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

Washington, DC

October 31, 2016

WELCOME

Ronald Petersen opened the meeting at 9:07 AM, thanked everyone for coming, and invited Council members to introduce themselves.

RACIAL AND ETHNIC DISPARITIES IN DEMENTIA

Moderator: Linda Elam, HHS Office of the Assistant Secretary for Planning and Evaluation

Three panels will discuss racial and ethnic disparities in dementia--first an overview, then a panel on barriers and gaps, and a panel on successful interventions.

Panel 1: Prevalence and Incidence of Dementia in Race/Ethnic Populations in the United States

Gwen Yeo, Stanford University [via telephone]

From a recent systematic review of 114 studies of the prevalence and incidence of dementia, it is clear that age is the most powerful risk factor, but there is wide variation in ages. The average annual incidences for the various populations show that the highest rates occur among Caribbean Hispanics, the majority of whom are Dominicans, followed by African Americans. The lowest rate is among Mexican Americans, and mid-range values are found among non-Latino Whites and Japanese Americans.

However, it is impossible to fairly compare these results because of differences in the age of subjects, diagnostic methods, recruitment and inclusion strategies, and how results are reported. Other factors may also affect the outcomes, for example, the massive relocation of Indians in the United States in the 1950s and 1960s, so that most are now urban. It is very important to disaggregate the data on ethnic populations within the large race/ethnic categories used by the Office of Management and Budget.

Recommendations to increase knowledge about disparities are: developing a standardized protocol for race/ethnic epidemiological research; prioritizing funding for ethnic-specific populations with little or no data; and requiring inclusion of target community members on research teams. We should also encourage other researchers to report dementia.

Once we have a clear picture of which populations have higher burdens of dementia, we need to determine the best way to intervene to decrease the disparities. The next major step will be to find out what the risk factors for dementia are in each population. Age and ethnicity are only two factors, and we need to know about conditions beyond that.

Comments and Questions

- ***Ellen Blackwell***: Disaggregating information offers an opportunity to separate men from women to determine whether there are sex differences in addition to ethnic difference. ***Dr. Petersen***: One recommendation is that the existing big databases be explored. Some variability has to do with diagnosis threshold for impairment and dementia. ***Dr. Yao***: Aggregated databases include more than one health system; this is a common problem.

- ***Bruce Finke***: Another issue is racial classification (e.g., rates of misclassification have been quite high for Medicare and Medicaid data).

- ***Laura Gitlin*** asked about methodological challenges and the role of stigma. ***Dr. Yao*** had seen no discussion of these issues, but groups for which stigma is worse have no data (e.g., among Vietnamese and Chinese populations, stigma often comes up with caregiver studies). She assumes it would be the same for prevalence or incidence. These ethnic groups don't want to talk about dementia outside the family--it's a family issue.

- ***Ronald Petersen***: What can be said about prevention of dementia among African Americans, Hispanic/Latinos, given the most-cited data, which come from the North Manhattan study? ***Dr. Yao***: We need to get the overall picture so we don't have to rely so heavily on the North Manhattan study. We conclude that when talking about disparities, African Americans are higher. For Hispanics, we can't lump the data because of biological, historical, and cultural differences among their subpopulations.

- ***Linda Elam***: Groups with the highest prevalence appear to be groups with the highest percentage of African American heritage. ***Dr. Yao***: The North Manhattan group looked at biomarkers among Dominicans. It's nothing definitive, but raises the whole issue of biomarkers. Among the many other issues to consider is the admixture of American Indian populations with Spanish populations. The genetic variations are very complex.

Panel 2: Barriers and Gaps to Reaching and Treating these Populations

Carl Hill, National Institute on Aging

The National Institute on Aging (NIA) collaborates with our partners within the Division of Neuroscience and the Office of Special Populations at National Institutes of Health (NIH). Two avenues are moving forward synergistically: recruitment and retention--how to get racial and other minority groups to participate in clinical trials; and stigma. Work from the Tuskegee University's National Center for Bioethics in Research and Health Care showcases the role of stigma for recruiting and retaining people in research studies and is beginning to shape a research agenda for disparities by race and ethnicity in dementia. We can think about Hispanic/Latino disparities in a new way to encompass the triple constraint around outreach and engagement, namely cost, time, and quality. In addition to stigma or people's beliefs about research, there is the real-world participant burden, namely that people have multiple responsibilities, such as employment, that prevent them from participating in research. Researchers should include on the research team members who have a real awareness of what some of those burden areas could be for potential participants.

NIA has developed a health disparities research framework, beginning with funding opportunities: a larger R01 announcement that calls for rigorous research in understanding disparities and Alzheimer's disease and related dementias (AD/ADRD), and a smaller-scale funding opportunity, an R03 program that calls for the analysis of secondary data. Forthcoming announcements from the Office of Neuroscience will focus on recruitment and retention to create robust data that will allow within-group analysis.

In sum, we need to examine recruitment beyond outreach and engagement, tailor studies to culture, educate researchers about the barriers, and define the motivating factors to participation. Finally, we need to think about the training component.

Stephanie Monroe, UsAgainstAlzheimer's African American Network
UsAgainstAlzheimer's, launched in 1990, uses a play as a vehicle to take concepts into the community--people learn by seeing. In fact, African Americans are very willing to participate in clinical studies, but 80% of people interviewed said they had not been asked. A research advantage is having data collectors who look like the subject population.

African Americans comprise 13.26% of the United States population, but they use 33% of Alzheimer's disease costs of care, making it a significant and not sustainable issue. It is also a problem in nursing care. Issues include the stigma of mental health disorders, in general; lack of trust in medical professionals; lack of disease state awareness, i.e., understanding that the symptoms relatives and friends see are not normal (e.g., the difference between forgetfulness [lost keys] and dementia [what a jar of spaghetti sauce looks like]) and why they should get a diagnosis for an ultimately fatal disease. To retain research populations, we must involve them in the research (e.g., outreach. Physical preparedness and time are also relevant factors).

Ms. Monroe offered five recommendations:

1. Use mapping tools: overlay a map with centers of people with Alzheimer's disease, with maps of where these people spend their time and where they live.
2. Encourage research team formation that reflects the ethnicity of the patient population.
3. Use social workers and others whom diverse communities interact with regularly and trust (e.g., cardiologists, pediatricians).
4. Rename "adult day-care centers." This is not an inviting term, and it transcends racial issues. It could be called the adult activities center. This is a creative solution that doesn't cost a lot.
5. Most important, collaborate.

Jason Resendez, LatinosAgainstAlzheimer's Network and Coalition

Part of the UsAgainstAlzheimer's network is LatinosAgainstAlzheimer's Network and Coalition, which was launched 2 years ago. We know advanced age is a risk factor; we know the number of Latinos 65 and older will increase tremendously (as much as 224%) by 2030; and we know the number of Latinos living with Alzheimer's or another dementia will grow to some 3.5 million by 2060. The cumulative indirect and direct costs of that 132% growth by 2060 will reach $2.3 trillion.

Caregiving organizations and support groups must be talking to each other, but several leading national organizations are not talking to each other about this health area. Meanwhile, there has been little to no coordination within the Latino community to address brain health issues, unlike with diabetes or cardiovascular disease. Other issues are data quality, advocacy, and awareness of available resources and their costs.

Latinos with Alzheimer's or dementia are less likely to use formal care services--whether because of cost or because of lack awareness of what services are available--so much of the hardship of caregiving is falling on the shoulders of family members. Most often daughters in their 40s are leaving the workforce, preventing them from qualifying for Social Security benefits while they're out of the workforce, and that number will only grow as the number of Latinos aged 65 and older increases.

Research and development of capacity locally must include diverse clinicians, diverse specialists, diverse research teams that include people who look like the population they are studying. Likewise, we need to look outside the primary health care role or the physician role and make better use of community health workers. This is a model that has been very successful in the Latino community in addressing obesity, diabetes, cancer, and reproductive and sexual health. Community health workers come from the community and receive specialized training in a disease area. That can build trust among health institutions, research institutions, and community-based institutions, which is vital.

Mr. Resendez recommended:

1. Develop and standardize a way to monitor the impact on Latino communities, particularly concerning subgroup data.
2. Incentivize that research and that subgroup analysis and provide funding opportunities to do that.
3. Prioritize funding for studies of ethnic-specific populations.
4. Tailor public awareness efforts targeting the Latino community, taking into account that a message to a Mexican American community might be different than a message to a Puerto Rican community. These are strategies that the private sector has used well to sell products from cars to chips and soda; it is a strategy that we must adopt in our public health promotion efforts.
5. Make the labor force culturally relevant.

Bruce Finke, Indian Health Service

We often see good work by good researchers, but that is not enough. We know that dementia and Alzheimer's disease are present in all communities, and that there are many social and cultural factors. Usually a young population has different priorities, and the youth focus takes attention away from the elderly who lack long-term services, but who don't necessarily need a pill. This is particularly true in tribal communities where most specialty care is provided by the government.

We know from conversations with leaders and elders in tribal communities that dementia has a significant impact. Caregiving is not perceived as a burden, but it is difficult. The Indian Health Service (IHS) is focused on caregiver support. When someone says they have a problem, we want to be able to say, here's what's going on and here's what's available (i.e., talk in terms of workforce capability rather than workforce training). We want to focus on care management and be able to help caregivers find what and whom they need, perhaps with a care manager in the primary care office.

Tribal communities have tremendous capabilities, but they need resources, and there are terrific non-Native resources. All long-term services are local and it is important to think about radiance of access. We have to get to community-level access and make sure that services are available where people live. We talk about what Alzheimer's disease means and the different effects on the family, but this must be done thoughtfully, respectfully, and compassionately, and, for that, we must go to people in the community to learn how.

Dr. Finke recommended:

1. Build a system of care with a family and person-centered approach.
2. Ensure that families get what they need and know where to get this support.
3. Ensure caregiver support.

Panel 3: Successful Interventions

Pernessa Seele, The Balm in Gilead, Inc.

Since its founding 28 years ago, the mission of The Balm of Gilead, Inc. has been to prevent disease among the African diaspora by providing support to faith-based and other institutions, especially regarding HIV. That focus has expanded to six African countries and the Eastern Caribbean. The faith community is the most influential resource in all these countries, and Balm of Gilead wants them to partner with the research community.

The Balm of Gilead's first objective is to raise awareness of current health issues. To raise awareness of dementia, the play, "Forget Me Not," has been performed. Churches are relational and as such are engaged in the process of caregiving. But, awareness is still a problem that prevents treatment.

The second objective is to train Hispanic/Latino professionals on issues affecting cognitive health among Hispanic/Latinos and among African Americans via a partnership with the National Black Nurses Association and the National Medical Association. We want to counter the lack of knowledge around this issue among Hispanic/Latino professionals. The third objective is to use the Balm of Gilead faith-based community mobilization model (e.g., the Harlem Week of Prayer for the Healing of HIV) to strengthen awareness. Understanding the strength of faith communities, the Hispanic/Latino public health community has already partnered with the faith community to have the faith community test people, promote capacity, and measure outcome. Now, they will implement Memory Sunday, the third Sunday in June beginning in 2017. We want to develop people in the churches who have the skills needed, and we want churches to be the community center around Alzheimer's disease.

The Balm of Gilead, Inc. will convene the Healthy Churches 2020 National Conference, November 15-16, 2016.

Donna Walberg, Minnesota Board on Aging
Nancy Lee, Minnesota Board on Aging [via telephone]
Minnesota has an overarching agenda to address minority, culturally diverse populations, which are located primarily in the metropolitan area, but also on reservations. In a state so sparsely populated, Minnesota needed a program for population infusion, so the Minnesota Board of Aging developed the role of "cultural consultants" (16 have been trained so far), who go into communities and establish collaborative relationships and can hear what the communities needs. Cultural consultants in Minnesota work on creating their own initiatives. At the same time, the film "Cultural Awareness in Dementia Care" was produced to address community experiences for Hispanic/Latino disparities.

Moreover, how to help aging caregivers give care varies, so they created an online training system, including modules for dementia training for aging service providers who need to know norms and values of the Native American community, as well as the Somali and Hmong (whose populations are expected to increase) and Hispanic communities. Minnesota provides free training and resources and then promotes their availability to the health care network.

Cultural training should focus on community health workers. The Minnesota State Legislature allotted money for these programs and awarded funds to 20 organizations in Minnesota. Six entities have a mission focus on an ethnic group, and 14 will offer plans that focus on ethnic groups.

Geraldine Woolfolk, Alzheimer's Association

The Alzheimer's Association recommends successful interventions in the six following categories: stigma, education, ethnic media and local newspapers, cultural relevance, engagement, and advocacy. A constant factor is stigma, which prevents people with Alzheimer's disease from visiting a doctor and getting a diagnosis or just talking about it. To counter that, the characterization of patients with Alzheimer's disease (crazy, catatonic) has to change; a brief discussion about what Alzheimer's is, with sensitivity to different communities, is the beginning.

For education, the Alzheimer's Association stresses the importance of culturally relevant forums (e.g., by offering translation headphones to monolingual people); listing scientists, doctors, and caregivers who are African American; giving Spanish resources in Spanish and Chinese resources in Chinese. They stress families rather than individuals and are working at state, local, and federal levels to promote excitement and awareness. They want the groundswell to come from the people they work with day by day, but they must also work collaboratively and give easily understandable information to share with others. In the lesbian, gay, bisexual, and transgender community, many dementia patients are going back into the closet because some caregivers still stigmatize them. We need competent, dignified care for all. Ethnic media and local newspapers distribute culturally relevant information (e.g., walks to support Alzheimer's disease). These media outlets are very important for distribution of information, and they are not expensive. Programs should be culturally relevant so people can deal with people they can relate to.

Advocates go to Capitol Hill and local city hall policymakers to explain why it is in their best interest to support these initiatives. We need to increase diversity among advocates. Advocacy should be used to break down barriers and to gain information to form policies. But, this information also needs to get back to the isolated peoples affected. The Alzheimer's Association will hold an advocacy forum March 27-29, 2017.

Discussion

- ***Sowande Tichawonna*** asked if a large measure of Minnesota's success were attributable to the state's small population and whether there a way to scale-up the cultural consultant program. ***Ms. Walberg***: A small population presents a challenge. The cultural consultants are much in demand, and the program has to search for people who have the time to fill this role. She thought it could be easily scaled up.

- ***Laura Gitlin***: Stigma is not readily discussed. There's a difference between perceived stigma and structural stigma. The former is how groups view themselves and the changes in their brain. Some structural stigma is rooted in the "no cure/no hope" attitude, rather than the "no cure yet" attitude. ***Dr. Elam***: Stigma is related to a reluctance to ask for help, which creates another barrier.

- ***Laura Gitlin***: People who don't call themselves caregivers do the same tasks as those who do call themselves caregivers. We need terms that capture the experience. ***Ms. Walberg***: The term caregiver is one we apply to other people. They don't call themselves that, but they perform caregiving. It isn't that they don't have a word for caregiving. Western culture is nuts about labeling. ***Ms. Monroe***: We label what we do, not who we are.

- ***Ellen Blackwell***: What about dementia care by culture? ***Ms. Monroe***: The first thing people hear when they go to a doctor for a diagnosis is that they cannot drive, and the result of that is often to isolate them immediately by keeping them from relationships that sustain life. It doesn't empower them or give them hope. ***Dr. Elam***: Views toward institutionalization vary among communities. It is good to state what resources are available in the community, but we should reframe how we serve people.

- ***Carl Hill***: NIA's R01 and R03 grants work on the assumption that caregivers are in the realm of the social network and offer support. Seeking help in these populations is relevant. ***Mr. Resendez***: The National Alliance for Caregiving found that despite being in similar situations, Latino caregivers are less likely to say they're in a high-stress situation, but they are also less likely to rely on formal caregiver services, so the task falls to daughters. Meanwhile, Latinas are having fewer children, so caregiver availability and utilization will have to be changed so it is available at an affordable price in a uniform way.

- ***Gary Epstein-Lubow***: What reliable information do we have about racial and ethnic disparities in later stages of illness and in end-of-life care? ***Rohini Khillan*** was not sure. The U.S. Department of Health and Human Services (HHS) plans to study the differences among racial groups and how they're treated in different caregiving facilities (e.g., how readily pain medication is given).

- ***Bruce Finke***: There is the question of community-based care vs. home-based care. The assumption is that people can't be cared for at home, and beyond that is the implicit notion of a hand-off. Caregiving doesn't end when an individual is admitted to a facility, yet we create barriers when the person is in that setting. We need much more intentional integration of the family into the care of that person admitted to a facility. One successful model is training family members and integrating them as paid caregivers (e.g., a relative who would otherwise be working at McDonald's). It's not an either/or situation. Those distinctions break down when it's family.

- ***Angela Taylor***: What about nonvascular forms of dementia or Lewy body dementia instead of Alzheimer's disease? ***Ms. Monroe*** cited an example in which it took a week for a patient in a psychiatric ward to be diagnosed. ***Mr. Resendez*** agreed that this area needs more work. Misdiagnosis and under and over-diagnosis occur in these communities. If someone gets a diagnosis of frontotemporal dementia (FTD), they may seek treatment for it and speak to a specialist only to find out that they have something else. Vascular dementia is a common diagnosis among Latinos, but we need to consider conditions beyond vascular dementia.

- ***Pernessa Seele***: A prayer offered daily says, "Lord, thank you for waking me up in my right mind." Responsibility for mental health is considered divine, which creates a barrier for the affected person to seek help. It is left to God, who knows what He's doing. Dr. Seele has heard people say they're not doing any intervention until the Lord speaks to them, that they are relying on Jesus to tell them what to do. Dr. Seele sees her role as ensuring that Jesus speaks sooner.

- ***Anthony Pacifico***: Stigma reaches a person trying to talk to the person with dementia. Is there a research gap concerning other caregivers in the family? ***Dr. Elam***: It is well recognized that caregiving covers any combination of all the family members. ***Dr. Hill***: It's kind of a way of life. We don't pay enough attention to this. ***Ms. Khillan*** agreed that there is no specific study of nieces, nephews, younger siblings, and others.

- ***Harry Johns***: We don't want to lose the point that underrepresented groups' researchers can contribute and can be funded.

- ***Ronald Petersen***: A big challenge in the field is getting people enrolled in clinical trials. ***Mr. Resendez***: It is important to communicate research as an opportunity. We must increase the pool of people willing to become involved and we must have researchers, health care workers, and cultural consultants who look like the person needing care.

- ***Carl Hill***: The point about silo-ing community interventions and clinical care was a good one. People in outreach and engagement can learn much from community-participatory strategies. There are also real opportunities for recruitment and retention.

- ***Stephanie Monroe***: Some 80% of African Americans and Latinos who were asked if they would participate in research said they had never been asked. Remedying this requires the personal connection of the physician who asks. That information needs to be at the physician's fingertips. We have to make it easy for them. ***Dr. Finke***: Responding to community needs opens the door to the research community, too.

- ***Stephanie Monroe***: We need research to understand whether physicians are reluctant to refer their patients, and, if so, what prevents them from doing so--fear of losing a patient? ***Dr. Hill***: NIA is thinking about best ways to retain patients. Do they view this as a real partnership, a collaboration? Or what is preventing them from making that connection?

- ***Charlene Liggins***: NIA is thinking about ways to create a repository of studies and the best practices they have used for recruiting and retaining.

NATIONAL RESEARCH SUMMIT ON CARE, SERVICES AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS: UPDATE

Laura Gitlin, Johns Hopkins Center for Innovative Care in Aging

The tentative date for the National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregiver is October 15-17, 2017. It will be convened in the Natcher Building at NIH. The goal for the summit is to identify what we know and what we need to know to accelerate development, evaluation, translation, implementation, and scaling-up of comprehensive care, services, and support for persons with dementia and their families and other caregivers.

The summit is focused on research needed to improve the quality of care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers. Cross-cutting themes are: diversity disparities, etiologies, disease stages, care settings, training and workforce, and technology. Outcomes may include research priorities, identifying evidence-based programs, strategies, and approaches that can be used. Research milestones will be used to track and guide acceleration and advancement of evidence-informed care and services.

The organizers want co-chairs from each stakeholder group to be identified using the iterative leadership/input approach with the advisory council, co-chairs, agencies, steering committees, and stakeholder groups (including family caregivers, persons with dementia, and service providers).

Katie Maslow, National Academies of Sciences

The organizers want stakeholder groups to help identify issues, disseminate information on the summit, identify ways to populate the audience, etc. Pre-summit activities include scientific meetings to provide foundational knowledge. They are in the process of forming focus meeting to write reports and recommendations.

The American Academy of Nursing will give the state of the science systematic review and will also bring information and recommendations. Other activity ideas include: epidemiology and demographics of persons with dementia and their family and other caregivers; methodological challenges, such as engaging persons with dementia and their families and creating a pipeline for interventions; next generation of interventions; international research/activities concerning care and service; and the role of technology.

The summit agenda to date is divided into six sessions over two days, from 8:00 AM to 4:00 PM, as follows:

- Session I: Research on Care Needs and Supportive Approaches for Persons with Dementia
- Session II: Research on Supportive Approaches for Family and Other Caregivers
- Session III: Involving Persons with Dementia and Family and Other Caregivers as Active Members of the Research Team to Identify Research Topics and Meaningful Outcomes
- Session IV: Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers
- Session V: Challenges in Involving Persons with Dementia as Study Participants in Research on Care and Services
- Session VI: Research on Translation, Dissemination, Implementation, and Scaling Up of Effective Care, Services, and Supportive Approaches for Persons with Dementia and Family and Other Caregivers

Next steps include monthly meetings, identifying session chairs (recommendations should be susbmitted by the end of November), confirmation of date and location, writing and disseminating press releases, fundraising, developing graphics and taglines, and creating a working timeline and a working budget. Ms. Maslow asked participants to email her or Ms. Gitlin with ideas and recommendations.

A contract was awarded to RTI to provide logistical help as well as content help for panelists, background papers, etc. and develop a series of issues, and co-chairs have been recognized.

Comments and Questions

- ***Laura Gitlin*** assured Dr. Petersen that a final report will result from the summit.
- ***Mary Worstell***: The Office on Women's Health (OWH) is interested in providing funding for a study to determine whether women and men experience Alzheimer's disease differently. They want to build on and extend the factors considered to include environmental science, behavioral science, etc. to see the whole gender side. OWH will offer a forum as a pre-summit activity.

- ***Bruce Finke***: You talked about services in a way analogous to research.
  Dr. Gitlin: We recognize that there's much need for services and outreach, and it's not a hard sell. Presentations will offer an opportunity to capture research questions. The process will generate recommendations of how to put things in place and then how to measure that.

- ***Katie Maslow***: The Alzheimer Association's document will be helpful for defining research issues. The next step will be more about timing.

- ***Ellen Blackwell***: It's not just the next generation of interventions, but interventions, services and supports across the spectrum of dementias.
  Dr. Gitlin agreed that this has been a cross-cutting theme. There are methodological issues that we need to discuss more, and in addition to research in interventions, are translation and use of terminology, which is important for relating to the community.

PUBLIC INPUT

Thomas Buckley

Over the last 40 years, disparities among people with developmental disabilities have been one of the main issues. On average, people with developmental disabilities die 21 years before they should; these are avoidable deaths. It's easy to say dementia, but many suffer needlessly because it's a complicated situation. Lucanus Developmental Center, Hollywood, Florida, has doctors and a dentist who specialize in geriatrics. In South Florida, we're going do our annual wellness health check for the very first time, we're going to train with these curricula for general practitioners and nurses on intellectual disabilities. The patient may need a transition plan from pediatric to adult care. We're partnering institutions with the state, and we are going to four churches to reach the African American community.

Mary Hogan

The population under Strategy 2H is disproportionately affected by dementia, but we cannot ignore fact that one population impacted is people with disabilities. We need a broader picture of what is happening, what needs to be done, what can be done. We need to work hard for people in the aging population to understand intellectual disabilities. It's the opposite side of a continuum and we need to come together in a different way for all ethnic groups. Palliative care cannot be overlooked in people with intellectual disabilities.

Matthew Janicki

Nomenclature is important and we need to develop a taxonomy. Words in this field are used inconsistently (e.g., dementia vs. Alzheimer's disease). Secondly is the complexity of language. Using high-science language is not always productive. It depends on your audience--caregivers vs. the lay public vs. researchers. Recommendation #4 in the

2016 report addresses this and should be implemented. There is a call for an integrative conference, and this issue too should be included.

Jodi Lyons

Care for dementia patients is never the same from one person to the next. You're dealing with different people, different dementias, different ethnicities, different families. We should go to the community to see what we're really talking about.

Susan Peschin

Representing the Alliance for Aging Research, Ms. Peschin offered three recommendations: (1) HHS should include for each funded trial recruitment of minority populations. (2) Trials should meet recruitment targets--in the past, 37% of trial sites failed to meet recruitment goals. (3) NIH should bridge Alzheimer's disease with gaps identified by Food and Drug Administration (FDA) (e.g., biomarkers). Since the science has developed rapidly NIA and FDA would benefit by ongoing communication. FDA should be included in the Alzheimer's Disease Care Summit. In the Centers for Medicare & Medicaid Services (CMS), there should be partnerships to provide dementia care, and there should be more focus on mental health care.

Matthew Sharp

Outside the few families carrying an autosomal dominant form of FTD, all people have an equal chance of developing the disease regardless of their racial or ethnic background, but we just don't know enough to say anything more about who may be at risk and why. The Association for Frontotemporal Degeneration offers services; it can be hard to find services and support for a disorder that affects 50,000-60,000 people. The goal of research should be targeted to the right treatment for the right person at the right time. At the same time, we want to understand all aspects of disparities in Alzheimer's disease. Accurate and reliable diagnoses will be available in the near future.

Mary Anne Sterling

December 3, the first Annual National Caregiving Conference will be held in Chicago. The conference offers a way for family caregivers and their supporters to connect--caregivers should not have to give up their lives to give care. Ms. Sterling invited everyone to join the conference; details can be found at http://www.caregiving.com/.

William Mansbach
At the research center of the Maryland Governor's Alzheimer's Disease Council, they are working to develop a construct called cognitive functional hardship, which will help identify at-risk adults and older adults in the community. The term at-risk refers to people who have challenges performing everyday tasks due to cognitive impairments, especially in the area of judgment. Second, the Alzheimer's Disease Council is developing a new test of practical judgment for people living with dementia, e.g., how and how much medicine to take, how to avoid safety risks such as falls. While researchers search for a cure, there's immediate need to increase early detection and mitigate safety risks posed by the disease. Access to screening in remote areas can be addressed with telemedicine.

FEDERAL WORKGROUP UPDATES

Long-Term Services and Supports

Erin Long, Administration for Community Living
The Administration for Community Living (ACL) has awarded 19 new grants since August, including for the Alzheimer's Disease Supportive Service Program, and for the National Alzheimer's Disease and Dementia Resource Center. ACL is involved in planning the fifth annual webinar series on Dementia Resources and Research and continues to work with states as they implement the Long-term Care Ombudsman Rule.

Comments and Questions

- ***Bruce Finke***: IHS's Resources for Enhancing Alzheimer's Caregivers Health in tribal communities reaches 45 communities (not necessarily tribes) and includes Tribal Workforce development--long-term services and supports and clinical care. The Tribal Long-Term Social Services Conference (November 14-17) includes a Dementia Core Course (November 14-15). Also, the IHS website recognized September as Alzheimer's month. The cumulative total number of caregivers served is 24-25. IHS is building capacity by enrolling caregivers. We need to build more awareness of these services to increase demand for them. Second is program sustainability, which IHS has funded for three years. Furthermore, we need evaluation not of the intervention, but of the implementation.

- ***Richard Hodes***: Ongoing research (funded by 18 recent awards) is furthering understanding of caregiver experience, decision-making, and other social issues.

- ***Joan Weiss*** reported that a Medscape article gave one-month data for 3,281 participants.

Clinical Services

Ellen Blackwell, Center for Medicare & Medicaid Services
Ms. Blackwell gave an update of CMS programs:

- Comprehensive Primary Care Plus--on the CMS Information on website.
- Medicare Advantage Value-based Insurance Design Model Test--request for applications will soon be released.
- Independence At Home Demonstration--is getting results.
- Medicaid Innovation Accelerator Project for Beneficiaries with Complex Needs--CMS will be hosting webinars starting in December.
- Advance Care Planning--a fact sheet has been issued.
- "Addressing Neuropsychiatric Symptoms in Patients with Dementia"--a popular presentation.
- Improving dementia care in nursing homes--new data from a national partnership were recently published.
- National Nursing Quality Improvement Campaign--underway.
- Improved care in long-term care facilities--will use a person-centered approach.
- National Quality Forum--Disparities is a new one-year project to obtain multi-stakeholder guidance on how performance measurement can be used to address disparities for five target conditions.
- Medicaid Home Health Care--approaches for strengthening and stabilizing this initiative.
- Home and Community-Based Services--CMS recommends that survey measures for advancement be endorsed although quality measures have not yet been defined; HHS will release a final report.

Research

Richard Hodes, National Institute on Aging
Dr. Hodes reported progress in the International Alzheimer's Disease Research Portfolio (IADRP) with more than 35 public, private, and international funding organizations in 11 countries. It captures some 7,000 projects built on Common Alzheimer's Disease Research Ontology (CADRO). NIA is collecting feedback for

updating CADRO. New federal partners include the *Federal Reporter* website. In addition, NIA has recently identified small portfolios of AD/ADRD research. AD/ADRD research milestones will be added to its database. The European Union Joint Programme--Neurodegenerative Disease Research enables users to track a project (e.g., population studies). A milestone database will soon be linked to *NIH Reporter* to view special projects with links and access to related publications.

New Alzheimer's disease funding opportunities include Inside NIA, a blog for researchers, and Advancing Research into Alzheimer's Disease. New Alzheimer's disease concepts include resource leveraging, caregiving, and clinical care; translation; basic research; and training. The activities of disparate studies should be coordinated, then integrated and harmonized so researchers can study and compare results. We need to clarify the relationship between delirium and AD/ADRD; NIA Small Business opportunities to advance Alzheimer's disease research; multi-morbidity in Alzheimer's disease impacts choice of ancillary treatments. NIA is enthusiastic about bringing areas such as exosomes to Alzheimer's disease to find commonalities and interactions.

Lastly, the second Alzheimer's Disease Care and Service Research Summit will be held October 16-17, 2017, and the third on March 1-2, 2018.

Comments and Questions

- In response to ***Dr. Petersen***, Dr. Hodes said that program announcements will have set-asides, but there are multiple receipt dates. Moreover, there has been tremendous progress on IADRP and people are using it--an average of 450-500 unique users per month. The Step Program in Neurodegenerative Diseases is an idiosyncratic system for co-funding. NIA will issue a call-in (program announcement) this year and then look for ways to have a joint meeting, and cooperate.

- To ***Mr. Johns***, Dr. Hodes replied that program announcements have been issued and similar to this year, with an appropriation received December 18, NIA can fund them.

2016 PLAN UPDATE

Rohini Khillan, HHS Office of the Assistant Secretary for Planning and Evaluation

Ronald Petersen: This year we are incorporating federal responses into our recommendations, which is incomplete because this is a national plan and not a federal plan. ***Ms. Khillan***: Is this useful to you? Would you prefer that we do a presentation of the federal response at a Council meeting? ***Mr. Johns*** thought it was helpful to include the comments. We don't have to speculate about why something was excluded, but the pursuit of individual responses was not so valuable.

Rohini Khillan: Should this meeting be limited to Federal Advisory Committee Act (FACA) members? ***Mr. Johns*** was not sure it would be useful for those working on the committee. They might be willing to contribute, but it wouldn't seem balanced. ***Dr. Petersen***: Some organizations are represented on the FACA, but some are not. ***Ms. Mead***: We could list recommendations and then the congressional feedback. Note that some recommendations are addressed to more than federal agencies.

Laura Gitlin finds it confusing. It is hard to understand the response. She suggests separating recommendations from responses. ***Helen Matheny***: It helps to see what is happening, what federal agencies are doing, and what else might be done--you don't have to spell out the business gap. This is an opportunity to clarify for Congress what is going on.

Linda Elam: We don't know how many organizations might respond. ***Ms. Khillan***: Another resource is page-specific comments on the plan, which are posted on the web. ***Dr. Weiss***: The states have their own plans, so it might be worth checking their websites, too. ***Dr. Finke***: With such a large number of comments, somebody has to be prepared to digest them.

Gary Epstein-Lubow: What might be the structure for the 2017 recommendations? ***Dr. Petersen*** thought the schedule would be pretty much the same; it will be finalized at the April meeting for 2017.

ADMINISTRATION TRANSITION

Rohini Khillan, HHS Office of the Assistant Secretary for Planning and Evaluation

Ronald Petersen, noting that Dr. Elam is a political appointee and will be leaving at the end of the year, thanked her for her services to the Council.

Rohini Khillan listed the process for transition of Administrations:

- November 8 is Election Day.

- January 20 is Inauguration Day.

- Over the first few months of 2017, depending on Congress' timing, we will have new political leadership at our federal agencies. The new Secretary of HHS will choose the leads of this agency. Until the Secretary is chosen, we will have an Acting Director.

- Currently the staff has been compiling briefing books of what's happening in each agency, giving an idea of what goes on day to day, and at a basic level, things they should expect in the first 30, 60, 90 days. After November 8, the transition team moves in and will get a more detailed set of materials. The agency landing teams are tasked with gathering information.

- Finally, a change in Administration will not affect the Advisory Council because the law enacting the Council specifies that it remain in place until 2025.

- In 2017, half of the nonfederal members will turn over again.

CONCLUDING REMARKS

Ronald Petersen adjourned the Council meeting at 3:07 PM.

The next Advisory Council meeting will take place on February 3, 2017, in Washington, D.C.

Minutes submitted by Rohini Khillan (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.

PARTICIPANTS

Advisory Council Members

Present

Ellen Blackwell
Billy Dunn
Linda Elam
Gary Epstein-Lubow
Bruce Finke
Laura Gitlin
Richard Hodes
Harry M. Johns
Rohini Khillan
Helen M. Matheny
Lisa McGuin
Jennifer Mead
Anthony Pacifico
Ronald C. Petersen
Marianne Shauhnessy
William Spector
Angela Taylor
Sowanade Tichawonna
Erin Long [*for Jane Tilly*]
Joan Weiss
Geraldine Woolfold
Mary Worstell

Absent

Richard Allman
Myriam Marquez
Deborah Olster

Presenters

Carl Hill
Nancy Lee [*conference call*]
Katie Maslow
Stephanie Monroe
Jason Resendez
Pernessa Seele
Gwen Yao [*conference call*]

Public

Thomas Buckley
Maria Carrillo
Rachel Conant
Roderick Corriveau
T. Craig
Phil Cronin
Patricia D’Antonio
Jordan Gladman
Mary Hogan
Matthew Janicki
Ian Kremer
Jeffrey Last
Christopher Laxton
Charlene Liggans
Jodi Lyons
Eliezer Masliah
Vijeth Nengar
Kelly Nickel
Susan Peschin
Creighton Phelps
Matthew Sharp
Nina Silverberg
Eric Sokal
Mary Anne Sterling
Yelda Sucer
C. Grace Whiting