

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

Washington, DC

April 17, 2017

WELCOME AND CHARGE

Ronald Petersen, Ph.D., M.D. (Mayo Clinic)

Dr. Petersen opened the spring meeting at 9:35 a.m. and thanked everyone for coming to this session on the U.S. National Plan for Alzheimer's Disease Research, Care, and Treatment. The session will generate recommendations for the U.S. Department of Health and Human Services (HHS) Secretary and for Congress for the 2017 version of the national plan. At the same time recommendations are submitted to the Secretary, they will be submitted directly to specific members of Congress.

Dr. Petersen asked everyone to give their name, institutional affiliation, and role on this council. Susan Cooley and Gary Epstein-Lubow joined via telephone.

LONG-TERM SERVICES AND SUPPORTS SUBCOMMITTEE RECOMMENDATIONS

Jennifer Mead, MPH (Oregon Department of Human Services)

The Long-Term Services and Supports Subcommittee built on past recommendations, trying to keep the recommendations short and to align with the goals of the original national plan. They also worked to provide measures of success for each recommendation, recognizing that it was important to be specific, including dollar amounts and specific agencies, yet also important to be broad so everyone can figure out what their piece is. In the end, they left recommendations fairly broad but with potential measures of success. They did not prioritize the measures.

The subcommittee had four recommendations, the first three of which fall under NAPA Goal 3 (expand services and supports) and the fourth under NAPA Goal 4 (enhance public awareness and engagement):

1. *Expand efforts to address the needs of family caregivers.* This continues a theme recognized every year, but substantially more needs to be done in this area. Since it is an area of particular concern, it has the most potential measures (e.g., increased federal funding, interventions, and the Older Americans Act). It recognizes the role of school-aged children in providing care and offers 15 measures of success.

2. *Increase identification of people with dementia who live alone.* Two measures of success are offered.
3. *Increase efforts to assess, prevent, and manage behavioral symptoms of dementia.* This recognizes the importance of the workforce.
4. *Expand public awareness and training, reduce stigma, and help connect people to information and available resources.* For this ongoing recommendation, the subcommittee adds specific areas of concern along with four measures of success.

The Long-Term Services and Supports Subcommittee collaborated with the Clinical Subcommittee on two more recommendations, which the latter subcommittee will report.

5. *Ensure that changes to the health care system include continuation of support.*
6. *Identify ways to implement recommendations that result from the 2017 National Research.*

Comments and Questions

- **Ellen Blackwell:** Caregivers also have health-related issues, so we should add something on dealing with them. **Ms. Mead** agreed. The recommendation focuses on family caregivers.
- **Jennifer Mead** agreed with **Mary Worstell** that race and gender should also be considered, and added rural populations. **Laura Gitlin:** In Recommendation 1, we should add a footnote or parentheses to explain what we mean by diversity. **Gary Epstein-Lubow** suggested for Recommendation 1 that we highlight the importance of “is designated” by 2020. This is a question about whether the persons living with dementia want their caregiver designated.
- **Ron Petersen** asked about metrics for people with dementia living alone. **Erin Long** and **Harry Johns** agreed that they have no information. **Dr. Petersen** concluded that the recommendation is intended to expand information-gathering on that. In answer to **Anthony Pacifico’s** question, **Ms. Mead** said residents of assisted living had not been included. **Myriam Marquez** lives in a community for people aged 62 or older and thinks more than half have some form of dementia. **Ms. Long** knows there are many more people living with dementia than one would think.
- **Valerie Edwards** reported that the HHS Centers for Disease Control and Prevention (CDC) collected some survey data on this and she can provide that information to the committee. **Joan Weiss** will reach out to the Housing

Department. **Dr. Petersen** thought this touched on the issue of how many people have the disease.

- **Anthony Pacifico** thought the phrasing “individuals with dementia and with inadequate support” could be incorporated, acknowledging that the adequacy of support is contingent on the stage of the disease. **Rohini Khillan** noted that the question asked how many caregivers were involved, but not how well they are giving care.
- **Mary Worstell** works with The Village, which focuses on facing the issue of independent living alone and identifying who those people are. One strategy is to reach out to the children of individuals who may be living alone, and make them aware of available resources. **Ms. Long** reported that the HHS Administration for Community Living (ACL) supports the Gatekeeper Program, which trains meter-readers, mail carriers, and others to identify people living alone. **Dr. Gitlin:** People living alone may need different kinds of support possibly making the support they routinely get inadequate. In addition, living alone affects delivery of services. There is a huge gap in the residency intervention, which assumes there’s somebody there to give the intervention. We need to understand the housing arrangements. **Dr. Pacifico:** There are various living arrangements--it may be with the family or in Senior Housing Association Groups, etc.
- **Mary Worstell** is involved with the Department of Transportation, which focuses on transportation as it relates to housing--it is part and parcel of access. They consider the impact of cognitive impairment around using public transportation. That opens a wide array of caregiver support because it’s not just a person, but a system.
- **Anthony Pacifico:** We need to look at how activities of daily living have changed. Recommendation 2 looks at a neglected aspect of supporting people. **Dr. Petersen:** This is a confounding factor. Because of the nature of the disease, caregivers may not know how much care is needed or what they are entitled to.
- Regarding Recommendation 4, there are good campaigns from the Federal Government on raising awareness, but they focus explicitly on Alzheimer’s disease. Should it be made less specific (e.g., dementia awareness)? **Ms. Khillan:** We are limited in our ability to change the name of the plan, but we have tried to broaden the focus and to talk about dementia more generally. These recommendations are for many different groups, not just the Federal Government.
- In response to **Dr. Petersen’s** question, **Ms. Long** said the website (Alzheimers.gov) is doing well, but we have no numbers as yet. **Richard Hodes:** There should be discussion about who will take responsibility.

CLINICAL SERVICES SUBCOMMITTEE RECOMMENDATIONS

Helen Matheny, MS (West Virginia University)

Only about half of those with Alzheimer's disease have been diagnosed. Therefore, the Clinical Services Subcommittee focused on timely and accurate diagnosis, as well as quality measures and workforce skills to enable competent and knowledgeable delivery of high-quality care. Quality measures should be implemented this year.

Recommendations follow:

1. *Continue to promote early detection and diagnosis of Alzheimer's disease and related dementias (ADRD).* To do this, encourage cognitive assessment, work to confirm measurement strategies to track progress. Specifically, within the next year, the HHS Centers for Medicare and Medicaid Services (CMS) should implement cognitive impairment assessment among at-risk older adults.
2. *Offer and support professional training and continuing education.* This would improve care providers' ability to recognize early signs of dementia and to offer counseling.
3. *CMS should annually report data by State/region and by diagnosis according to the G0505 billing code.* This may indicate a need for additional training.
4. *The Advisory Council should discuss best practices.* Specifically the Council should advance the work HHS's Office of the Assistant Secretary for Planning and Evaluation (ASPE) has conducted with RTI, including in-depth review of the Examining Models of Dementia Care report from the Aging Brain Care Program, the multi-disciplinary care team model used in Personalized BRAIN Care Services, and the model used in the University of California-Los Angeles's Alzheimer's and Dementia Care Program.
5. *CMS should create a fixed per beneficiary per month (PBPM) payment for reimbursement of comprehensive dementia care services.* To do that they should build on promising practices, including the results of the Center for Medicare and Medicaid Innovation's (CMMI's) dementia demonstration projects, combined with definitions of best practices for comprehensive dementia care. Fee for service doesn't necessarily translate to well-managed, high-quality, coordinated service.
6. *With changes in national health care, ensure continuation of support.* This would include Medicare annual wellness visits that include cognitive assessment, protection of preexisting conditions, and funding for research.
7. *Industry stakeholders should identify ways to implement recommendations that result from the National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers (October 2017).* We continue to

struggle with milestones and their designation. Maybe they can help us get closer to milestones.

Comments and Questions

- **Richard Hodes:** Recommendation 1 should include information on what cognitive exams CMS will reimburse. **Ms. Blackwell:** CMS does not specify. It is up to the clinician what they want to use.
- **Ron Petersen** asked about uptake of Medicare’s annual wellness visit? **Ms. Blackwell** reported that it had gone up a little. Cognitive assessment is part of the annual wellness visit.
- **Susan Cooley** encouraged cognitive screening, but **Dr. Petersen** noted that screening is not a recommendation for the general population; only in a medical setting and context. **Dr. Cooley** agreed that the U.S. Department of Veterans Affairs (VA) and U.S. Public Health Service do not recommend screening for asymptomatic people. **Dr. Hodes:** We need guidance on what the assessment might be if screening reveals it is necessary. **Dr. Cooley:** There is a perception that the annual wellness visit requires giving a cognitive test. We need to clarify that the person needs to have an indication of dementia before the test is given.
- **Harry Johns:** Only about half the people who have dementia are diagnosed; of the ones diagnosed only half the families are told and a third of the patients are told. There are huge potential advantages to the individual, the system, and others being aware that screening is not wrong. It is an opportunity to do some of those things that would change lives and change costs for the better. Moreover, people fail in protocols because of co-morbidities, which cause unnecessary hospital stays. **Dr. Petersen** likened putting a cognitive index in the medical record to putting a blood pressure measurement in the record. **Dr. Cooley** was only pointing out that it’s inconsistent with other directives.
- **Laura Gitlin:** Recommendation 2 is critical and should be expanded to include evidence-based dementia care. This would involve more than federal agencies. We should add verbiage for all the health professional associations that have to develop competency for their group--speech, occupation therapy, home care, etc.--in terms of dementia. **Dr. Weiss:** Primary care providers do not know the differences among the various exams. Recommendation 2 should include integrating dementia training into the curricula of health care providers.
- **Ellen Blackwell** suggested removing the word “beneficiary” from Recommendations 5 and 6, calling “care-partners” “caregivers” throughout to lessen confusion, and ending Recommendation 5 with “community-dwelling persons with dementia and their caregivers.” **Dr. Gitlin** thought 5 was critical. We should consider CMMI in addition to other funding-based programs.

- **Ellen Blackwell:** In Recommendation 5 and 7, we should not connect pay to what is being done. We don't want to restrict this to the "clinical entity"; it should be the "accountable entity." Guidance could help develop a model for CMMI. **Dr. Epstein-Lubow** agreed and asked what possibilities might CMS accept. **Bruce Finke:** Payment for the services we need could be one PBPM with associated activities, or it could be the capitated or episode-based model. We could add this to the PBPM model, adjusting the risk for dementia to create an adequate funding scheme for care. **Ms. Blackwell** would leave specificities off the table so as not to limit it to a monthly payment. **Dr. Finke** was trying to capture adequate funding for the services; PBPM is one effective way to do that. We could even add language for alternative funding mechanisms. **Dr. Gitlin** agreed.
- **Laura Gitlin:** In Recommendation 7, it is important to continue to say that we are now moving from recommendations to milestones.
- **Helen Matheny** asked whether the subcommittee should further expand the recommendations (e.g., listing approved tools). **Dr. Hodes** thought having a standardized tool would be useful, but CMS cannot tell anyone what they must use specifically. Now that assessment is required, we should say, "If assessment is indicated, use an appropriate measure."
- **Anthony Pacifico:** U.S. Department of Defense programs compare and contrast symptoms and assessments. **Mr. Johns:** Anything we can do to get people to use these assessments would be helpful. **Dr. Gitlin** suggested having a list of resources (e.g., websites). **Dr. Petersen** suggested adding specificity to the recommendation.

RESEARCH SUBCOMMITTEE RECOMMENDATIONS

Ronald Petersen, MD, PhD, Chair (Mayo Clinic)

Dr. Petersen summarized the Research Subcommittee's recommendations as follows:

1. *Continue to provide a robust, comprehensive, and transformative scientific roadmap.* This is the backbone of the plan and should include specific milestones.
2. *Continue to increase the annual federal research funding.* Currently the United States spends less than 0.5% of its annual costs for AD/DRD on research. The recommendation suggests 1% of what is spent on care, but there is no rationale for binding the research budget to the care budget; \$2 billion or more is needed.
3. *Establish research goals to improve uptake, spread, and delivery of evidence-based and informed care and services.* This would involve enhancing methodologies, developing and implementing quality care measures, and

identifying and evaluating non-drug care strategies, developing and evaluating effective care programs, developing and evaluating technologies to link families to care providers, and convening a conference of key stakeholders to enable this.

4. *Standardize terminology regarding cognitive and dementing disorders.* This is important for all involved--physicians, patients, families, caregivers, and other stakeholders.
5. *Support global efforts to address issues of research, care, and services.* We should be aware of other programs and participate, promoting collaborations on international research efforts.
6. *Enhance recruitment efforts for randomized controlled trials for ADRD.* This type of activity will be essential if we are to reach our goal by 2025. This would include building features (e.g., diversity and inclusiveness) into grant applications.

Comments and Questions

- **Ellen Blackwell:** Recommendation 3 is a larger issue and she likes that “evidence-based care and services” does not specify dementia.
- **Sowande Tichawonna** wondered about Health Insurance Portability and Accountability Act (HIPAA) restrictions that might affect Recommendation 4 (developing a technology system to link families). **Dr. Gitlin** said the subcommittee had entertained no discussion of this, but this is a recommendation for research so the researcher would have to address those concerns. **Dr. Pacifico** noted that this had been obviated for traumatic brain injury, which could serve as a model to advance research here.
- **Joan Weiss:** We should use the same terms throughout the report, and define them in a central place.
- **Mary Worstell:** Under long-term changes, “diverse populations” are not inclusive; sex and gender should be specified, given the prevalence of dementia among women. She also noted that we need to include caregivers. Because women are more commonly patients, we need to address male caregivers. **Mr. Johns** added the numerous children giving care. **Dr. Weiss** asked whether the needs for the kinds of support differ for male caregivers than for female caregivers. Caregivers also need respite care to remain healthy.
- **Bruce Finke** thought clinical services should develop services in addition to the research base.

COUNCIL VOTE ON 2017 RECOMMENDATIONS

Ronald Petersen, MD, PhD, Chair (Mayo Clinic)

The recommendations will be merged and presented as coming from the entire council in the same format as was used last year: Bold-face recommendations will be listed on the first page followed by more complete explanations. Dr. Petersen asked participants to give Ms. Khillan permission to edit the recommendations. The revised recommendations will go out over Dr. Petersen's signature on Advisory Council stationery to the Secretary and to certain members of Congress.

Comments and Questions

- **Jennifer Mead** clarified that the recommendations go out before the National Plan does.
- In Recommendation 1, include journal articles as tools.
- **Jennifer Mead** suggested adding the definition of “diverse” and changing “care partner” to “caregiver” throughout.
- **Jennifer Mead:** In Recommendation 2, add a measure to identify across agencies persons living with Alzheimer's disease. Include health professional associations in those who need to develop competency.
- **Jennifer Mead:** In Recommendation 4, define “diverse” and add a note about <brainhealth.acl.gov> and <alzheimers.gov>. **Dr. Petersen:** How we specify diversity will be standardized across documents.
- **Mary Worstell** liked the discussion about persons living with Alzheimer's disease and noted that we are rethinking the concept of caregiver and looking at a system and community, not just the individual. **Ms. Khillan** added housing and transportation. **Dr. Weiss:** Keeping people in their homes and communities longer involves the workforce, financial services, and transportation.
- **Helen Matheny:** More discussion is needed around the PBPM payment mechanism. Do we advocate for a particular payment method? **Dr. Epstein-Lubow** liked the suggestions for refining this recommendation. He was hesitant to remove PBPM, but would like to leave it as one of the options for what to do next. **Ms. Blackwell** asked about comprehensive risk-based payment. **Dr. Weiss** thought it a good compromise because in the early stages of Alzheimer's, not as much money is needed as in later stages. **Ms. Blackwell:** This is how hospice now pays. **William Spector:** We really want adequate payment and evidence-based care, so we should downplay the particular payment mechanism. The CMS Dementia-based Demonstration Project has moved to evidence-based programs.

- Change “care-partners” to “caregivers.”
- Change “clinical entity” to “accountable entity.”
- **Sowande Tichawonna**: The privacy issue around technologies and HIPAA should be mentioned.

Dr. Petersen asked non-federal members to vote. The recommendations were unanimously approved.

PRESENTATION ON CONGRESSIONAL LANDSCAPE

Alexandra Khalife (HHS Office of the Assistant Secretary for Legislation)

The Capitol Hill climate has become increasingly partisan and polarized and Ms. Khalife does not expect easy approval of discretionary funding. Republicans want health care reform, tax reform, and infrastructure rebuilding, and in addition to big ideas, limited time is a factor. Only 8 months remain in the calendar year, only 40 days before the August recess, and 40 days before the end of the fiscal year (FY). As a result of the constant change, stakeholders need to constantly identify and cultivate Hill representatives for their cause.

The actual message you present should be clear and precise, personal if possible, and, most importantly, realistic. There is a caucus group for everything. The one for Alzheimer’s disease has some 170 members. It is an effective group because it has bipartisan support and it is a big group. These are good people for NAPA members to approach. Congress also has key authorizing committees.

The second point is transitioning. Several organizations have focused on Alzheimer’s disease and they need to be sure the whole field is speaking with one voice. Informal coalitions are a good mechanism for this kind of work. The various groups provide different insights. NAPA needs to think about strategy and work in unison for the same goals. Do not talk about more money. The budget will remain the same, so any allocation of money will come at the expense of another program. Be clear and concise. Congressional members are often distracted and they need the simple take-away. As federally funded entities, your feedback is part of the evaluation of impact and the number served of the funding allocated, which is difficult to capture in program evaluation. Anecdotal information is therefore important. Make your presentation personal if you can. What does funding for this actually mean? Be realistic in your ask. What’s realistic? What’s achievable? It is also important to remain optimistic. Now the climate is limiting government spending, eliminating duplication, having smaller programs, etc. Establish yourself as a resource for the Congressional member by providing current information.

Comments and Questions

- **Ellen Blackwell** asked whether NAPA has the latitude to arrange meetings with Hill staffers. **Ms. Khalife:** Some are proactive and some reactive. Consider whether the issue is complex and whether they need the information.
- In response to **Dr. Gitlin**, **Ms. Khalife** said that often reports to Congress are required to be delivered to key committees. Her office always delivers a report in person. It's their report and they can share it widely or not. Unless the report is not to be shared, they would distribute it to others as well.
- **Ellen Blackwell:** The Alzheimer's Association had a forum about a week ago that attracted some 1300 marchers. Did that have an effect? **Ms. Khalife:** Interested parties organize to be heard, and that's important.
- **Ron Petersen** asked how many Federal Advisory Council Act committees (FACAs) there are. **Ms. Khalife:** There are some 900 FACAs for all government agencies; HHS has the second highest number.
- **Mary Worstell:** Where is Capitol Hill on aging now? **Ms. Khalife** has seen it percolating, but the primary emphasis is on decreasing the budget. The Senate has a Special Committee on Aging, which would be a good group to contact. The interest is there, but the real challenge is all of the competing "noise." The economic impact of health care costs could be an approaching train wreck, but this group can emphasize the importance of the issue.
- **Joan Weiss** asked about reauthorization of this FACA. **Ms. Khalife:** Sometimes it's best not to point out that your group is up for reauthorization. It's a tricky game in a time of limited spending and the desire to streamline. What's moving is so limited; it would be good to tack onto something that will move.
- **Laura Gitlin:** Are there new strategies for moving recommendations forward? **Ms. Khalife:** That would be a good way to leverage ASPE. It could be framed as complementary recommendations.
- **Ron Petersen:** Does your office have authority to take something to the Hill? **Ms. Khalife:** No. They are bound by the President's budget; administration policy, mainly from the President's budget proposal, is their guidance. That's their roadmap for the year. After something makes it into the budget, they have the leverage to talk about the budget. The Advisory Council charge is outside that.
- **Ellen Blackwell:** What are the Secretary's priorities? **Ms. Khalife:** Traditionally there is a whole process to work on the next budget. HHS has to negotiate with the U.S. Office of Management and Budget (e.g., people on the Hill are interested in Zika virus and opioids, but they are not in the budget). However, there are ways outside the budget for those things to work.

PUBLIC INPUT

Three comments were presented.

Susan De Santi, Paramount Imaging

Dr. De Santi is vice-president of medical affairs for North America and Asia Pacific for Paramount Imaging, a diagnostic radioimaging company that uses β -amyloid positron emission tomography (PET) of the head to reveal the brain injury for Alzheimer's disease and types of other cognitive decline. These conditions are usually diagnosed after clinical impairment has been observed using in-depth clinical work-ups, including computed radio-tomography and magnetic resonance imaging. Despite access to these work-ups we are far from being able to definitively diagnose Alzheimer's disease and other cognitive disabilities. We can only diagnose with certainty post-mortem, whereas 10-30% of diagnoses based on clinical examination alone are incorrect. We are still far from being able to early and accurately diagnose ADRD. However, β -amyloid PET scanning can detect or rule out the presence of β -amyloid plaques in the living patient and measure cognitive impairment in Alzheimer's disease and other cognitive disorders.

However, Medicare beneficiaries are eligible for only one β -amyloid PET scan if they are enrolled in a Medicare-approved clinical trial. Enrollment is expected to be 18,488 patients by 2018; that is, fewer than 1% of Medicare beneficiaries, whereas an estimated 15-20% of Medicare beneficiaries have dementia. Coverage is lower than other Medicare coverage with evidence development (CED) programs (e.g., the National PET Registry enrolled over 100,000 patients, and the Transcranial Aortic Valve Program enrolled more than 55,000). By not using it, we are missing an opportunity for better care and management of these conditions. CMS is not approving other clinical trials, which denies access to this diagnostic tool. Moreover, Medicare is an entitlement program, so all beneficiaries are supposed to have access to covered services and benefits. CMS has not approved enough trials to see whether β -amyloid PET imaging meets criteria for coverage. The Advisory Council should ask CMS to reexamine whether β -amyloid PET evidence meets criteria for inclusion in services offered; to recruit investigators to launch more trials; and to update stakeholders on the CED examination, as well as the type of research the agency would like to have in the future.

Matt Sharp, Association for Frontotemporal Degeneration

The FTD (frontotemporal degeneration) Disorders Registry, launched March 10, 2017, is both a contact and a research registry. Mr. Sharp appreciated NAPA's focus on behavioral symptoms in younger populations, and the recommendations of the Long-Term Services and Support Subcommittee, as well as the recommendations concerning assessment and comprehensive coverage. Both diagnosis and payment for the over-65 population would miss many people with FTD. Essential benefits could come from a group working on dementia nomenclature. A common complaint caregivers have is the isolation and exhaustion of having to explain that their relative is not too young to be cognitively impaired and does not have a memory problem. Developing uniform nomenclature is a challenge, but we need fair and accurate language to share the

news. How we talk about dementia will guide what we do about it. In addition to awareness we need to gain support to achieve our goals.

Eric Sokol, Alzheimer's Foundation of America

The HHS Food and Drug Administration (FDA) has approved genetic testing for Alzheimer's disease, which can create problems, like depression and psychological issues. Mr. Sokol would like to see the Advisory Council bring up the need for genetic counseling and best practices, including counseling, in that, so people who find that they have a genetic predisposition can get help to deal with the psychological as well as physical results.

EXAMINING MODELS OF DEMENTIA CARE

Elizabeth Gould, MSW (RTI International)

Last year, ASPE funded a 1-year project to review models of dementia care. Despite the growing number of interventions and the numerous guidelines, little has been done to systematically synthesize them. The focus of this project was to see how best practices correspond with the models being used. This project synthesized 37 sets of care guidelines, identified 14 key components, and conducted five site visits to address whether and how the components are being implemented. They reported with an overview statement of what is addressed and gave specific details separately. The dementia care components are:

1. Detection of possible dementia
2. Diagnosis
3. Assessment and ongoing reassessment
4. Care planning
5. Medical management
6. Information, education, and informed and supported decision-making
7. Acknowledgment and emotional support for the person with dementia
8. Assistance for the person with dementia with daily functioning and activities
9. Involvement, emotional support, and assistance for family caregiver(s)
10. Prevention and mitigation of behavioral and psychological symptoms of dementia (BPSD)
11. Safety for the person with dementia
12. Therapeutic environment, including modifications to the physical and social environment of the person with dementia
13. Care transitions
14. Referral and coordination of care and services that match the needs of the person with dementia and family caregiver(s) and collaboration among agencies and providers

To identify models of dementia care, the investigators conducted an environmental scan from a variety of settings (e.g., nursing homes, residential care facilities, homes, primary care facilities, hospices, etc.). Focusing on evidence-based programs and interventions,

they identified 55 interventions, mostly in community-based settings, that provided support for caregivers. To determine how programs actually address the 14 care components the investigators selected five programs as case studies:

- BRI Care Consultation (Cleveland, Ohio)
- Comfort Matters (Phoenix, Arizona)
- Healthy Aging Brain Center (Indianapolis, Indiana)
- MIND at Home (Baltimore, Maryland)
- RCI REACH (Georgia)--They did not visit this site, but used conference calls instead.

None of the five sites had procedures to detect dementia in the general population. (People who come to the program have already been identified as having dementia.) None addressed all 14 components. Programs used three ways to address the components: direct provision of the needed assistance, referrals to another agency, and information, education, skills training, and encouragement to family caregivers. All conducted assessments, reassessments, and care planning activities. Programs with medical staff provided formal diagnoses while other programs referred out for diagnosis.

In conclusion, there is no cure for Alzheimer's disease, but there are a substantial number of evidence-based interventions that affect outcomes. Despite the many guidelines, there has been no qualitative research. Most programs address the vast majority of dementia care components either directly or indirectly. Most programs focus on caregivers rather than the person with dementia, however residential and medical programs are more likely to have substantial interaction with the person with dementia. Programs varied in the degree to which they were involved in medical management. Several programs had invested in developing a library of resources, which might be a good federal initiative to bring together.

Comments and Questions

- **Joan Weiss** clarified that many had the same resources, but covered certain domains.
- In answer to **Mr. Tichawonna** and **Dr. Gitlin, Ms. Gould** said they looked at domains and used their exact wording for an overview statement. Then they looked at the indicators and used them as a cross-check.
- **Rohini Khillan** explained that the project came out of a publication about the desired qualities of a good care system. **Dr. Gitlin:** Some programs had a greater impact in more outcomes and some programs were not designed for this purpose. **Ms. Khillan:** We want to find out what's there and be more descriptive. **Ms. Gould:** A table in the report compares the sites and how they operated.

- **Elizabeth Gould:** It would be interesting to find out whether all are doing the same two or three things and if they were whether they were having a larger impact. We assume that doing all 14 care components would not necessarily lead to better outcomes. We tried to present the data in various ways.
- Responding to **Ms. Blackwell, Ms. Gould** said new approaches occurred with components about information that involves emotional support and what supported the decision-making. We want the person with dementia to have as much involvement as possible and we want to support the family.
- **Mary Worstell:** The focus is on caregivers and their need to take care of themselves while they care for someone else. Is the content directed to the caregiver more about caring for themselves or caring for the person living with dementia? **Ms. Gould:** So much is fluid. We talk with the family and update them during which emotional support for the caregiver can be given. We want to allow caregivers to be as much a part of the process as they want to be. We tell them to feel free to disagree. They are taking in and distilling a lot of information.
- **Mary Worstell:** Safety of the person with dementia is assumed. In the training modules, have they considered safety of the caregiver in dealing with difficult behaviors of the person with dementia? **Ms. Gould:** Yes and we reworded the prevention and mitigation part to reflect that.
- **Jennifer Mead:** We can influence these programs via short-term funding, but should we spend more time getting funding? Or do we go back to the list and try to get some of those things funded? On the other hand, we have no way to scale them yet.
- **Laura Gitlin:** We have shared processes and all have education, skills, and resources. **Ms. Gould:** There's something to be said for synergy. **Dr. Finke:** Primary care takes the characteristics of patterned care. It could be useful to attempt to cross settings with components. The patterns-of-care approach depends on the context of care, which may not be the usual.
- **Ron Petersen** and **Ms. Gould** agreed, the ultimate application will be that Ms. Gould makes a recommendation. This is the first step. **Ms. Killan:** We have followed-up with outcomes for patients at these sites. Can we come up with a basic overarching framework that defines high-quality care for dementia?
- **Gary Epstein-Lubow** congratulated RTI and the Clinical Care Subcommittee for giving their recommendations this morning, and he wants the Council to look more in detail at them. Safety should include the caregiver, as well as the patient. Medical management of co-morbidities, as well as pharmacological care, should also be included. **Ms. Gould:** That was taken into account as well as the interventions being done.

RESEARCH SUMMIT ON CARE AND SERVICES UPDATE

Katie Maslow, MSW (Gerontological Society of America)

The summit may lead to recommendations for the National Plan. The website for the Research Summit on Dementia Care is now live and material will be added as it becomes available. The summit will take place October 16-17, 2017, at the Natcher Building, HHS National Institutes of Health (NIH). Sign up begins in June. The Steering Committee, chaired by Dr. Gitlin and Ms. Maslow, includes two people with dementia. It welcomes comments. The lead is Dr. Epstein-Lubow.

For the opening plenary sessions, Dr. Petersen will lead off, followed by Maria Carrillo, Ken Langa, Jennifer Manly, and Maria Aranda. There are six sessions:

- I. Research on Care Needs and Supportive Approaches for Persons with Dementia (Co-chairs: Richard Fortinsky and Ann Marie Kolanowski)
- II. Research on Supportive Approaches for Family and Other Caregivers (Co-chairs: Linda Teri and Lisa Fredman)
- III. Involving Persons with Dementia and Family and Other Caregivers as Active Members of the Research Team to Identify Research Topics and Meaningful Outcomes (Co-chairs: Mark Snowden and Lee Jennings)
- IV. Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers (Co-chairs: David Reuben and Vincent Mor)
- V. Challenges in Involving Persons with Dementia as Study Participants in Research on Care and Services (Co-chairs: Darby Morhardt and David Bass)
- 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 (Co-chairs: Chris Callahan and Alan Steven)

Cross-cutting chairs: Technology--Sara Czaja; Race/ethnicity/culture--Ladson Hinton; Etiologies/disease stage--Angela Taylor; Women/gender--pending

Dr. Gitlin and Ms. Maslow have asked co-chairs to select speakers and panelists for their sessions. When that is settled they will circulate an agenda. Women's health issues should include women's risk and the number of women involved in family caretaking. A new, short session on nomenclature will be given.

Stakeholder groups have become more important. The ones represented at this summit are: persons with dementia, family caregivers, service providers, State governments, payors, and workforce development (chaired by Dr. Weiss). Each has between nine and 12 members and will discuss what is important to them. Stakeholders can ask questions which will be incorporated into the session.

Laura Gitlin, PhD (Johns Hopkins University)

We are planning six pre-summit activities, and the NIH National Institute on Aging (NIA) and the Alzheimer's Association are planning two others:

- Evidence for Home-based Dementia Care (Constantine Lyketsos, Quincy Samus and team, Johns Hopkins University)
- Determinants of Behavioral Symptoms--Systematic Literature Review (Ann Marie Kolanowski and team, Penn State University)
- Diversity and Alzheimer's Disease Caregiving Conference--Race/Ethnicity and Caregiving (Oanh Meyer, University of California-Davis)
- Caregiving and Program Research on Caregiving of Persons with Intellectual Disability and Dementia Practices (Tamar Heller, Alzheimer's Association)
- 2015 Survey Data on Family Caregivers (National Alliance on Caregiving and the Alzheimer's Association)
- Methodological Considerations in Research on Dementia Care and Services (Lori Frank, Patient-Centered Outcomes Research Institute)
- Caregiver Intervention Workshop (NIA)
- Outcome Measures (Alzheimer's Association)

Research recommendations come from: plenary summit speakers; co-chairs, speakers, and panelists; cross-cutting chairs; audience members; stakeholder groups; pre-summit activities; public listening sessions; and RTI background papers etc. Core recommendations are to develop, evaluate, and disseminate: new models of long-term care and support, and new payment models; preparation of a dementia-competent workforce; new and existing technologies to link families to care providers and share information; a National Plan to address barriers to home-based care; and education of consumers and payers about the needs and benefits of home-based dementia care.

In 2016, the Council of the Advancement of Nursing Science published *Personal, Interpersonal and Environmental Determinants of Behavioral and Psychological Symptoms of Dementia*, a literature review on the determinants of vulnerability. They reviewed some 2000 articles for factors such as determinants of agitation. In the research samples these are not well characterized, so it was difficult to match determinants with etiology. In addition, nomenclature is confusing, and not all implementations are equally effective.

Current research has exposed significant methodological flaws, lack of consensus as to how to define and operationalize BPSD, and failure to appreciate BPSD as a "moving target" for which the determinants vary across individual symptoms rendering interventions unequally effective. Incorporating biomarkers and neuroimaging in studies would be helpful. BPSD goals fit with Goals 1-5 of the National Plan.

They continue to work on the following timeline for the summit: April, NAPA website goes live; April to May, identify speakers and panelists; May to June, distribute save-the-date card; June to July open registration; April to October, generate recommendations.

FEDERAL WORKGROUP UPDATES

Long-Term Services and Supports Subcommittee

Erin Long, MSW (ACL)

ACL has released two funding opportunity announcements (FOAs): applications for one are due May 12, and the other will be announced April 19. They hosted several Alzheimer's and dementia sessions at the March 2017 Aging Society of America Chicago conference. They are coordinating a special electronic Alzheimer's and Dementia edition of *Generations: Journal of the American Society of Aging* for publication later in 2017. In early March, ACL hosted, with CDC and NIA, the first webinar targeting research and research professionals. Free continuing education is available for as long as 2 years (through April 4, 2019).

The Association on Disabilities (AOD) Arizona University Centers for Excellence in Developmental Disabilities Education, Research, and Service is using leveraged funds to identify and address Alzheimer's and dementia in adults through prevention and training. AOD State Councils on Developmental Disabilities are building on public and private partnerships to support a comprehensive public education campaign addressing the medical and social impacts of the correlation between aging adults (50 year and older) with Down syndrome who are at risk for developing Alzheimer's disease.

Bruce Finke, MD, (Indian Health Service [IHS])

For the past 2 years, REACH into Indian Country has concentrated on training interventionists--American Indian caregivers, community health nurses, community health workers, et al. No single pathway works in every community. In this, the last year of funding, IHS will focus on sustainability and application, and most important, how to reach the caregivers. They will shift from trying to reach more communities to trying to get more involvement with the current caregivers.

Clinical Services Subcommittee

Ellen Blackwell, MSW (CMS)

Current CMS projects are:

- Photographing Medicare recipients who have dementia.
- The Accountable Health Communities Model, which tests whether identifying and addressing health-related social needs through referral and community navigation services impacts health care costs, reduces inpatient and outpatient health care utilization, and improves health care quality and delivery.
- The National Partnership to Improve Dementia Care in Nursing Homes whose goal is to reduce the use of anti-psychotic medication in long-stay nursing home residents.

- Through the Geriatric Competent Care Series, the Medicare-Medicaid Coordination Office held two webinars--“Applying Promising Practices to Advance Care of Medicare-Medicaid Enrollees with Dementia,” and “Beyond Alzheimer’s Disease--Other Causes of Progressive Dementia in the Older Adult.” A third webinar on Parkinson’s disease diagnosis is forthcoming. The Integrated Care Resource Center helps health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults with Alzheimer’s disease and in working with their caregivers.
- Comprehensive Primary Care Plus (CPC+) is a national advanced primary care medical home model that aims to strengthen primary care through regionally based multi-payer payment reform and care delivery transformation. Its three payment elements are a care management fee, a performance-based incentive payment, and payment under the Medicare Physician Fee Schedule. CPC+ just closed its solicitation for round 2, which begins in January 2018. One element is extra payment for dementia, although no data are yet available.
- In March, CMS announced three issue briefs on the evaluation of the Medicare-Medicaid Financial Alignment Initiative--care coordination, beneficiary experience, and special populations--which have some synergies with dementia. The Financial Alignment is designed to provide Medicare-Medicaid enrollees with a better care experience and to better align the financial incentives of the Medicare and Medicaid programs.
- The Connected Care Initiative, in collaboration with the HHS Health Resources and Services Administration (HRSA), is intended to raise awareness of the benefits of chronic care management services for Medicare beneficiaries. It is a nationwide effort in fee-for-service Medicare that includes a focus on racial and ethnic minorities, as well as rural populations, which have higher rates of chronic disease. New resources include a toolkit for providers and partners. This involves the Office of Minority Health as well as the Medicare Advantage Quality of Care Disparities, including gender disparity (e.g., women are more likely to be prescribed antipsychotics).

Alzheimer’s and Related Dementias Research: Budget and Funding Opportunity Announcements

Richard Hodes, MD (NIA)

In FY 2016, NIH’s budget received a \$32 billion increase, including \$1.6 billion for NIA. The 2017 draft appropriations bill includes an additional \$350-\$400 million NIH funds for Alzheimer’s disease. However, the continuing resolution level runs through April 28, and the President’s budget for FY 2018 calls for a \$5.8 billion decrease for NIH, but with no specifics as to Institutes and Centers. Dr. Hodes was concerned about the outcome, especially for new investigators.

As for Alzheimer’s FOAs, there are six active in resource leverage, four in caregiving and clinical care, three in translation, nine in basic research, and two in training. In addition is the new National Institute of Neurologic Diseases and Stroke (NINDS) FOA

in partnership with NIA: Detecting Cognitive Impairment, including Dementia, in Primary Care and other Everyday Clinical Settings for the General Public and in Health Disparities Populations.

The Agency for Healthcare Research and Quality (AHRQ)-National Academies study is a two-part assessment of science to prevent Alzheimer's disease-type dementia, amnesic mild cognitive impairment, and age-related cognitive decline. This should be completed in June 2017.

Comments and Questions

- **Harry Johns:** People work on these projects relentlessly with the same intent.

CONCLUDING REMARKS

Ronald Petersen, Ph.D., M.D. (Mayo Clinic)

Trish Vradenburg, the wife of former member, George Vradenburg, died this morning (April 17). Both were recognized for their contributions to Alzheimer's disease work.

This is Jennifer Mead's last meeting. Dr. Petersen thanked her for all the work she has done on the Long-Term Services and Supports Subcommittee over the last 4 years. Donna Walberg will assume her position with the subcommittee.

The next NAPA meeting will be held Friday, July 28.

Dr. Petersen adjourned the Council meeting at 3:16 PM.

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

Ronald Petersen, Mayo Clinic (Chair)
Marie Bernard, NIA
Ellen Blackwell, ACL
Susan Cooley, VA [*via telephone*]
Billy Dunn, FDA
Valerie Edwards, CDC
Gary Epstein-Lubow, Brown University
[*via telephone*]
Bruce Finke, IHS
Laura Gitlin, Johns Hopkins University
Elizabeth Gould, RTI International
Richard Hodes, NIA
Harry Johns, Alzheimer's Association
Ruth Katz, ASPE
Alexandra Khalife, HHS/Office of the Assistant
Secretary for Legislation
Rohini Khillan, ASPE
Erin Long, ACL
Myriam Marquez, person living with dementia
Katie Maslow, Institute of Medicine
Helen Matheny, West Virginia University
Jennifer Mead, Oregon Department of
Human Services
Deborah Olster, National Science Foundation
Anthony Pacifico, DoD
Marianne Shauhnessy, VA
William Spector, AHRQ
Angela Taylor, Lewy Body Dementia Association

Sowande Tichawonna, caregiver
Donna Walberg, Minnesota Board
on Aging
Joan Weiss, HRSA
Geraldine Woolfolk, caregiver

Absent

Richard Allman, VA
Sophia Jeon, NINDS
Shari Ling, CMS

Public

Melissa Andel

Erin Cadwalader

Rachel Conant

Phil Cronin

Lisa Daigle

Susan De Santi

Robert Egge

Elena Fazio

Julie Georgi

Matthew Janicki

Melinda Kelly

Ian Kremer

Kelley Landy

Robert LeRoy

Eliezer Maslian

Katherine Maynard

Suzanne Maynez

Dorie Paos

Creighton Phelps

Joanne Pike

Colleen Reilly

Matthew Sharp

James Scott

Eric Sokol

Laura Thornhill

Charlotte Wincott

Courtney Wallin

Mary Worstell

April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Monday, April 17, 2017, in Washington, DC. The Advisory Council spent the majority of the April meeting considering recommendations made by each of the three subcommittees for updates to the 2017 National Plan. Afternoon presentations included a presentation on results from a research project on dementia care components, planning progress towards a Care and Services Summit, and federal workgroup updates. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2017>.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

LTSS Subcommittee 2017 Recommendations	[HTML Version] [PDF Version]
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Presentation Slides

2017 Research Subcommittee Recommendations	[HTML Version] [PDF Version]
Alzheimer's and Related Dementias Research	[HTML Version] [PDF Version]
Clinical Care Subcommittee Report	[HTML Version] [PDF Version]
Clinical Services Subcommittee Federal Update	[HTML Version] [PDF Version]
Examining Models of Dementia Care	[HTML Version] [PDF Version]
Long Term Services and Supports Subcommittee Recommendations	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers Progress to Date	[HTML Version] [PDF Version]

Videos

Welcome, LTSS, and Clinical Care Recommendations	[Video]
Research Recommendations, Council Discussion/Vote, Overview of Legislative Processes	[Video]
Public Comments and Examining Models of Dementia Care	[Video]
Care Summit Update and Federal Workgroup Updates	[Video]

Last Updated: 06/27/2018