

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

Washington, DC

**April 29, 2013**

## Advisory Council Members in Attendance

- *Non-Federal Members Present:* Ronald Petersen (Chair), Laurel Coleman, David Hoffman, Harry Johns, Jennifer Manly (by telephone), Helen Matheny, Julie McMahon (by telephone), David Hyde Pierce, Laura Trejo, and George Vradenburg
- *Federal Members Present:* Regina Benjamin (Surgeon General), Bruce Finke (Indian Health Service [IHS]), Richard Hodes (National Institutes of Health [NIH]), Christa Hojlo, (Department of Veterans Affairs [VA]), Russell Katz (Food and Drug Administration [FDA]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Donald Moulds (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), William Spector (Agency for Healthcare Research and Quality [AHRQ]), Amber Story (National Science Foundation [NSF]), Jane Tilly (Administration for Community Living [ACL]), and Joan Weiss (Health Resources and Services Administration [HRSA])
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)

## General Proceedings

At 9:35 a.m., Chair Dr. Ronald Petersen called the meeting to order.

Dr. Peterson provided an overview of the agenda. After presentations by two international colleagues, the council will hear an update on the budget and other federal issues. Progress on the research milestones identified in the *National Plan to Address Alzheimer's Disease* (National Plan) will be presented, and the council will discuss plans for developing a research agenda for long-term services and supports (LTSS). Public comments will be received.

Advisory Council members introduced themselves.

## Dementia Initiatives in England

Dr. Alistair Burns, the United Kingdom (UK) national clinical director for dementia and professor of old age psychiatry at the University of Manchester, described strategies being undertaken to address dementia in England.

- In February 2009 the UK Department of Health published a national dementia strategy containing 17 objectives with related strategies to improve dementia diagnosis and treatment over the next 5 years.
- An early major initiative addressed the use of narcotics for the management of behavioral and psychological symptoms in dementia. A 2009 report commissioned by the Department of Health, *The Use of Antipsychotic Medication for People with Dementia: Time for Action*, estimated that 180,000 people with dementia were prescribed narcotics. It contained 11 recommendations to reduce the inappropriate use of such drugs. A subsequent campaign launched to reduce inappropriate use of antipsychotics in dementia resulted in a significant decrease in the percentage of patients given prescriptions for such drugs.
- Another significant report, *Dementia 2010*, described the funding needs for dementia research and clinical care. It reported that more than 800,000 people (1.3 percent of the population) in the UK live with dementia, costing the UK economy £23 billion per year. In research, for every £128 million spent on cancer, £1.3 million is spent on dementia.
- The 2010 election of Prime Minister David Cameron has had a very positive effect on dementia initiatives in the country. In March 2012 the Prime Minister's challenge on dementia was issued, with initiatives focused on awareness, quality care, and research.
- In 2012 the Department of Health solicited proposals for the best ways to address dementia. It organized 180 applications into five major clinical areas:
  - Timely diagnosis and support in primary care.
  - Dementia in the general hospital.
  - Dementia in care homes.
  - Reduction of antipsychotics.
  - Support for caregivers.
- The overall rate of diagnosis in the UK is 46 percent, but the rate in Northern Ireland and Scotland is more than 60 percent. Public attitudes, general practitioners' (GPs') attitudes, and limited provision of assessment services were determined to be contributors to the low diagnosis rate outside of Northern Ireland and Scotland. To improve the rate, a public information campaign was implemented to change attitudes and raise awareness about dementia, an incentive payment system was developed for increasing the diagnosis of

dementia in hospital patients, and dementia screening was included as part of the free National Health Service (NHS) health check.

- New guidelines for hospital care of patients over age 75 were developed to improve the identification of dementia and to prompt appropriate referral and follow-up after they leave the hospital. The guidelines call for a member of the hospital staff to ask family or friends of a person admitted to hospital if in the last 12 months the patient has been more forgetful to the extent that it has significantly affected his or her life.
- Analysis of studies suggested that more than 80 percent of residents living in approximately 20,000 UK care homes have dementia.
- The NHS underwent a major reorganization in April 2013. The reforms initiated have three emphases: (1) using outcome measurements to assess progress, (2) using commissioning groups as an organizational structure, and (3) putting patients first.

Discussion following Dr. Burns' presentation included the following comments:

- The research community in England would welcome opportunities to collaborate with United States researchers.
- The UK funding for research will be increased from £25 million to £65 million by 2015.
- The UK Department of Health has a big push right now to link the national social care system and resources with those in the community. Although day care is available for people with dementia, lack of awareness of such resources can result in unnecessary hospital admissions.
- Raw data such as the prevalence of dementia diagnoses are often used as an outcome measurement, but "soft data" obtained from surveys also are used. An example of a soft outcome measurement is the change in the number of families reporting that the quality of life of the affected individual is better.
- Increasing the capacity and willingness of primary care providers to diagnose dementia is a challenge. Changing attitudes must be addressed both during training and during the providers' careers.
- The use of the single question, "Has the patient been more forgetful in the last 12 months" has led to identifying about 4,000-5,000 individuals who were then referred to dementia assessment services. The question is not a diagnostic one but is used to raise awareness.

- A worldwide coalition is looking at data in the literature regarding concerns providers have about evaluating people for subjective impairment. A study at the Mayo Clinic asked 1,800 people living in the community about the state of their memory. Even after controlling for age, sex, education, and numerous other variables, the results showed that subjective concerns about memory problems predict progression to the next level of impairment. Dr. Burns noted that the screening question used in the UK uses the word “forgetful” rather than asking about memory lapses during the previous 12 months.
- Guidelines call for the screening question to be used only in the hospital, not in the outpatient setting, but the Department of Health suggests it to GPs as an example of good practice and invites GPs to report other approaches they use.
- A study has not been done in the UK to determine if early care planning is effective in improving care in later years, but a strength of the NHS is its ability to collect data on the entire population, so Dr. Burns deems such a study to be a good idea.
- In the UK, data from the electronic medical record (EMR) are not used very often as a way to integrate information between the GP and the hospital because the EMR systems are not generalizable. Use of electronic means is seen as a great opportunity for enhancing interchange.
- A new organization called Health Education England, with a budget of £5 billion per year, has been formed to address training NHS staff. The NHS goal is to have 10 percent of NHS staff become dementia experts, 50 percent become trained in dementia overall, and 100 percent become more aware of dementia. Many nongovernmental organizations in the UK include training about dementia as a priority.
- The discrepancies in the rates of dementia diagnosis in England compared to Scotland are partly the result of initiatives in Scotland for GPs to be proactive with dementia screening. For example, in Scotland everyone who receives influenza immunization is screened for dementia. In addition, the small size of Scotland, which is about the size of northwest England, makes it easier to promote awareness initiatives.
- UK educational initiatives that are part of the Prime Minister’s challenge include teaching school children, beginning as early as ages 7 and 8, about dementia.
- Dr. Burns is a part-time civil servant, serving both the NHS and the Department of Health. His role of national clinical director for dementia provides a focus for energy and enthusiasm within the country.

## Canadian Approach to Dementia Research

Dr. Yves Joanette, scientific director of the Institute of Aging of the Canadian Institute of Health Research (CIHR), described dementia research initiatives in Canada.

- Projections of the prevalence of Alzheimer's disease indicate that Canadians living with Alzheimer's disease or a related dementia will increase from 500,000 in 2010 to 1.1 million within a generation. Accordingly, costs for dementia care are projected to grow from \$15 billion to \$153 billion in the same period.
- Each of Canada's 13 provinces and three territories has its own health system funded by taxes. Half of them have developed plans to provide services for Alzheimer's disease and related disorders. These plans focus mostly on public awareness campaigns and services provided by community GPs, but they do not incorporate a research plan.
- Within CIHR's research budget, \$27 million is designated for investigator-initiated research in Alzheimer's disease and related disorders. To strategically direct funding, CIHR has adopted eight Roadmap Signature Initiatives, one of which is the International Collaborative Research Strategy for Alzheimer's Disease (ICRSAD), which has been in place for a number of years. ICRSAD focuses on strengthening Canadian research through the Canadian Consortium on Neurodegeneration in Aging (CCNA) and collaborating internationally on research for Alzheimer's disease and related disorders.
- ICRSAD is currently collaborating with the European Union Joint Programme-- Neurodegenerative Disease Research, with the United States on the Alzheimer's Disease Neuroimaging Initiative 2, and with the National Natural Science Foundation of China.
- CCNA has identified three main themes of research: primary prevention, secondary prevention, and quality of life. Teams of researchers representing each of these themes use common resources and bring interdisciplinary perspectives to collaborative research. Research teams submit a proposal for a 5-year research program that must be comprehensive (including all three themes as well as cross-cutting topics such as ethics, knowledge translation, and training), inclusive (incorporating both established and new investigators as well as knowledge users), innovative, and globally connected.
- CCNA has a number of partners, which include nonprofit organizations as well as private industry groups. These partners contribute to funding and participate in providing direction for research.
- The CCNA process for receiving and reviewing research proposals has just been launched, with expressions of interest due in May 2013. The first Partner's Forum

for applicants, partners, and international experts will take place in August, and final applications for research funding are due in December 2013.

Discussion following Dr. Joannette's presentation included the following comments:

- Canadian funding for the CCNA research comes from the CIHR budget. Some additional national funding for research related to aboriginal people and women has been contributed to stimulate research in those areas.
- Peer reviewers are being instructed to take risks on transformational, innovative research rather than following the tendency to fund incremental research in which pilot data are available.
- The collaboration with the NSF of China is working well, and Chinese and Canadian research teams have worked together through many rounds of support from both countries. Canada has had a longstanding presence in health and research in China. Prominent examples of the ties between Canada and China are significant contributions to Chinese medicine made by the Canadian thoracic surgeon Norman Bethune in the first half of the 20th century, and Prime Minister Pierre Trudeau's recognition of the People's Republic of China in 1970, making Canada one of the first Western countries to recognize the People's Republic.
- The CCNA policy for international funding is to have at least three countries participate in a research proposal, with representation on the peer review committee from each country. The research proposals are ranked according to excellence. Each country contributes \$100,000, and researchers receive the funds from their own country. If a country does not have enough money, negotiation takes place and tradeoffs can be made.
- Having a multilateral funding mechanism in which countries contribute money to a common fund to be distributed for research according to an agreed-on plan is not likely to be successful with European partners. A number of countries in the European Union have a significant number of people with Alzheimer's disease but do not have any research enterprise, so significant political hurdles exist for such a funding mechanism to be put in place.
- A number of Canadian groups are working on research supporting health and wellness. Much of this research is directed toward tools for caregivers. In addition, a large community care initiative is undertaking research on ensuring seamless transitions among sources of care such as the hospital, long-term care, home care, and palliative care.

## **Update on Budget and Federal Activities**

Dr. Moulds reported on federal budgets and other activities.

- Budgeting has been extremely challenging because of reduced funds but also because the amount of available funds has repeatedly changed. The federal budget sequestration has had a significant effect and resulted in staff furloughs. Cuts to the NIH budget were especially significant. The Department of Health and Human Services (HHS) budget for FY 2013 was reduced by \$15.9 billion.
- On the positive side, the president's 2014 budget includes an additional \$100 million for the national Alzheimer's strategy. This funding dedicates \$80 million to research and \$20 million to be split across HRSA, ACL, and other budgets that support the awareness campaign, the caregiver campaign, and the health provider education outreach campaigns that HRSA is leading. It is also good news that the prevention fund is being maintained in addition to the \$80 million for research.
- The Brain Initiative recently announced by President Obama will have separate funding and will not use funds proposed in the FY 2014 budget for the National Plan. Estimates of sources of funds for the Brain Initiative include \$40 million from NIH, \$50 million from the Defense Advanced Research Projects Agency, and \$20 million from the NSF.
- Another positive note is that Dr. Francis Collins, the NIH director, blunted some of the potentially disastrous cuts to Alzheimer's disease research by moving \$40 million from the director's office budget to fund FY 2013 National Institute on Aging (NIA) requests for applications (RFAs).
- The Senate Special Committee on Aging held a very successful hearing on April 24, 2013, on progress on the National Plan. Very moving testimony was given by Ms. Ashley Campbell, daughter of the singer Glen Campbell, about how her family and her father have coped with his diagnosis of Alzheimer's disease. Dr. Moulds and Dr. Peterson also testified at the hearing.

## **Strategic Planning and Program Updates**

Dr. Moulds described a strategic planning tool being implemented in HHS that allows agencies to use a web-based tool for planning activities. The tool structures strategic plans and includes implementation, strategy, timelines, deliverables, and responsible agencies. The Advisory Council received a printout of a preliminary version of the tool. When the tool is fully realized, it will include a narrative and will not be in a spreadsheet format.

Dr. Tilly highlighted several activities pertaining to LTSS:

- The partnership between NIA and ACL to increase enrollment in clinical trials has been successful, resulting in increasing enrollment by 25 percent. This project, “Connecting to Combat Alzheimer’s Initiative,” was one of six recognized by Secretary Sibelius with a HHS *Innovates* award. The program also won the People’s Choice award, which is voted on by HHS employees.
- ACL’s Legal Services Network has presented a series of webinars for legal professionals aimed at increasing capacity for people with Alzheimer’s disease and providing information about the kind of planning people with a diagnosis of dementia need at any point in the progression of the disease. About 300-500 legal professionals participated in each webinar. The good reviews received by the webinars are significant because participants tend to be thought leaders in their communities and will be instrumental in spreading information.
- The Specific Populations Task Force, a partnership between ASPE and the administration, developed recommendations for people with early onset dementia, people with intellectual or developmental disabilities who also have dementia, and ethnic groups that are at higher risk for dementia. The task force report is expected in May.
- The National Center for Health Statistics is conducting a study of housing patterns and services.
- The National Health and Aging Trends Survey is developing a report on the unmet service needs of people with dementia.
- The Office of Management and Budget is preparing a report of a survey of public awareness of long-term care.

Dr. Ling reported on several CMS activities:

- The Hand in Hand training series, which includes six 1-hour videos and an orientation guide, was distributed to nursing homes. The training focuses on how to deliver person-centered care.
- The CMS antipsychotic reduction initiative launched in 2012 has a goal of reducing antipsychotic use by 15 percent. As part of this initiative, CMS has created an action plan that will use a multidimensional approach to caring for individuals with dementia. The Hand in Hand training series is part of that plan. To date, the use of antipsychotics has dropped several percentage points.
- The Foundation of NIH convened a meeting focusing on improving measurements in different aspects of care for persons with dementia. Three work groups identified some 60 measures in the United States and an additional 50



outside the United States. A small subset of those measures was recommended to the Measure Application Partnership for consideration in various physician reporting programs. These measures will build on evidence and will need stewards to drive the process of evaluation in the National Quality Forum.

- CMS has enlisted 105 communities in the Community of Care Transitions program. Although none of these communities is specific to dementia, opportunities to build on this initiative can help meet the needs of the dementia community.

Discussion related to Dr. Ling's report included the following comments:

- A set of ICD-9 and ICD-10 diagnosis codes would be extremely helpful in tracking progress in addressing dementia and health outcomes.
- Re-educating physicians and providing incentives to using appropriate codes would be necessary to capture care costs related to dementia, because physicians typically focus on the two or three codes related to the main purpose of the patient visit.
- In estimating the costs associated with Alzheimer's disease it is important to include costs associated with comorbidity.
- It is critical to identify the kinds of measurement needed to determine how well we are doing with event interventions.
- It is important to note that costs related to dementia are not simply those for medical care, but also include housing and home care costs.
- Dr. Hojlo addressed how the VA is approaching cost data:
- The VA's approach in developing Community Living Centers rather than nursing homes is in part aimed at eliminating the notion of "place," which implies housing options, and instead addressing the kind of services needed to provide the highest quality of life available for a person with certain conditions. In effect, this is shifting the paradigm away from the diagnostic or medical model.

## **Preview of 2013 National Plan**

Dr. Lamont gave an overview of the status of the updated National Plan.

- A final decision on a few details of the plan has not been made, and a specific release date has not been set, but the updated plan should be issued in May.

- The updated plan includes ten pages of new action steps initiated by the agency, resulting from a lot of hard work from a number of departments. New activities include the following:
  - Developing health provider education curriculum.
  - Identifying measurements for high-quality dementia care.
  - Improving collaboration on caregiver support services between the Aging Network and the VA.
  - Implementing activities related to prevention of elder abuse.

## **Progress on Research Milestones to 2025**

Dr. Hodes described how milestones in implementing the recommendations from the May 2012 Alzheimer's disease research summit are tracked and gave examples of specific milestones.

- The 2012 research summit resulted in six categories of research recommendations:
  1. Interdisciplinary approach to discovering and validating the next generation of therapeutic targets for Alzheimer's disease.
  2. Challenges in preclinical therapy development.
  3. Whom to treat, when to treat, and what outcomes to measure.
  4. Drug repurposing and combination therapy.
  5. Nonpharmacological interventions.
  6. New models of public-private partnerships.
- Specific milestones were developed for each of these six recommendations. A chart (<http://aspe.hhs.gov/daltcp/napa/042913/Mtg8-Handout1.shtml#milestone1>) lists specific milestones and an expected time to complete them. For instance, for category 3, the first specific milestone is to initiate treatment trials in asymptomatic, at-risk individuals using uniform biomarkers and cognitive outcomes informed by data from Alzheimer's disease trials using patients with more advanced disease. For each milestone the chart contains links to success criteria.
- Lists of specific research projects that correspond to the milestones can be found by searching the database maintained by the International Alzheimer's Disease Research Portfolio (IADRP) (<http://iadrp.nia.nih.gov/cadro-web>). The IADRP database contains details including the investigators, funding organizations, abstracts, and any publications emanating from the research.
- Numerous funders of Alzheimer's disease research participate in IADRP, which is actively encouraging submissions from additional organizations, especially

those outside the United States. A new process for coding and validating data is being developed and will be launched on the IADRP website in July 2013.

- Four requests for funding announcements totaling \$73 million have been issued for FY 2013:
  - Interdisciplinary approach to identification and validation of novel therapeutic targets for Alzheimer's disease (R01) (\$23 million).
  - Alzheimer's disease therapeutics program (U01) (\$1 million).
  - Alzheimer's disease prevention trials (R01) (\$45 million).
  - Alzheimer's disease phase 1 clinical trials (R01) (\$4 million).
- A meta-analysis of data from nearly 6,000 African Americans found that the association with ABCA7 was 60 percent stronger among African Americans than among individuals of European ancestry. This study will help identify targets for genetic testing and intervention. The study was published in the April 10, 2013, issue of *JAMA*.
- Another study used data from the United States Health and Retirement Study to analyze costs attributable to dementia. In 2010 actual spending was \$10 billion, or \$28,000 per individual; additional costs for informal care were estimated at \$159-\$215 billion, or \$42,000-\$56,000 per individual per year. In 2040 actual spending is projected to be \$259 billion, with additional spending in informal care of \$379-\$511 billion. The sharp increase is due to the anticipated increase in the older population. The study was published in the April 4, 2013, issue of the *New England Journal of Medicine*.
- On April 16-17, 2013, several NIH institutes and nonprofit organizations collaborated on a research update meeting, *Advancing Treatments for Alzheimer's Disease in Individuals with Down Syndrome*. About 40 leading researchers in dementia and in Down syndrome participated.
- NIA and the National Institute of Neurological Disorders and Stroke are hosting a workshop May 1-2, 2013, to solicit input and develop recommendations on priorities and timelines for research on dementias related to Alzheimer's disease.

Discussion following Dr. Hodges's presentation included the following comments:

- At the May 1-2 workshop, participants will prioritize how available funding should be distributed across RFAs, given all of the targets and milestones in the research recommendations. Some research projects might have to be delayed. Every year such prioritization will occur.
- In prioritizing research to be funded, it is important not to focus on just the coming year, but to keep in mind the big picture of milestones necessary to reach

the goals by 2025. Participants in the research summit will be encouraged to be innovative and, if called for, revise the milestones established in 2012. Another enhancement of the May 2013 summit is that webcast capabilities will facilitate input from the public and from advocacy groups.

- Scientific progress in meeting the research milestones is difficult to assess, because the outcomes of research cannot be predicted. This situation makes it difficult to meet subsequent milestones, which are dependent on successful outcomes of previous research.
- Scientific publication is one metric to use in assessing the state of the science and determining whether scientific milestones have been reached. The annual state-of-the-science summit meeting is another method used, wherein scientists from different fields, such as epidemiology, preclinical research, and clinical research, evaluate progress.
- A method faster than publication is needed to transfer knowledge gains into field use, because of the delays inherent in publication. Nevertheless, peer-reviewed publication is needed to ensure that data and scientific conclusions are valid.

## **Research Agenda for Long-Term Service and Supports**

The Advisory Council discussed approaches to ensuring that the goals for LTSS and for clinical care include research in those areas.

- Just as the research recommendations have specified a monetary goal, the recommendations for LTSS and clinical care should have associated monetary goals. Such goals should quantify the costs to bring LTSS and clinical care up to scale so they are available to people in communities across the country, not just as demonstration projects.
- Defining a monetary target is especially challenging because the costs include many systems, payers, and individuals as well as insurance companies and government-funded programs. Because dementia is a continuum and involves so many parts of these systems, an associated dollar figure is overwhelmingly high, and significant consideration must be given to establishing priorities.
- A blue-ribbon panel on advanced dementia is needed. One of the tasks of such a panel should be to identify research priorities and gaps in knowledge about the care for people with dementia.
- There is very little research on early dementia and on what works for support of caregivers.

- Reviewing the research summaries in IADRP would be a good way to analyze gaps before establishing a blue-ribbon panel.
- In defining goals it's important to determine what metrics are going to be used to measure progress. For example, how will quality of care be measured? Such metrics will help define what research is needed. Once goals are established, it is critical to periodically reassess progress and adjust goals as needed.
- A current HRSA project has established a continuing education program in dementia care, with a pretest and posttest upon completion of training. A planned pilot with ten grantees will assess individual practitioner and practice improvement.
- Before the July Advisory Council meeting, the LTSS Subcommittee and the Clinical Care Subcommittee should discuss the issues raised today.

## **Public Input**

The public comments portion of the meeting was moderated by Dr. Lamont.

Thirteen members of the public presented testimony, including persons living in the early stages of Alzheimer's disease, family members and caregivers of persons with cognitive disabilities, and representatives from the National Capitol Area Alzheimer's Association, the National Alliance for Caregiving, Leaders Engaged in Alzheimer's Disease, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), the Elder Workforce Alliance, the Alliance for Aging Research, and the Alzheimer's Impact Movement.

Speakers made the following recommendations and observations:

- The suggestion in the National Plan to designate within the White House and HHS an office on Alzheimer's disease and cognitive disabilities is appropriate.
- A national campaign and spokesperson to update the public about Alzheimer's diseases are needed.
- It is urgent for more support to be offered to caregivers.
- The Alzheimer's Association released updated statistics in March 2013, estimating that 5.2 million people are living with Alzheimer's disease and projecting that by 2050 up to 13.8 million people aged 65 and older will be living with Alzheimer's disease. It is the sixth leading cause of death, but may be responsible for more deaths because of how deaths are recorded. From 2000 to 2010 deaths from Alzheimer's disease increased 68 percent, while death from

other diseases decreased. In 2013, an estimated 450,000 people will die with Alzheimer's disease. In 2012, over 15 million Americans provided 1.5 million hours of unpaid care for those with Alzheimer's disease. Eighty percent of care provided in the community is provided by unpaid caregivers; this care has an estimated value of approximately \$216 billion. By 2013, 3.5 million additional health care professionals are projected to be needed to care for individuals with Alzheimer's disease. The total cost of care for people with dementia will reach \$203 billion in 2013 and is projected to increase to \$1.2 trillion by 2050.

- The government should put the same resources into research on Alzheimer's disease that it has put into diseases such as cancer, HIV, and heart disease.
- The Advisory Council membership should include an individual with Alzheimer's disease. Suggested qualifications for such a representative are diagnosis of early-stage Alzheimer's disease, participation in a clinical trial, confident and articulate personality, understanding of caregiver issues, user of technology, understanding of government politics, loyalty to the cause rather than to one organization, ability to think outside the box, ability to be a team player, passion for the mission, and experience working with support groups. It would also be helpful for the individual to be a visionary and to have a business background.
- The Advisory Council should consider changing the meeting format to include a question-and-answer session after each speaker or at the end of the day's presentations. Such sessions would prevent information from being misrepresented and would serve as a learning platform for participants.
- Dementia awareness outreach should include providers at large, in addition to healthcare providers. Such an addition would help reduce barriers and information silos. Consideration should be given to using corporations for outreach and to providing information in non-healthcare settings, such as grocery stores.
- The National Down Syndrome Society recently published a very well-written and useful book, *Aging and Down Syndrome: A Health & Well-Being Guidebook*.
- More effective federal leadership on issues related to Alzheimer's disease is needed to ensure appropriate cooperation between public agencies. For example, an individual with Alzheimer's disease should not be refused admission to an intermediate care facility funded by CMS.
- The National Plan does not have a clear strategy for addressing early-onset Alzheimer's disease. Formation of a panel or work group that focuses on early or mid-stage LTSS is recommended.

- The medical home model of care represents an appropriate approach to addressing Alzheimer's disease. Such an approach would include important elements such as respite for caregivers and transportation for individuals with Alzheimer's disease.
- All programs proposed in the National Plan should include funding mechanisms and should not burden caregivers.
- Evidence-based research regarding LTSS and patient and family-centered interventions is needed, and the Advisory Council's plan for pursuing this is supported. Patients and caregivers should be involved in deciding what the research questions are, shaping the ongoing research, and disseminating the results.
- As more energy is directed to international research, consideration should be given to developing international registries of family caregivers as well as registries of the workforce and family caregivers.
- NTG has developed practice guidelines for the evaluation and management of dementia in adults with intellectual disabilities, to be published soon in the *Mayo Clinic Proceedings*. The early detection screening tool developed by NTS is in wide use and has been translated into German and Italian. The organization is also developing an in-service training curriculum for direct care professionals that will emphasize what agencies can do to train their staff and family caregivers.
- The inclusion of the elder care workforce in the National Plan is very much appreciated.
- The National Plan's recommendation that funding and incentives for individuals to pursue careers in geriatrics and gerontology is appropriate and appreciated.
- The National Plan's recommendation that family caregivers receive adequate training and compensation is supported.
- The decisions of Dr. Francis Collins to direct \$40 million to Alzheimer's disease research in FY 2013 and of President Obama to include \$100 million in the FY 2014 budget are appreciated.
- Congratulations were extended to ACL and NIA for the People's Choice and Innovation awards.
- The Senate Special Subcommittee on Aging's bipartisan support for funding of Alzheimer's disease strategies is gratifying.

- Providers sometimes prescribe medication without appropriate discussion with the patient or with caregivers. The National Plan's provisions for education of both professionals and family caregivers are extremely important in this regard.
- The Rand Corporation study's estimates of the current and projected costs related to Alzheimer's disease were extremely low.

## **Concluding Remarks**

Chair Dr. Ronald Petersen thanked the public participants for their input, noting that such contributions help ground the council's feelings about dementia. He thanked Dr. Katz for his service on the Advisory Council and commended him for his important contributions.

The next Advisory Council meeting will take place on July 19, 2013.

The meeting adjourned at 4:15 p.m.

Minutes submitted by Helen Lamont (ASPE).

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