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

Washington, DC

April 28, 2015

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Ronald Petersen (Chair), Laurel Coleman, Yanira Cruz, David Hoffman, Jennifer Manly, Helen Matheny, Jennifer Mead, Dennis Moore, George Vradenburg, and Geraldine Woolfolk

- *Federal Members (or representatives) Present*: Billy Dunn (U.S. Food and Drug Administration), Linda Elam (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Bruce Finke (Indian Health Service) (by telephone), Richard Hodes (National Institutes of Health [NIH]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Anand Parekh (Office of the Assistant Secretary for Health), William Spector (Agency for Healthcare Research and Quality), Amber Story (National Science Foundation), Jane Tilly (Administration for Community Living [ACL]), and Joan Weiss (Health Resources and Services Administration)

- *Guest Speakers*: Marie-Therese Connolly (Woodrow Wilson International Center for Scholars), Naomi Karp (Consumer Financial Protection Bureau [CFPB]), Rebecca Katz (author, educator, and culinary translator), Marla Lahat (Home Care Partners), Susan Lynch (U.S. Department of Justice [DOJ] Civil Division), Carolyn McClanahan (Life Planning Partners, Inc.), and Tia Powell (Albert Einstein College of Medicine)

- *Quorum present?* Yes

- *Advisory Council Designated Federal Officer*: Rohini Khillan (ASPE)

General Proceedings

At 8:34 a.m., Chair Dr. Ronald Petersen called the meeting to order.

Dr. Petersen introduced himself, welcomed meeting participants, and outlined the meeting agenda.

Dr. Linda Elam, Deputy Assistant Secretary for Disability, Aging and Long-Term Care Policy at ASPE, welcomed meeting participants to the special edition of the quarterly meeting, which included an overview from the White House Conference on Aging

(WHCOA). Dr. Elam introduced Dr. Mary Wakefield, Acting Deputy Secretary of the U.S. Department of Health and Human Services (HHS).

Dr. Wakefield welcomed meeting participants, highlighted the important issues surrounding Alzheimer's disease, and thanked all panel members for their work and contribution to Alzheimer's research, finding the cure, and supporting people with dementia and their families and caregivers.

- The year 2015 marks the 50th anniversary of the Medicare program and the 80th anniversary of the Social Security program.

- As many as 5 million Americans are living with Alzheimer's disease. By 2030, this number will increase to 8.5 million. Millions of family members and caregivers will also be affected.

Overview of the White House Conference on Aging and the Importance of Today's Meeting

Kathy Greenlee, Assistant Secretary for Aging at HHS, presented an overview of WHCOA, which will be held later this year.

- The first WHCOA was held in 1961 and approximately every 10 years afterward. The sixth WHCOA will be held this year.

- The White House is fully committed and involved with the 2015 conference. The key supporter is Carole Johnson, who serves on the White House Domestic Policy Council.

- Five regional forums have been held to provide input on selection of topics for the upcoming conference.

- Alzheimer's disease affects all areas that WHCOA covers: healthy aging, retirement planning, long-term services and supports (LTSS) provision, and elderly justice.

- Health disparities are a real concern because some groups are at a higher risk of having Alzheimer's disease. These groups include Latino and African American populations, as well as people with intellectual disabilities such as Down syndrome.

- Definition of *dementia capable*: someone who can recognize that dementia has a unique aspect, characteristics, and an immediate need that should be addressed at any entry point into the system, not only for the person with dementia but also for his or her family members and caregivers.

- Many states developed statewide Alzheimer's plans and have received federal funds and supports to achieve the dementia capability objective. However, access to services and stigma continue to affect individuals with dementia and their family members.

- HHS worked with the Alzheimer's Association to fund the National Alzheimer's Call Center in Chicago and provided support for a national campaign.

- The field of aging is evolving, and the focus is shifting to person-centered services and addressing specific needs of the individual, conducting needs assessments, and providing family support.

- Extraordinary costs of providing care affect LTSS delivery. Many people in early stages of Alzheimer's disease can live in the community for a long time and be independent with appropriate support provided.

Elder Justice and Dementia Panel, Followed by Q&A

Susan Lynch, from the DOJ Civil Division, presented DOJ's efforts to combat elder abuse and financial exploitation.

- DOJ efforts to implement the Elder Justice Coordinating Council (EJCC) Elder Abuse Prevention Campaign include the following recommendations:
    - **Recommendation 1**: Support the investigation and prosecution of elder abuse cases. through prosecuting criminal schemes; protecting seniors from financial, lottery, and mass marketing scams; pursuing civil "failure of care" cases; and providing critical resources to victims, families, investigators, and prosecutors.
        - The DOJ Elder Justice Website (http://www.justice.gov/elderjustice) provides resources to prosecutors, victims, families, and practitioners.

    - **Recommendation 2**: Enhance resources for elder abuse victims. These resources are available on the aforementioned Elder Justice Website.

    - **Recommendation 4**: Develop a federal research agenda. This research funding comes from DOJ's National Institute of Justice.

    - **Recommendation 6**: Provide law enforcement training. The resources include *Legal Issues Related to Elder Abuse: A Pocket Guide for Law Enforcement* from the Bureau of Justice Assistance and online training for legal aid providers from the Office for Victims of Crime.

    - **Recommendation 7**: Combat elder financial exploitation.

- Alzheimer's and other dementias put older Americans at higher risk of elder abuse.
  - In a United States study, caregiver abuse and neglect of people with dementia by their caregivers was detected in 47% of caregivers surveyed.
  - One study shows that 60% of caregivers had been verbally abusive to the person for whom they were providing care.
  - Of caregivers, 5%-10% reported that they were physically abusive toward their care recipients.
  - Characteristics associated with mistreatment of people with dementia include the caregiver's anxiety, depressive symptoms, perceived burden, emotional status, and role limitations due to emotional problems; as well as the care recipient's psychological aggression and physical assault behaviors. These behaviors were the best indicators for elder mistreatment as defined by the expert panel convened for this research study.

- Older Americans with dementia are more vulnerable to financial exploitation.
  - Studies have found that financial exploitation is related to cognitive deficits.

- Alzheimer's and other dementias can make it more challenging to prosecute elder abuse cases.
  - Individuals with dementia can make less credible witnesses.
  - The defense can use an individual's cognitive capacity to discredit allegations.
  - More research is needed to support expert testimony on issues of elder abuse and capacity.

- More research on dementia is needed to support prosecution.
  - Conduct event-based studies to examine contexts and situations that create a high risk for abuse.
  - Conduct longitudinal research with a primary focus on elder mistreatment.

Helen Matheny, Advisory Council member, Services Director of the Blanchette Rockefeller Neurosciences Institute's Alzheimer's Outreach and Registry Program, and patient advocate presented on elder justice issues and resources available to help people with dementia.

- Dementia can affect a range of elder justice issues, such as advanced care planning that clarifies who will make decisions and the duties involved. Health and long-term care (LTC) advanced planning and financial advanced planning include direct deposit, joint accounts, automatic bill pay, power of attorney, and so forth.

- Financial exploitation is not uncommon. According to AARP, elder financial exploitation is a form of elder abuse. Other forms include fiscal abuse, sexual abuse, and neglect. Financial exploitation may include failure to provide goods or services that have been paid, such as when paid caregivers bill for services that were not performed or inadequately performed. Financial exploitation may also include identity theft, such as when an adult grandchild obtains a mortgage or a credit card in the grandparents' name, and misappropriation of assets, such as when a caregiver steals money or jewelry.

- As individuals age, their financial capacity or their ability to judge trustworthiness and risk may decline, and financial management skills vary. For example, one partner in a marriage typically manages the household finances, and when that individual dies, the other spouse is often not well equipped to handle those finances. However, several programs are available to aid the elderly and individuals with dementia. The AARP partners with local police and sheriffs' departments in many states to hold scam jams, which are information sessions for older adults about financial risk and protection. The organization has a fraud watch network that sends alerts and news about scams, fraud, and identity theft for those who sign up for the service.

- Wells Fargo's Elder Client Initiatives program provides information for its network of advisors to recognize suspicious activity in their clients' accounts. It is critical for individuals to be observant and informed, and it is important for physicians to be aware of the patient's family and support system.

- Sometimes an elderly person may have a "new best friend," which could be a red flag. The "friend" may be trying to scam the older individual. In addition, drug diversion is not uncommon.

- Individuals with Alzheimer's disease and related dementias are often viewed as easy targets for caregivers and family members.

- A dementia-friendly community is informed about and respectful of individuals with dementia and is prepared to support living with people with Alzheimer's and those touched by the disease. In addition to the medical community being aware of potential abuse, legal and financial advisors should be aware of dementia and offer supportive services and learn more about the signs and symptoms of Alzheimer's and other dementias.

- A new report titled *Cognitive Aging: Progress in Understanding and Opportunities for Action* focuses on how cognitive aging can affect judgment in a wide variety of situations. There is a need for local and national communities to provide sound, unbiased information to those who need it; there is a need for programs to help people compensate for their cognitive challenges, and there is a need for policies to protect those who are having trouble making decisions independently. Many public and private organizations already make contributions. This report offers opportunities for action that require multiple efforts involving several agencies, organizations, and sectors, as well as individuals and families. Joint and collaborative efforts will greatly strengthen these opportunities. This report is available at http://www.iom.edu/Reports/2015/Cognitive-Aging.aspx.

Marie-Therese Connolly, Senior Scholar at Woodrow Wilson International Center for Scholars, presented on elder abuse prevention.

- The data indicate that people with dementia are at a much higher risk for abuse, neglect, and exploitation. That happens much more than was previously known before prevalence data were obtained. The initial research indicates that about one in ten people aged 60 years or older and people with dementia are at a four-fold or five-fold risk compared with the general population.

- Before dementia is even detected, signs of financial incapacity may emerge so often that the money is gone before you even know a problem exists. With signs of financial incapacity, there is an opportunity to begin asking questions about dementia and obtain earlier treatment and intervention.

- Elder abuse takes a huge toll on people with dementia and on their caregivers, families, and society--a health toll, a human toll, and a cost toll. That toll is beginning to come into focus. Although no numbers are available, people who have been abused, neglected, or exploited are roughly four times as likely to be admitted into nursing homes and three times as likely to be admitted into hospitals. That is a lot of Medicare and Medicaid costs given the population. People who are financially exploited are much more likely to become dependent on Medicaid. If mistreatment can be reduced, the well-being of people with dementia and their families and caregivers can be greatly improved.

- People who are abused, neglected, and exploited are much more likely to become dependent. The toll on caregivers is formidable in terms of health, mental health, and financial cost.

- Autonomy and safety issues are another of barrier to addressing elder abuse. When is it right to intervene, and when are you allowing somebody to be exploited, neglected, or abused? These profound philosophical questions need to be addressed more, with the assistance of ethicists, philosophers, and other experts.

- Another barrier is that people with dementia are often not believed when they say that they have been abused, neglected, or exploited. Some preliminary data suggest that emotional memory lasts longer than other kinds of memory. We should believe people with dementia much more than we do, yet we hear prosecutors and untrained law enforcement officers all over the country saying that people with dementia are bad witnesses and that their testimony is often false.

- Another problem is that a lot of the gatekeepers, adult protective services, financial advisors, and the like are not experts and lack training on how to assess financial capacity, so they do not know how to determine whether somebody has decision-making capacity.

- Another challenge that elder abuse poses is stigma.
- Elder abuse issues are hard to talk about in a way that either gains traction or resonates with people with dementia, their caregivers, or policymakers.
- Better prevention research is needed in the area of elder abuse to find out what works, what does not work, and what the costs are. The U.S. Government Accountability Office found that the National Institute on Aging (NIA) allocated $1 million per year to elder abuse research, and the Centers for Disease Control and Prevention (CDC) allocated much less.
- Elder abuse is a serious public health issue, along the lines of domestic violence, child abuse, sexual assault, and dementia, but there is no framework for a public health response or even any acknowledgment that it is a serious public health problem.
- Elder abuse is preventable, and prevention could reduce suffering and improve the well-being of countless people with dementia and those who care about and for them.

Discussion after the presentation included the following comments and clarifications:

- One of the greatest things about WHCOA and EJCC has been a lot of cooperation. There has been partnership with banks on many different levels. One partnership involves training people at all levels to notice when there is a problem.
- The Office of the Comptroller of the Currency and the Federal Reserve Bank of San Francisco recently made statements on this issue and encouraged the financial services industry to do more by way of training.
- Another important issue is not only when bank clients become impaired, but also how large financial management firms understand that it is not beneficial for anyone if the person helps with financial accounts has lost his or her executive function. Many people in the financial services field are aging, and there is a human resources responsibility on behalf of the people who employ them, and that will be tricky and complicated and can compound the problem.
- Financial abuse issues highlight the importance of good assessment that continues over time--not just physical assessment, memory assessment, function assessment, and emotional assessment, but also financial capacity. Financial capacity is as important an indicator of health among older people as diet, exercise, and sleep.

- Emphasis of this Advisory Council on the fields of aging and dementia is moving earlier and earlier in the spectrum, trying to identify people at the beginning of the process or even earlier with biomarkers (earlier intervention equals earlier treatment). But that raises another conundrum: autonomy versus safety. Somebody with mild cognitive impairment, by definition, has some cognitive difficulties but really is functionally intact. Yet, they may not be totally functionally intact. Clinicians sometimes are faced with the notion of a vulnerable adult and whether they should intervene and bring it to the attention of family and other individuals because they also have to be mindful of the autonomy issue.

- The definition of *vulnerable adult* differs from state to state and community to community, and it is somewhat controversial because some states deem all older people vulnerable, which is not the case and somewhat patronizing.

- Talking to patients about what they want in terms of both putting protections in place or having conversations with others in their lives might have a protective impact. This is something that Wells Fargo Advisors is doing: trying to get a second person--a trusted person--while an individual is still in a position to decide who to trust on the account. This person would not have control over the account; they would just be notified if there is trouble.

- In summer 2015, DOJ, as part of the work for WHCOA, is going to launch the anatomy of an elder abuse prosecution. In that particular context, several experts will speak about these issues.

Healthy Aging and Dementia, Followed by Q&A

Anand Parekh, Deputy Assistant Secretary for Health (Science and Medicine) at HHS, presented on healthy aging.

- Healthy aging is one of the four themes of WHCOA. As a person ages, chronic diseases become more prevalent. The most important takeaway is that healthy aging and living with chronic diseases such as Alzheimer's are not incompatible. For many chronic diseases, healthy lifestyles and healthy aging are part of the treatment plan. They are important in ensuring that those chronic diseases are well managed. For Alzheimer's, the research is still under way as to how healthy aging lifestyles might modulate the course of the disease.

- Although the ways lifestyle interventions can prevent or modulate the course of Alzheimer's dementia still remain to be definitively seen, the fact is that healthy aging helps the person with Alzheimer's.

- Nearly 50% of Medicare beneficiaries with Alzheimer's disease have an additional five or more chronic conditions, and 75% of Medicare beneficiaries with Alzheimer's disease have at least three or more chronic conditions. Many of these chronic conditions are heart disease, diabetes, stroke, chronic obstructive pulmonary disease. The course of these conditions can be managed and modulated through healthy aging and engaging in healthy lifestyles, such as proper nutrition, exercise, and avoiding substance abuse. Therefore, when looking at the person with Alzheimer's, not just the disease itself, healthy aging is absolutely critical.

- As part of WHCOA, an important policy brief was released. The brief discusses the importance of healthy aging and the array of activities ongoing in the Federal Government to support these areas, which include physical activity promotion for adults, enhanced nutrition, increased uptake in preventive services such as immunization, fall prevention, civic engagement for seniors, aging in place, and age-friendly communities. These areas align with the section of the National Plan that addresses housing needs for people with Alzheimer's disease and optimal cognitive and behavioral health. The Healthy Aging Policy Brief can be found at http://www.whitehouseconferenceonaging.gov/blog/policy/post/healthy-aging-policy-brief.

- Within the government, these efforts are not only occurring at HHS, but also at other departments. For example, the U.S. Department of Housing and Urban Development is taking the lead in addressing affordable senior housing. The U.S. Department of Transportation is focusing on transportation to health care services (rides to wellness) and safe driving at older ages. The Corporation for National and Community Service, another federal agency, focuses on connecting seniors to volunteer opportunities. In addition, HHS is partnering with many private-sector entities, including the National Council on Aging, AARP, the Association of State and Territorial Health Officials, and others.

Laurel Coleman, Advisory Council member, internist, and geriatrician, presented on healthy aging and how clinicians deal with this issue in an aging population and persons living with dementia, as well as their caregivers.

- The last 5-10 years have been an exciting time because before that, not much was known on the value of some of these lifestyle changes and how they might affect aging and living with chronic illnesses.

- Important ongoing research tells us about the impact of lifestyle changes on physical and cognitive function. Significant research on exercise and persons living with dementia shows that they can be stronger, more cognitively aware, and more cognitively active. Some studies even show some improvement.

- At the same time, it is important to remember that at this point, Alzheimer's disease does not have a cure, and a focus on quality of life is also important. In fact, it is crucial. There is a tremendous variability among persons and among individuals living with dementia. They may be 95 years old and have two chronic illnesses, or they may be 64 years old and be otherwise healthy.

- Lifestyle changes and approaches to healthy aging can actually cause a lot of conflict between the person living with dementia and his or her caregivers or family members. For example, a person for whom walking and being physically active was important throughout their whole life has been diagnosed with Alzheimer's, and this person has strongly wanted to continue physical activity, even when it became obvious that there was a safety concern due to wandering, inattention to the weather and being prepared, inattention to how long they have been walking, and forgetting to eat. This safety concern created a conflict and presented an important opportunity to engage and think about safety.

- Clinicians need to think about the whole person, who they have been in their life, what kind of choices they have made, their preferences, and issues that they are dealing with. It is crucially important to see not just Alzheimer's disease and not just dementia but the whole person, which also includes thinking about the caregiver and who they are and what their capabilities, strengths, and challenges are.

Sandy Halperin talked about his own life as a person living with dementia.

- The individuals, groups, the National Alzheimer's Project Act (NAPA) Advisory Council, and WHCOA should all focus on what persons with dementia can do. It would be helpful to have individuals with dementia attend WHCOA to provide firsthand insights into their lives.

- CNN was present during the Advisory Council meeting because they are filming a documentary about Dr. Halperin's life with Alzheimer's disease.

- Dr. Halperin mentioned a book written by Spencer Johnson, *The Precious Present*. This book taught him how to live in the present and is meaningful when he does not remember the past and does not remember what he had planned to do in the future. He said the book represents a treasure in his life.

- Technology helps Dr. Halperin in many aspects of his life, such as remembering to take medication. He mentioned a new face recognition application in development by Sean Fahey: WindowMirror™, which is designed for people living with dementia. Another example of technology is Narrative Clip, a wearable camera that takes pictures every 30 seconds. The images serve as a diary for the person with dementia and his or her family members.

- Advancements in technology can allow people with dementia to stay in their homes and have a better quality of life.

- Dr. Halperin made several scrapbooks to document his life for his children and grandchildren and will begin creating video messages soon.

- Dr. Halperin always carries what he calls the "end of life book." This book covers his wishes in terms of advanced care planning. He suggested that everyone should have that sort of book, and he hopes that one day, technology will replace the need for a physical book and replace it with an electronic version that can allow the important information to be accessed anywhere.

- One of Dr. Halperin's wishes is to donate his brain, but he still has doubts about whether his brain will be harvested efficiently and appropriately to help his family and science.

- He considers his family and friends as primary backup and supportive brains. "It's like each of their brains are directly connected with mine as they assist me with a huge number of my moment-to-moment thoughts and activities, all through the day."

- Florida State University College of Medicine has established the Alexander "Sandy" Halperin, DDS, Alzheimer's Research Fund.

Discussion after the presentation included the following comments and clarifications:

- On the behalf of the White House, Nora Super thanked Dr. Halperin for participating in the meeting.

Food for a Healthy Mind, Followed by Q&A

Rebecca Katz, author of *The Healthy Mind Cookbook: Big-Flavor Recipes to Enhance Brain Function, Mood, Memory, and Mental Clarity*, presented on how food can influence us and can help our brains.

- Ten years ago, a series of studies were conducted on food and the brain and food's impact on the brain, and half of those studies have just come about in the last 5 years. These studies are certainly not definitive, and they are not saying that these are foods that are going to be the cure. But what they are saying is that what we eat does affect the way we feel, the way we might think, whether we might be stressed, the way our moods change, and the way we handle the day-to-day little things that happen in our lives.

- The presentation highlighted "smart foods" (lentils, salmon, walnuts, mint, pumpkin seeds, cauliflower, fennel, avocado, citrus, kale, eggs, and chocolate) through a series of stunning photographs of healthy foods.

- The MIND diet is being studied and examines the role of dark leafy greens and dark berries as being important for people with dementia.

- Food plays many roles. It is not just how it nourishes our brains. It is about how it nourishes our relationships. It is how we connect with people. When we do not always have the words that we want to say, but we want to communicate, we can communicate with food. Ultimately, food is an expression of love.

- Food is empowerment, and during a time of fragility with dementia, when things are so out of our control, when we have to live in the present, food is a great tool to keep us there and to nourish us and our loved ones. Food plays a role in healing, well-being, and nurturing a healthy mind and a healthy life.

Discussion after the presentation included the following comments and clarifications:

- We all know what we should do, but it is rare that we always do what we should do in life. This diet may be useful for those who have a nearby farmers' market or Whole Foods, but we compete with fast food, we compete with in-school food, which frequently does not have this kind of healthy material, so how do we change our national behavior in a way that matches the delicious plate in front of us?

- We are competing with a lot of processed foods, fast foods, and convenience foods. These look glamorous on the screen, but they are more readily available than we may think. One of the challenges is making them more accessible to people and training people how to prepare food in this way.

- When looking at the dollars and cents, this food is not as expensive as one may think. Lentils are one of the most inexpensive foods. When looking at what we spend on processed foods and packaged foods, the difference is not that much.

- Most of what one hears about hunger in America today is that we cannot find this food affordably in most of our communities. The District of Columbia has extraordinary problems with getting healthy foods into the schools, east of the Potomac River, or into low-income areas.

- A new study about the MIND diet, which is a cross between the Mediterranean diet and the DASH diet, recommends one glass of wine a day. The use of alcohol is an individual question of how people metabolize it. There is a role for it in moderation.

- The Cherokee Indian Hospital being built in North Carolina is an expression of the tribe and of the community. It is mostly an outpatient facility, but every inpatient room is about a third bigger than standard, and that extra third is family space. They are also building a "teaching kitchen" to educate about healthy lifestyle and healthy eating.

- CDC and the Institute of Medicine (IOM) have some wonderful guidelines in terms of policy system and environmental change. There are tremendous strides in terms of farm to school, farm to health care settings, farmers' markets, and community gardens. Those are just some examples of best practices that can be replicated and are working well.

Long-Term Services and Supports and Dementia Panel, Followed by Q&A

Helen Lamont, ASPE, provided an overview on LTSS.

- A WHCOA Issue Brief was released in April 2015. The major issues covered in the brief included family caregivers, direct care workers, quality, financing, and planning for LTC.

- Most people will need very little LTSS, 30% will not need any, and 20% will need it for more than 5 years. People with dementia will need LTSS for a much longer period.

- Findings from the National Health and Aging Trends Study, funded by NIA and representative of the population aged 65 or older living in the community, show that people with dementia will need LTSS, have higher level of need, and need more supervision.

Dave Hoffman, Advisory Council member, provided an overview of LTSS recommendations.

- The area of LTSS requires some additional research. With no cure currently available, the health of so many caregivers should be of concern.

- One of the challenges LTSS is facing is that lots of pieces of the public and private sectors 'are responsible for one component, which is the good news. However, none of them have adequate resources to address their component of LTSS, which is the bad news.

- A sense of urgency is absolutely essential to bring LTSS to a meaningful scale. The World Health Organization (WHO) and the Federal Government have identified these issues as important.

- New York State is one of the places that has made some progress. This year in the New York State budget, a new allocation will primarily go to caregiver supports. New York has been seen as a leader in the resources it puts into Alzheimer's programs and Alzheimer's caregiver programs historically. This year, our governor proposed and our legislature adopted an additional $25 million to focus on these important issues.

Marla Lahat, Executive Director at Home Care Partners, presented on providing services to people with dementia.

- Home Care Partners is a nonprofit home care agency located in Washington, DC, that serves the whole metro area. It has about 200 home care aides who are certified health aides and certified nursing assistants. Home Care Partners is not a Medicare agency and is not a Medicaid provider, but it serves primarily a low-income to moderate-income population and receives local government grants and contracts from the DC Office on Aging and the Area Agencies on Aging and Departments of Human Services in Montgomery County and Prince George's County.

- Working with people with dementia can be challenging. But working with an individual who does not necessarily recognize the need for care, does not remember that their home care worker is supposed to come or who their home care worker is when they arrive, and does not necessarily cooperate can be even more challenging.

- Family members and family caregivers are facing their own challenges and the emotional, physical, and financial stress of taking care of somebody with dementia, and sometimes that spills over to the home care worker who is there to provide the help.

- Home Care Partners is not a Medicare or Medicaid provider; therefore, its main challenge is funding, so it can provide adequate service for those who need it because people with dementia often need more care, more supervision, and more assistance with activities of daily living and instrumental activities of daily living than those who do not have dementia. Funding is needed to pay the workers a living wage and provide work benefits. These workers deserve a living wage, benefits, adequate supervision, and adequate training, and those essentials are not always available.

- The other important area is the ability to provide adequate and innovative training to the workers, not only on the basics of dementia, but also on the best way to engage clients, to keep clients as independent and as engaged in society as possible.

- The overwhelming majority of people want to remain in their homes. The overwhelming majority of family caregivers want to keep their relatives at home in the community, and by doing this work, Home Care Partners plays a role in helping them achieve that.

Discussion after the presentation included the following comments and clarifications:

- In the earlier presentation, it was mentioned that the family caregiver cost is $0. To clarify, the cost is usually not $0 for those family caregivers. If a caregiver needs to stay home, leave their job, or work part time, they are risking their financial retirement and security. There are emotional, physical, and financial costs.

- One article published in 2013 provided estimated costs of caregivers, and the number was between $50 and $100 billion.

- In the metropolitan DC area, three jurisdictions have come together and have different rules. All the local areas have a living wage, but for the first time, DC made sure to include home care workers as well. Home Care Partners has been able to negotiate with the local governments, so that when it receives its reimbursement, it is high enough to can pay the aides the living wage.

- CDC is developing a workplace survey targeted toward small businesses. The survey will include several questions about the kinds of caregiving benefits are included.

- Access is one of the challenges of LTSS. The cost is an element of access when the services are available, but individuals cannot take advantage of them; however, in rural settings, there are often no services to be had.

- It is unconscionable that someone should have to drive 2 hours to attend a support group. Bringing LTSS up to scale means making them available in communities where people live.

- ACL continues to work on translating evidence-based programs to address the unique needs of particularly at-risk populations by examining how to make those interventions fit into the needs of the community so that caregivers do not have to drive 2 hours to go to a support group. Instead, they can receive telephone or electronic consultation.

Retirement Security and Dementia Panel, Followed by Q&A

Naomi Karp, from CFPB, presented on retirement security.

- The Office of Financial Protection for Older Americans is the only office in the Federal Government specifically dedicated to the financial well-being of seniors. Together with other divisions of the CFPB, this office helps older consumers prevent unfair, deceptive, and abusive practices aimed at seniors and helps them make sound financial decisions as they age.

- Older consumers in the marketplace are a growing population, living longer, and facing several challenges as they age, including:
    - Increasing threat of financial exploitation;
    - A shifting retirement landscape that places greater decision-making responsibility on consumers; and
    - Cognitive impairment, which creates the need for financial caregivers.

- CFPB initiatives include the following:
    - Educating financial caregivers about their fiduciary duties.

    - Educating older consumers and other stakeholders about senior financial advisor designations:
        - A report on senior certifications and designations for financial advisors to Congress and the Securities and Exchange Commission was released in April 2013. This report is available at http://files.consumerfinance.gov/f/201304_CFPB_OlderAmericans_Report.pdf.

    - Protecting older consumers and alerting them about managing debt, pension advances, reverse mortgages, and other financial decisions:
        - The Older Americans blog is available at http://www.consumerfinance.gov/blog/category/older-americans.

Geraldine Woolfolk, a caregiver, shared her personal story about retirement planning and how those plans were altered by her husband's diagnosis of Alzheimer's disease.

- The couple had clear goals from the beginning, and they obtained help from financial services providers early on to ensure that they would be ready for retirement. Once Alzheimer's entered their lives, Ms. Woolfolk became the decision maker and caregiver.

- Mr. Woolfolk was able to get LTC insurance policy, but Ms. Woolfolk was not able to receive it because of her family medical history.

- At first, Ms. Woolfolk was taking care of her husband with the help of family members and home aides, but after many of the support services had failed and her own health took a toll, the family decided to look for an LTC facility in the area where they lived. They found a dementia care facility. The cost was $6,500 per month, and they were not sure how long Mr. Woolfolk would be able to stay there. They had to adjust their plans and use some of their other assets to pay for Mr. Woolfolk's care.

Carolyn McClanahan from Life Planning Partners, Inc., presented on retirement safety.

- The game changed for retirement safety in the 1980s as the plans moved from defined benefit to defined contribution plans. In addition, there was a general lack of financial education on dealing with a new paradigm, and investment professionals were rewarded for selling products and paid for managing money, not for providing the true planning needed for this scenario.

- More than half of elderly people with cognitive decline receive no help with finances other than from their spouse.

- As an unintended result of those changes, baby boomers are left to fend for themselves, and many will lose the cognitive ability to do so. The incentives in the investment industry are not aligned to help them with this problem.

- Individual recommendations include the following actions one can take:
  - Simplify day-to-day finances by minimizing the number and types of accounts; automating income and outflows; setting up auto-deposit for Social Security, pensions, and monthly paychecks; and using auto-pay for bills and using one credit card that gets paid off monthly.
  - Structure investments appropriately by simplifying investments, creating an investment policy statement, and annuitizing some investments. Retirement is the time to protect your money, not beat the market.
  - Identify future financial caretakers and consider a joint account holder on checking; put in place a power of attorney pre-approved by institutions; and provide that person with all financial information directly or by using a fiduciary advisor as an intermediary.
  - Use a financial portal to help consolidate information for easy tracking. This does not allow access to accounts--only viewing. Provide account access to a future financial caretaker for monitoring, and set alerts for unusual activity or balances.
  - Hire an appropriate advisor, such as a real "financial planner," not an "investment manager or broker."

Discussion after the presentation included the following comments and clarifications:

- A concern was voiced that that type of advice is applicable to only the top 20% of Americans.

- Most of what is considered good financial planning now is available to only those with higher net worth, but that is why hourly planning has become a much more robust profession. Financial planners charge $75-$200 per hour, similar to what one would pay an accountant.

- Ideally, if people knew that they could get a real financial planner on an hourly basis, a much wider group would take advantage of it--at least maybe the top 50%.

- The Elder Financial Safety Center in Dallas, Texas, provides a variety of financial services from protecting people against financial abuse to benefits counseling and financial counseling and coaching.

- Workplace financial education is an important service, but it is not available for those who are not working.

- During Financial Literacy Week in Jacksonville, Florida, the Financial Planning Association is providing free help.

- If we expect people to be in charge of their financial lives, financial literacy should be part of the process from elementary school and on.

- The slides from the presentations about retirement security could serve as a great handout in physicians' offices.

Summary and Closing

Nora Super, Executive Director of WHCOA, thanked all the guest speakers and provided closing remarks.

- Nearly everyone in this room has been affected by Alzheimer's in some way. These issues really resonate and make us think about ways we can do things differently, and today offered an opportunity to look at different fields and how we can apply them to help all of us as we get older, but especially those struggling with dementia in our families.

Public Input

Rohini Khillan moderated the public comments portion of the meeting.

Eleven members of the public presented testimony either in person or by email and included people living in the early stages of Alzheimer's, family members and caregivers of people with dementia, and representatives from Planetree, Inc., WindowMirror, Inc., National Task Group on Intellectual Disabilities and Dementia Practices, Leaders Engaged on Alzheimer's Disease, Alliance for Aging Research, and the Lewy Body Dementia Association, Inc. (LBDA).

- It is time for NAPA to take charge against dementia using the country's best health care resources. The funding is necessary, but it all begins with ideas and building strong relationships among all individuals and groups. They must all rally together to see results as they seek solutions for care and cure.

- NAPA should increase visibility throughout the country to more vigorously deal with complex challenges. NAPA can be one of the strongest partners in forging nation's path to success in providing care and finding a cure.

- NAPA's imperatives and recommendations should be freshly communicated and branded to ensure that its concrete imperatives are being accomplished. Is NAPA prepared to efficiently take on this challenge with vigor?

- The NAPA Advisory Council should bring together individuals and groups and government and private-sector organizations from throughout the United States to inaugurate the first NAPA Care and Cure action oriented summit. This would not be a technical summit in which attendees would just recite the well-known facts or figures. Rather, it would be a gathering in which each stakeholder and everyone sitting at a table would be mandated to speak to the specific actions that can be taken, with or without funding.

- It is disheartening to see so many well-intentioned individuals and groups doing great work in their silos separately instead of working together with a holistic approach and unified voice to get things done.

- Too many individuals and groups are blaming the U.S. Congress for not appropriately increasing the funding for care and cure. But at the same time, these individuals, groups, and organizations continue to be weighed down by intergroup politics where they are not communicating well.

- Questions for NAPA include the following:
  - If $5 billion were allocated to NAPA by public-private partnerships during this year for all dementias and other diseases with dementia-like symptoms would these funds be appropriately allocated for care and cure?
  - Do you believe that the National Plan defines the specifics on how each dollar should be spent for care and cure?
  - Do you feel that the National Plan has detailed how all funding would be assessed and evaluated?

- The book *Take Your Oxygen First: Protecting Your Health and Happiness While Caring for a Loved One with Memory Loss* coauthored by Leeza Gibbons and the 2013 Geriatric Clinician of the Year, Rosemary Laird, was mentioned as a great caregiver resource.

- In 2014, an Alzheimer's Action Group at the Westminster Oaks community in Tallahassee, Florida, was formed to promote awareness of the global crisis; emphasize the importance of collaboration among caring organizations in the area; and encourage local, state, and national elected officials to give far more urgent priority to research, awareness, and education to enhance care for those living with dementia. The group is impressed with the potential for further advancements with the robust, comprehensive recommendations from the

Advisory Council's public members and urges for early implementation of these recommendations and the reinforcement of these fresh initiatives with bold action.

- Brain Health Clinic sponsored by CareMore provides care for people with dementia and support for caregivers. They provide free education for patients, their families, and caregivers on disease management and legal aspects of dementia.

- Early detection and education are crucial, mostly to provide the patient with the best quality of life during his or her last years and to teach caregivers the coping skills needed to care for the patient.

- Protocol for early detection of dementia and Alzheimer's should be placed on an annual exam where people can be referred to the Brain Health Clinic for further evaluation. If dementia or Alzheimer's was not detected, it would still bring awareness to the patient and family. If it was detected, it will provide information about the disease, knowledge of how to handle it, and the support to do so successfully.

- WindowMirror, Inc., is developing a smartphone app for people living with Alzheimer's.

- Planetree, Inc., is part of a distinguished group of organizations known as the Dementia Action Alliance, which is dedicated to improving the lives of people living with dementia now as we wait for a cure.

- Planetree is building on the patient passport tool created through the National Quality Forum and is looking at how that tool was used between providers and persons living with dementia to connect them to LTSS and community-based resources.

- NAPA should more deeply engage with the wealth of resourceful nonfederal organizations such as the Dementia Action Alliance and Planetree, as well as personal experiences of people living with dementia and their care partners whose firsthand knowledge can really strengthen your work and improve the outcomes.

- The scale of data collection needed to inform NAPA's scope of work requires greater inclusion of persons living with dementia and their loved ones. We heard earlier about increased prevalence of dementia among certain ethnic and racial minority groups. The experiences and perspectives from these minority groups are underrepresented. Strategic recruitment to bring greater diversity to the various councils that feed into NAPA's work is needed; inclusive decision making is a hallmark of person-centered care. The principle is often illustrated with the phrase "nothing about me without me." One strategy to increase the perspectives of people around the table is to collaborate with more nonfederal organizations that are in the field working side by side with persons living with dementia from a variety of socioeconomic and ethnic and racial backgrounds, their families, LTC staff, and residential councils.

- Additional evidence of the exclusion of persons living with dementia is the appearance of NAPA's website. The font is small and difficult to read, and the webpages offer little information that the average layperson could understand. To achieve the aims of NAPA, the scaffolding for the structures by which information is shared and exchanged needs to be inclusive and accessible to persons living with dementia and their loved ones. NAPA should revisit the design and usability of the website in partnership with people living with dementia through all phases, not just after it is designed.

- People living with dementia are often excluded from participating fully in life, including meaningful involvement in decision making. In addition to exclusion based on ageism, it is often assumed that we know what people living with dementia need and we know what is best for them. Although we all have personal experiences with dementia, we are not the people who have it. For most of us, our experiences are primarily as family members of people living with dementia, or, as Dr. Halperin called it, "second brains." We have vast education and experience in the field, as well as extremely valuable and important lived experience to inform our work as caregivers and support people. But that is very different from an embodied experience of living with dementia. Thinking that we can operate without adequate and diverse representation of people living with dementia puts us at risk of thinking that we know what is best for them. To exclude these diverse perspectives perpetuates a position of powerlessness and reinforces age inequalities and health disparities.

- We need urgency and sober nationwide cooperation to do what is necessary to defeat this enemy of our shared human rights. The attacks on our nation by Alzheimer's disease will soon be upon us with an aging baby boomer generation. We need to act aggressively. We cannot surrender our nation and its values to an enemy that seeks nothing less than the total destruction of millions of Americans, their families, their communities, and their economies. We cannot and must not let Alzheimer's disease dictate the future of our nation and its people.

- If it will take decades to find a cure, then we need to find treatments to allow those affected by this human rights-stealing disease to preserve as many of their constitutional and human rights as possible and to live with as much normalcy as possible.

- The aging baby boomers who are parents of children with intellectual disabilities are now experiencing the challenge of finding resources and services to provide for their aging children who are possibly now affected by Alzheimer's disease or related dementias. The challenging is creating a parallel system where the parents are advocating for the service agencies they are affiliated with to create a system that provides dementia care or is able to integrate the dementia care into the general system so people recognize it. People with intellectual and developmental disabilities should be part of that whole process.

- Focus on intellectual disabilities should be included within all of the recommendations that go on in the National Plan.

- There are 50 states, a few territories, DC, and the resources of the states that should be incorporated into this National Plan. There is a whole state structure that delivers services to people with disabilities and their families. We need to encourage them to think of this as a priority area, and even if there is no federal money flowing in, there should be state money flowing in. There need to be stronger partnerships with the states.

- The National Plan should be a national plan, not a federal plan, and should include the private and public sectors.

- Call for NAPA to hold a National Research Summit focused on care and services. So far, there have been three national summits organized by NIH, primarily focused on biomedical research.

- The recent policy brief on the subject of LTSS states that private options including LTC insurance, whole life insurance or life insurance riders, reverse equity mortgages, and annuities are available to help some individuals plan ahead to pay for their future care, but there is no comprehensive LTC financing program available to all older adults.

- The medication therapy management benefit is a great opportunity for CMS to require health care providers to capture information on over-the-counter (OTC) medication and prescription use by older adults in electronic health records. Although public programs may not pay for OTC medication in most cases, it is in their interest to capture this information.

- The current Advisory Council recommendations process is off kilter with the budget and should be started much earlier. HHS is gearing up for the fiscal year (FY) 2017 budget process, which will be the last budget process for this administration.

- LBDA is grateful to HHS, the NAPA Advisory Council, NIA, and all of the advocacy organizations that have invested a lot of time, energy, and leadership in advancing the national discussion on dementia. However, more can be done to help raise the public's understanding of dementia. There is a great ambiguity among the general public about the difference between Alzheimer's disease and dementia. The general public has a great need to know the most common forms of dementia, and we need NAPA's help to give the non-Alzheimer's dementias much greater visibility.

- There are currently no dedicated voices for any of the non-Alzheimer's dementias on the NAPA Advisory Council. LBDA calls for two seats, one for on Lewy body dementia and a second for frontotemporal dementia. Nonprofit advocacy organizations such as LBDA and the Association for Frontotemporal Degeneration are ready to contribute and help maintain the balanced composition of the NAPA Advisory Council.

- The United Kingdom had estimated prevalence numbers similar to those of the United States, then after much research, the United Kingdom realized that the numbers were wrong and had more than doubled. When you see all of these big numbers, remember that the reality is far worse.

Discussion after the presentation included the following comments and clarifications:

- As a response to a request to hold the care and support services summit, George Vradenburg proposed that the Advisory Council should vote on that issue. The motion for preplanning for the summit was recommended. The Advisory Council has voted in support of planning for the summit.

- Linda Elam committed to reviewing the need to further determine what is feasible but noted that planning the summit now would be premature and may be considered an emotional reaction to urgency calls.

Institute of Medicine Report on Cognitive Aging

Tia Powell provided an overview of the IOM report titled *Cognitive Aging: Progress in Understanding and Opportunities for Action*, which was published on April 14, 2015. A free PDF of the report is available at http://www.iom.edu/cognitiveaging.

- *Cognition* refers to the mental functions involved in attention, thinking, understanding, learning, remembering, solving problems, and making decisions.

- Cognitive aging is a process of gradual, ongoing, and highly variable changes in cognitive functions that occur as people age.

- Cognitive aging is a lifelong process. It is not a disease or a quantifiable level of function.

- In the context of aging, cognitive health is exemplified by an individual who maintains his or her optimal cognitive function with age.

- Cognitive aging is not the same as Alzheimer's disease.

- Alzheimer's disease is characterized by chronic neuron loss that affects approximately 10% of older Americans, often with severe, progressive declines.

- Cognitive aging is described as the part of aging during which neuron numbers remain relatively stable, but neuronal function may decline. It occurs in everyone, but the extent and nature of changes vary widely. These changes are variable and gradual.

- Misconceptions about cognitive aging include the following:
  - Maintaining cognitive health means preserving your memory.
  - Cognitive function always declines with age.
  - There is nothing you can do to improve your cognitive health.
  - Brain neurons die as you age, so there is no way to prevent cognitive decline.

- Facts about cognitive aging include the following:
  - Cognitive health is far more than having a good memory. It also involves decision making, attention, and problem solving.
  - Aging can have positive and negative effects on cognition. Wisdom and expertise can increase with age. Older adults experience fewer negative emotions, such as anger and worry, than people in young adulthood and middle age, and they report feeling greater satisfaction with life in general.
  - Individuals and families can take action to help support their cognitive health and adapt to age-related cognitive changes.
  - In the absence of disease, neuron death is minimal. One can take many actions to support cognitive health.

- Key messages about cognitive aging for health professionals include the following:
  - Age affects all organs, including the brain. The impact of cognitive aging varies widely among individuals and throughout the life span.
  - Cognitive aging is more than a decline in memory or speed of processing; it can also have positive effects on cognition.
  - Scientific understanding of the nondisease changes in cognition with age is rapidly advancing, but much remains to be learned.
  - Cognitive changes can affect daily activities.
  - There are opportunities for action at many levels: individuals, families, senior centers, communities, nonprofits, federal and state agencies, and the private sector (finance, transportation, technology, health care).

- Key messages about cognitive aging for consumers include the following:
  - The brain ages, just like other parts of the body.
  - Cognitive aging is not a disease.
  - Cognitive aging is different for every individual.

  - Some cognitive functions improve with age.
  - Patients can take steps to protect their cognitive health.

- The top three actions one can take to help protect cognitive health as one ages are: (1) being physically active, (2) reducing cardiovascular risk factors (including hypertension, diabetes, and smoking), and (3) managing medications. Other actions that may promote cognitive health are being socially and intellectually active, getting adequate sleep, and talking to a health care provider to learn more about preventing delirium.

- Monitor medications with patients. Older adults take an average of 14 prescription drugs per year, putting them at heightened risk for adverse drug reactions, drug-drug interactions, and drug-disease interactions. Health care professionals, particularly primary care providers, play a critical role in monitoring medications and avoiding inappropriate use by older adults.

- A complete medication review should be performed frequently, especially during care transitions such as post-surgery or hospital discharge.

- OTC medications may have significant cognitive side effects, so their use should be carefully assessed.

2015 Update to the National Plan

Rohini Khillan provided an overview of National Plan updates, next steps, and timing of recommendations.

- The National Plan is expected to be released in early May.

- The new narrative format lists projects completed in 2014, as well as ongoing projects that have updates. A more detailed look, at the activity level, is still available in the Implementation Milestones appendix.

- There are more references to related dementias and/or dementia generally in an effort to expand the National Plan's focus.

- Collaboration efforts are listed, and other federal partners doing relevant work are identified.

- Many of the actions in the original National Plan and the 2014 update are ongoing, but any relevant updates are included in the narrative.

- The new format allows for increased accessibility. Feedback from the public and discussions with federal members revealed that the previous National Plan format is hard to read and getting longer and more complicated as more activities are added. It now reads more like a progress report, rather than a list of activities; combines the old "Highlights" section with the National Plan generally; is still organized by goals and strategies; and includes links to completed reports.

- Tentative National Plan for Summer 2015
  - The Advisory Council, in conjunction with federal colleagues and the HHS Strategic Planning team, will clean up the Implementation Milestones (currently 22 pages). There are 121 activities listed in the National Plan: 50 completed, 56 ongoing, and 15 not completed.
  - The completed activities will be moved, and new activities that build on completed ones will be added.
  - The activities listed will be consolidated.
  - The Advisory Council will construct a timeline for ongoing projects.

- Timing of Recommendations
  - Having recommendations come out in January means that they come out too late to be considered for the budget that is released that same year, and they come out too early to be considered for the next FY.
  - Agencies need more lead time when determining how best to incorporate recommendations.

Discussion after the presentation included the following comments and clarifications:

- In the revised format of the National Plan, Implementation Milestones are still included but are presented as a narrative. More details are presented in the appendix.

- Dr. Richard Hodes provided an overview of the NIH Bypass Budget process. The timing for the bypass is not necessarily identical to the budgetary considerations for the conventional process. The enacted requirement is that NIH will provide each year beginning with the FY 2017 budget a professional judgment budget that will identify the resources required to successfully accomplish the goals of the National Plan. NIH will eventually build the 2017 budget from this current 2015 National Plan and include the milestones that came from the 2012 Summit, the 2013 Related Dementia Summit, the Down Syndrome Meeting, and the February 2015 Summit. In the next phase, each milestone will be accompanied by a cost estimate.

- The Advisory Council voted and approved the motion of moving the recommendations development back one cycle to October.

International Updates--George Vradenburg

- The prime minister in the United Kingdom launched a dementia summit in 2013. Four legacy events stemmed from that summit in the United Kingdom and Canada, with Canada and France hosting with Japan.

- In February 2015, the United States hosted an Alzheimer's disease research summit hosted by NIH and an adjacent update for the Group of 7. As an outcome of that meeting, the United States will work with the EU Joint Programme--Neurodegenerative Disease Research in Europe and the WHO in beginning to structure a coordinated international research plan.

- The culmination of all the work since December 2013 came together in a meeting in March 2015 at the WHO in Geneva. About 50-60 nations spoke about how important the problem with dementia was to their societies and how incredibly important it would be for the world to take action. The action will be multisectoral and involve many partnerships. It would be aimed at reducing stigma and discrimination and would focus on social inclusion, integrating people living with dementia in society, paying increasing attention to technology and technology assistive efforts, facilitating the increased delivery of health and social care, building a direct care workforce, supporting intergenerational supports for people who require care, strengthening supports and services for caregivers and families, and supporting an gender-sensitive approach to all of these efforts.

- For the first time, there was a recognition that gender differences exist among us and that there ought to be a gender-sensitive differentiation in our approach, focusing very much on low resources--not only low-income families but also low-resource countries.

- One more meeting of the World Dementia Council has been appointed by Prime Minister David Cameron. It will occur in the second week of June in the Netherlands, and a determination will be made about how to constitute a continuing world council and a "global cockpit" for the leadership. The global momentum has massively picked up in the last year and a half, as have the scientific opportunities and the drug development effort.

Concluding Remarks

The next Advisory Council meeting will take place on July 27, 2015.

The meeting adjourned at 4:23 p.m.

Minutes submitted by Rohini Khillan (ASPE).

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