer’s disease detection and diagnosis.
- Calls on HRSA, working with other agencies and partners, to develop a “unified curriculum” for primary care practitioners relating to Alzheimer’s disease.
- Form a blue ribbon panel of experts on advanced dementia to develop innovations in clinical care practice and quality.
- Expand funding incentives (such as HRSA’s geriatrics health professions training programs, and creation of new loan repayment programs) to attract more individuals to careers in geriatrics.

**Long-Term Services and Supports**

- Many of the recommendations are similar to those made by the subcommittee in 2012, and focus primarily on actions states can take to improve services with assistance from the federal government.
- Calls on state education and health agencies to require Alzheimer’s disease curriculum for all professions affecting LTSS.
- Urges Congress and CMS to “redesign” Medicare coverage and physician reimbursements to encourage “appropriate diagnosis of Alzheimer’s,” and to provide care planning to those diagnosed.
- Calls for the creation of grants through CMMI for medical home projects targeting Alzheimer’s disease.
- Calls for CMMI pilot grants aimed at reducing preventable emergency room visits, hospitalizations, and length of stays for people with Alzheimer’s disease.

**Sources and Additional Information:**

- PowerPoint presentations from the meeting, including the status reports from the three subcommittees, can be found at: [http://aspe.hhs.gov/daltcp/napa/011413/Mtg7-Slides1.pdf](http://aspe.hhs.gov/daltcp/napa/011413/Mtg7-Slides1.pdf).
- The recommendations of the three subcommittees can be found at
  - Clinical Care: [http://aspe.hhs.gov/daltcp/napa/011413/Mtg7-Recom2.pdf](http://aspe.hhs.gov/daltcp/napa/011413/Mtg7-Recom2.pdf)
- Full background on NAPA, the Advisory Council, and the National Plan can be found on the NAPA website at: [http://aspe.hhs.gov/daltcp/napa/#top](http://aspe.hhs.gov/daltcp/napa/#top).