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

Bethesda, MD

August 1, 2016

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Ronald Petersen (Chair), Gary Epstein-Lubow, Laura Gitlin, Harry Johns, Myriam Marquez, Helen Matheny, Jennifer Mead, Angela Taylor, Sowande Tichawonna, Donna Walberg, Geraldine Woolfolk

- *Federal Members (or Representatives) Present*: Ellen Blackwell (Centers for Medicare and Medicaid Services [CMS]), Susan Cooley (Veteran's Administration [VA]), Billy Dunn (Food and Drug Administration), Linda Elam (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Erin Long (Administration on Community Living [ACL]), Bruce Finke (Indian Health Service), Lisa McGuire (Centers for Disease Control and Prevention [CDC]), Anthony Pacifico (Department of Defense), William Spector (Agency for Healthcare Research and Quality), Jane Tilly (ACL), Joan Weiss (Health Resources and Services Administration [HRSA])

- *Quorum present?* Yes

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

General Proceedings

This meeting was held at the National Institutes of Health (NIH) in Building 35a (Porter Building), Room 620/630.

Welcome and Charge

At 9:14 a.m. ET, Dr. Ronald Petersen called the meeting to order. Dr. Petersen thanked the NIH for the meeting space, and thanked the guest presenters for their attendance. Council members present in the room, as well as those on the telephone conference line, introduced themselves and indicated on which subcommittees they serve.

Dr. Petersen highlighted that this quarterly meeting includes four presentations from CMS Innovation Center awardees.

Ellen Blackwell introduced the core goal of the CMS Innovation Center mission, which is to support public and private sector experiments on how to provide better care, promote better health, and lower costs. Approximately 2,300 applications were received in Round One.

UCLA Alzheimer's and Dementia Care: Comprehensive, Coordinated, Patient-Centered: Achieving Better Health, Better Care and Lower Costs of Care for People with Dementia

Dr. Lee Jennings shared highlights from the University of California, Los Angeles (UCLA) innovation project.

- The UCLA Alzheimer's and Dementia Care Program is based in the geriatric clinic at UCLA, and includes a home-based service component. The program approaches both caregiver and patient with services.

- Currently, the program has enrolled 1,825 individuals, 66% of whom are female and the average patient age is 82 years. Enrolled patients have a variety of dementia types (Alzheimer's disease, 35%; Lewy Body Dementia [LBD], 4%, vascular, 4%, other/mixed/unknown, 53%) and 18% are dual Medicare-Medicaid insured.

- Patient eligibility parameters include a diagnosis of dementia, individuals who are community-dwelling, and individuals with a referring/partnering UCLA physician.

- Direct community-based services are supported by program-funded vouchers to help match resources (e.g., adult day care, counseling, case management) with patients, and encourage trial of new supports.

- Dr. Jennings reviewed the findings of several evaluation assessments on program participants and outcomes.
    - Caregivers reported high satisfaction with the program: 90% felt the intake visit was time well spent, 91% felt concerns were listened to and addressed, and 92% would recommend the program to others.
    - Physicians engaged in the program also reported satisfaction in several areas: 61% reported receiving valuable medical recommendations, 85% received valuable behavioral recommendations, 68% reported an enhanced relationship with their patient, 56% considered that the program saved them time, and 90% would recommend the program for other patients.
    - After one year in the program, caregivers and consumers noted significant improvements in their experience and self-efficacy, including: ability to access community services, confidence in dementia issues, awareness of resources, and having helpful health care professionals to access.
    - After two years, on average, there was a decrease in depressive status and behavioral symptoms, even as disease was progressing, suggesting that

program components are stabilizing decline in those areas. Over two years, caregivers reported declines in distress, strain, and depression.

- After the initial pilot, UCLA engaged in efforts to build greater infrastructure and enhance the support available to caregivers. These "spinoff" activities include:
  - o Dementia Care Management Software.
  - o Website with caregiver training videos and webinars (http://dementia.uclahealth.org).
  - o Enhanced support for caregivers.
  - o I-CareD (personalized caregiver training program).
  - o TIMEOUT@UCLA (student respite program).
  - o Support Groups (English, Spanish, Early Onset, frontotemporal dementia [FTD], and LBD).

- The program engages and requires a variety of staff and other resources, including:
  - o 5 full-time equivalent (FTE) Nurse Practitioner Dementia Care Managers (DCMs).
  - o 2 FTE DCM Assistants.
  - o 0.5 FTE Medical Director.
  - o 1 FTE Program Administrator.
  - o 0.15 FTE Psychologist Support Group Leader.
  - o Software maintenance and supplies.
  - o Vouchers for community-based organizations (CBOs) (approximately $200,000 per year).

- The cost of the program per person is estimated at $1,400 per year, which is lower than the annual cost of generic donepezil ($2,190), memantine ($2,880), or combination therapy ($5,070).

- The UCLA model is designed to bill for Medicare-allowed services, which covers approximately 3% of all costs. All other services are free of charge to patients and their caregivers. These no-charge services include: care coordination with primary care providers and CBOs, telephone follow-up, support groups, and education. Grants and philanthropic funding supports 68% of costs, and institutional support covers 29% of costs.

- Despite the success seen in this proof-of-concept model, there is insufficient Medicare billing opportunities to sustain or expand this type of program from a financial and economic perspective.

- Several barriers to dissemination exist, including:
  - o Medicare coverage for program: for in-person visits, nurse practitioners are reimbursed 85% of what physicians are paid; for all clinical work that is not in-person, there is no reimbursement; and there is no coverage for CBO services.

- A shortage of qualified nurse practitioners.

- The external program evaluation is too preliminary to share at this time, but initial data suggest that there may be some trend in cost reduction.

Indiana University's Dissemination of the Aging Brain Care Program

Dr. Malaz Boustani described the Aging Brain Care (ABC) Program that is licensed by Indian University. Dr. Boustani disclosed his financial equity in this program, as well as the federal and private funding that supports his work.

- Dr. Boustani noted that the ABC Program reflects Indiana University's response to the burden of dementia in the United States. The program was initiated in 2000 and builds upon a collaborative care model that had demonstrated success in depression. In 2007, the model was translated into a local clinical program that served approximately 1,000 patients in Indianapolis. A scalable version of the program was developed in 2012 and expanded to serve 5,000 patients in Indiana. Currently, an advanced scalable version is being developed.

- The rationale for scaling up and disseminating the program was that primary care clinicians do not have the capacity to manage the true burden of dementia patients in their practice without significant resources. The collaborative care model is designed to reduce the barriers to primary care, provide effective tools and resources, and connect providers with additional staff and clinicians.

- The initial model was not scalable largely because patients and caregivers were required to travel to the clinic to receive services, primarily from a small pool of expert physicians (geriatricians, geriatric psychiatrists). The CMS Innovation funding allowed them to increase staffing and add care coordinator assistants (CCAs) who can work with client by phone, travel to meet clients, and provide engagement in a more dynamic manner. Persons with a high school degree can become CCAs, which opened up opportunities to expand that workforce without requiring individuals with more specific clinical credentials who are in shorter supply.

- The second iteration of the program, ABC 2.0 has four main components that comprise the standardized minimum care and is designed to be personalized for each family and client:

  o **Check hospital and emergency room (ER) alerts every day**.

  o **Coordinate with inpatient services**. If an enrolled patient is admitted for any reason, the coordinator engages with the hospital:
    - Alert hospital team of presence of cognitive or mood problems.
    - Medications conciliation.

- Connect with family caregiver.
- Request geriatric consult (If available).
- Coordinate post discharge transition.

o **Post discharge care**:
- Home visit within 72 hours of discharge.
- Medication reconciliation.
- Coordinate home care visit.
- Coordinate post hospital orders.
- Deliver delirium protocol and handout.

o **Ongoing aging brain care**:
- Manage Depression: Problem Solving Therapy, Pharmacotherapy, Cognitive behavioral Therapy.
- Manage Cognitive Impairment: cholinesterase inhibitors (if needed), D/C medications with adverse cognitive effects (anticholinergics, histamine 2 antagonists, benzodiazepines), caregiver problem solving coaching, medication adherence support.

- The program also targets caregivers, encourages support group participation, recommends eight-hour blocks of non-caregiving time, crisis planning exercises, and other planning tools. The ABC 2.0 tools also include items that support caregivers and patients in ways that do not require office visits, assessment tools, caregiver guidance, and other materials.

- The initial program (ABC) demonstrated improvements in acute care service utility (percentage of patients with at least one ER visit, percentage with at least one hospitalization, as well as total number of ER visits and hospitalizations) compared with patients engaged in the traditional primary care model. There were also benefits to patients in the ABC 1.0 program in other health outcomes (e.g., cholesterol management, blood sugar management, cardiovascular medication use).

- The ABC 2.0 program involved a significant shift in the type of staff engaging with patients and providers, as well as the type and site of care; thus, an evaluation of program benefits needed to take these factors in consideration. As reported in a 2015 publication, improvements due to ABC 2.0 have been observed in:
  o Full dementia care giver responders at 12 months (66%).
  o Full major depression patient responders at 12 months (51%).

- Preferred Population Health Management, LLC is a company engaged to broadly distribute ABC programs and scaling up using an existing workforce within the Area Agencies on Aging, which is comprised of individuals comfortable with and experienced in working directly with clients in their homes and other settings.

California Long-Term Care Education Center: Care Team Integration of the Home-Based Workforce

Corinne Eldridge described the California Long-Term Care Education Center's (CLTCEC's) innovation project.

- The project goals were to train 6,000 in-home supportive services (IHSS) consumer-provider pairs over a 3-year period to provide better care, improve health, and lower costs. In the context of this program, providers refer to home care workers (not including home health aides).

- In California, there is a consumer-directed care model for IHSS; consumers can conduct training and manage staff hires and terminations for IHSS providers.

- The training program and curriculum for IHSS providers included:
  - 17 weeks, 3.5 hours per session, 62.5 hours total.
  - Recruitment honors consumer directed care.
  - Consumer **and** provider attend second and last session together.
  - At home assignments.
  - Competency checks and skills demonstration.
  - Attendance policy (mandatory modules and attendance level).
  - Curriculum designed for population:
    - Adult education pedagogy.
    - Group activities.
    - Integration activities.

- Core competencies covered during the training included both hard skills (e.g., CPR, First Aid) and soft skills (communication, monitoring, coaching, care aide skills, health care system navigation). The curriculum competencies were designed to support the IHSS's awareness of issues and provide strategies for management or referral to clinicians or other parties, if needed. The curriculum competencies and topics include:
  - Roles, rights, and the understanding the system.
  - Consumer directed care.
  - Communication and teamwork.
  - Activities of daily living and body mechanics.
  - Personal care.
  - Infection control and standard precautions.
  - Adult and child CPR/first aid/automated external defibrillator.
  - Home safety.
  - Nutrition, diet, and physical activity.
  - Medication and introduction to vitals.
  - Body systems and common diseases.
  - Heart and lung diseases.
  - Diabetes.
  - Behavioral health and developmental disabilities.

- o Dementia and Alzheimer's disease.
- o Career exploration.
- o Integrated care.

- Ms. Eldridge shared a subset of content for a training module specific to Dementia and Alzheimer's disease (Module 15). By the end of this training module, participants are able to:
  - o Define Alzheimer's disease and dementia and identify their symptoms and warning signs.
  - o State important considerations in the care of a consumer who has Alzheimer's disease or dementia.
  - o Define sundowning and identify its symptoms.
  - o State important considerations in the care of a consumer who experiences sundowning.
  - o Describe strategies for responding to challenging behaviors.
  - o Describe strategies for communicating with someone with Alzheimer's disease or dementia.

- Modules include several components to ensure uptake and support trainees in their progression, including: communication, competency checks, and at-home assignments (communication, monitoring, feedback and sharing with consumer).

- Trainees also were required to demonstrate specific skills in:
  - o Infection control and standard precautions: tracheostomy and nasogastric tubes, personal protective equipment, catheters and colostomy.
  - o Oral care and dental care.
  - o Grooming and personal hygiene.
  - o Body mechanics in lifting objects.
  - o Body mechanics in transferring individuals.
  - o Body systems and most common diseases: arthritis, cancer, kidney disease, multiple sclerosis, Parkinson's disease, and stroke.
  - o Fall and fire prevention.
  - o Diet and nutrition.
  - o Medication management and introduction to vital signs: measure or record vitals, but no diagnoses.
  - o Communication and working relationship with patient's health care providers on chronic conditions, such as heart and lung, diabetes behavioral health conditions, and dementia.

- By the conclusion of training in November 2015, 5,552 providers and 6,390 consumers had graduated from the program. Approximately 89% of students completed the program after attending a class. The program maintained a focus on the needs and considerations of trainees and their clients, specifically those related to language, time availability, and location. Two hundred and forty-seven (247) Innovation Center classes were held across Los Angeles, San Bernardino,

and Contra Costa counties. Classes were held in English, Spanish, Armenian, Korean, Mandarin, and Cantonese.

- Integration of the home care training program was achieved through a bottom-up and top-down approach. IHSS providers were provided tools to empower them and the consumer, providers are included in the consumer's electronic medical record, and the provider helps to educate the traditional clinical care team about the program and its benefits. Health plans and clinical staff partner on training and educate their teams about the program; however, more work is needed in this area. Integration is also furthered by frequent contacts, consideration of language needs, and availability or training and services outside of standard 9am-5pm business hours.

- Many providers reported satisfaction and accomplishment upon completing training and feeling confident in their ability to care for a family member or other consumer.

- The program was evaluated to assess if the intervention met project goals, determine the impact of the training, measure the health care costs and utilization (e.g., ER visits, inpatient stays, nursing home utilization) before and after the intervention, capture information on provider trainees and consumers.
  - Trainees had a variety of educational and training backgrounds: less than high school education (42.8%), high school graduate (17.1%), some college or associate's degree (29.0%), and bachelor's degree or higher (11.1%).
  - At the conclusion of training, graduates reported that the training was satisfactory, class sessions were convenient and timed appropriately, and generally reported sufficient time to learn the material covered. Trainees also reported feeling more knowledgeable and prepared to provide care.
  - Following training, consumers reported increase integration.

- Utilization data from one health care plan show that in the 2 years following trainee graduation, several utilization parameters improved, including: ER visits declined by approximately 50% and the mean length of inpatient stays decreased by approximately 50%.

- In data from a different health plan, in which patients were at lower risk (e.g., had lower utilization at baseline), significant reductions in ER visits and inpatients stays were also observed. An ER cost savings of $210 per plan member who participated in the training intervention, and a $19,200 savings for inpatient stays was observed compared to members within the non-trained group.

Four Seasons Compassion for Life Project with Duke University: A new model for Community-Based Palliative Care

Janet Bull described the Four Seasons program, which is in round two of funding.

- The community served by Four Seasons (Hendersonville, North Carolina), reflects the national trend with respect to the growing aging population. Twenty-five percent of the population over 65 years old (compared to 13% nationally). Hendersonville has a high dementia population, with dementia being the number one referring diagnosis for both hospice and palliative care.

- Providing dementia care in the palliative setting is a logical approach that is aligned with the palliative mission of providing exceptional end-of-life care; however, it is financially unsustainable, as Medicare reimbursement is limited to provider services.

- The CMS Innovation grant was awarded to:
  - Scale the palliative model into 14 counties, delivered longitudinally across all care settings.
  - Track quality.
  - Define costs.
  - Test innovation -- tele-palliative care.
  - Developing/testing a new payment system.

- Goals and drivers of the program included:
  - Improve health care outcomes.
  - Improve patient/family and provider experiences of care.
  - Reduce total Medicare costs of care.
  - Increase access to high-quality care.
  - Develop a new palliative care financing approach.

- Patient eligibility included those who are Medicare age eligible, have life-limiting illness and are in the last 3 years of life, those for whom there is uncertainty on appropriateness of therapy (e.g., curative, palliative, hospice). These parameters exclude 54% of palliative care patients (e.g., younger, Medicare Advantage beneficiaries).

- Four Seasons utilizes a standardized tool to track the initial palliative care visit, performs risk assessments, and plans for post-visit follow-ups as needed. A digital quality data assessment tool is used during visits to note progress since previous visits, as well as identify if the care being given has an impact at the time (e.g., resuscitation).

- Of the 2,450 patients enrolled in palliative care services, 522 (approximately one-fourth) have dementia.

- The palliative performance index is a measure used in the palliative care space. Most patients with dementia who are referred to palliative care have some degree of functional mobility impairment at the time of referral.

- Several policy issues may pose barriers to palliative care, including the lack of long-term care benefits and little reimbursement for non-clinical disciplines. New Care Management codes (advance care planning, transitional care, and chronic care) may alleviate some of these challenges.

- Approximately 20% of all hospice diagnoses are for Alzheimer's disease or other dementias. Hospice care is limited to persons with less than six months to live, is designed to provide comfort, and is reimbursed under Medicare hospice benefits which are associated with significant resources. Palliative care is available at any time, can be curative, but has limited resources and reimbursed under Medicare Part B.

Panel Discussion: Innovative Approaches to Dementia Care and Services

Dr. Gary Epstein-Lubow facilitated a panel discussion on the CMS Innovation Center project findings and implications.

Key lessons learned:

- Scalability should be considered at the outset of the project and needs to include policy and workforce development.

- The current fee-for-service model is not aligned with the demand for value from patients and caregivers; CMS' focus on alternative payment models is critical to addressing this misalignment.

- Community health, in addition to individual-focused medical care, needs to be prioritized, particularly in the areas of workforce development and consideration of non-clinical contributing factors to health.

- Health exists largely outside of the "health care system", so a consideration of all of the life settings, caregivers, and experiences that are related to a patient is necessary.

- Workforce preparation is a key emerging need, especially as the competencies are somewhat unique and distinct from the traditional care workforce.

Management of patients who do not have a caregiver:

- Persons with dementia do not need to have an identified caregiver to enter the UCLA program. In those cases, there are attempts to match them with an individual, if possible. In some instances, referral to the program is prompted because an individual lacks a caregiver.

- Having a caregiver is not a requirement for the Indiana University program either. The CCA is tasked with problem solving and can investigate oral health options. If they are unsuccessful, the problem is escalated per protocol to different members of the team.

- The CLTCEC project requires that patients have a caregiver in order to participate. Interested patients without a caregiver are counseled on a process to obtain one (visiting a primary care clinician, being visited by a social worker), which takes approximately 30 days.

Integration of oral health:

- The UCLA program is working on a partnership with the UCLA dental school, as well as dentists who are able to make home visits to provide care.
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- In the CLTCEC's project, oral health is covered in a 2.5-hour competency assessment during the training and is one module that requires competence testing.

Plans for workforce expansion of the UCLA program:

- Dr. Jennings noted that due to an at-capacity waitlist, they have discontinued advertising the UCLA intervention to clinicians. The program is experiencing challenges related to the community need far exceeding the current capacity.

- Currently, there are no plans to expand staffing until additional funding is secured; efforts to increase financial support are ongoing. Adding a DCM is a high priority. The current load per manager is approximately 250 patients, but a more appropriate target is 200 persons.

Outstanding research needs:

- Indiana University's collaborative care model has a platform that is flexible. The outcomes need not be disease-specific (e.g., quality of life), and the evidence-based protocols can be changed to reflect evolution in the program.

- One major challenge is determining how to de-prescribe unnecessary or harmful medications -- more guidance is needed. A study of polypharmacy in palliative care has shown that statin removal had no impact on life expectancy. There is a great need to address medication removal, as many older patients are on many medications and clinicians tend to be reluctant to investigate and consider discontinuing unnecessary or harmful medications.

- There is a need for interventions to halt or slow functional disability in Alzheimer's disease beyond six months; a demonstrated benefit that is observed after two years or longer is desired.

- Alzheimer's disease and dementia should be destigmatized to avoid communicating a lack of hope. Most patients, families, and eve some providers are not aware that there are tools and strategies that can help and improve some outcomes (for patients and their caregivers), even if there is no cure or effective treatment for the advancing disease process.

Understanding and addressing health disparities

- The CLTCEC -- The program is capable of being conducted (not simple translated) in 13 languages, which helps in cultural competence and access to communities.

- In the Indiana University program, issues related to health disparities tend to self-resolve through engagement of the CCAs, who are by definition community health workers. Barriers related to patient-provider communication (e.g., willingness to share comprehensive home details) can be overcome through the relationships built between families and CCAs.

- At Four Seasons, issues related to racism, disparities, and other topics are addressed with the health care workforce to increase understanding and improve patient interactions.

Needs from CMS for program expansion and duplication:

- CMS should consider setting up a task force to investigate a bundled payment option for Alzheimer's disease (e.g., similar to those in place for joint replacement surgeries).

- UCLA is piloting using the new chronic care management codes, which pay approximately one-third of the costs, yet are somewhat cumbersome to use. Additionally, the benefit is not designed to be disease-specific, so challenges remain for obtaining reimbursement for all services provided. Growing programs can be further challenged by this, which require piecing together reimbursements rather than leveraging a comprehensive care reimbursement model (especially the non-face-to-face care). Private entities do look to CMS to be a leader in this area, even as the responsibility falls on the entire health care system.

- Training of home care workers is not funded -- recommendations need to include that trainings should be covered under funding approaches.

- Medicare is one of many CMS programs, so there are many components to the system. The Innovation Center activities are designed to be wholly transparent so that states, private insurers and managed care plans, and other entities can learn from the programs and adjust their policies and procedures as well and not

simply await changes at the level of CMS. States also can serve as opportunities to pilot and expand innovative programs.

- The evidence required to meet the CMS actuarial criteria for further policy development or program expansion is a complex determination to make and is the responsibility of the CMS actuaries.

Diagnosis-specific outcomes:

- Caregivers for FTD are typically much younger as the disease presents earlier than Alzheimer's disease. Patients with LBD experience fluctuations that often prompt questions about whether ER care is required; they also experience mobility issues that impact caregivers.

Public Input

Six members of the public provided comments to ASPE and they included: a person living with dementia, a dementia care consultant, a family advocate, caregivers and family of people with dementia, and representatives from the National Task Group on Intellectual Disabilities and Dementia Practices and the Eldercare Workforce Alliance.

Rohini Khillan read two public comments that were submitted prior to the meeting. Four commenters present at the meeting read their comments to the Council. The public comments provided perspectives on the following:

- ASPE should increase accessibility to Council meetings, particularly to support participation from persons with dementia. The requirement for submission of written public comments is a significant challenge for some and other participation options should be made available.

- The Council should develop public-private partnerships, further engage with thought leaders and researchers, and develop resources and tools, and promote caregiver and patient health and wellness.

- Housing for persons with dementia and intellectual disabilities need to be designed with the patient and caregivers in mind. A fragmented system cannot be improved if additions are also fragmented. Systems need to focus beyond just the patient. The caregiver and environment are also critical. It is important to continue to try and meet the "unmet needs" as they require constant improvement and addressing. Costs associated with dementia and intellectual disabilities are largely due to avoidable incidents that are not sufficiently addressed (e.g., wandering prevention programs).

- The $35 million grant supported by NIH, National Institute on Aging (NIA), and National Institute on Child Health and Human Development on biomarkers is

appreciated by those working to advance progress for individuals with intellectual disabilities. Additional supports are needed for aging parents and caregivers of younger persons with intellectual disabilities; these caregivers are also often managing a dementia diagnosis of their own.

- The connection between Down syndrome and Alzheimer's disease is still not widely understood and should be emphasized in order to increase awareness and improve outcomes.

- Persons with intellectual disabilities should be managed in ways that mirror management of the general population -- including avoidance of overmedication, attention paid to psychosocial factors in addition to medical factors.

- The focus on caregivers during today's meeting is greatly appreciated. Approximately 95% of adults with intellectual disabilities live with family, friends, or other persons and receive some support. As onset and progression of Alzheimer's disease in these individuals occurs, many caregivers lack awareness of signs and symptoms, and do not have the tools to manage the changes. Recent legislation, the Alzheimer's Caregiver Support Act, would provide for education and support for caregiver of persons with Alzheimer's disease. The legislation as drafted *does not* include persons with intellectual disabilities, which is unfortunate and amendments are being requested to include this. The Council should consider supporting the legislation, as well as the broadening of eligibility language to include persons with intellectual disabilities.

- The Council's support of gerontology training programs is important. In recent years, funding for these programs have remained flat, yet need to increase substantially to meet the needs of the growing population. Geriatrics Workforce Enhancement Program (GWEP), funded by HRSA, is the only workforce enhancement program focused on geriatrics and involves a multidisciplinary approach to patient and client management. Congress may authorize language in Title VII to include language from the GWEP initiative.

Federal Workgroup Updates

Long-Term Services and Supports (LTSS)

Jane Tilly and Erin Long provided updates from the LTSS workgroup.

- ACL's public awareness campaign *What Is Brain Health?* is ongoing and is reaching many audiences in many arenas including: television, social media, and live events. A new iteration of the campaign in Spanish is under development.

- Grant programs focused on building dementia capability and expanding services are supporting efforts in most parts of the United States (grants dated 2012-2015).

- Two new grans were funded in 2016:
  - Alzheimer's Disease Supportive Services Program will fund both new and current grantees:
    - Highlight -- Ohio: Ohio Success Story! [https://www.youtube.com/watch?v=SP_zGBXGboY&index=4&list=PLmhj3Uq6-ZoyiAItkgXojKfVw6VL5ORLG] -- expanded their music-based approach to behavioral modification (e.g., calming of patients). There is a film called "Alive Inside" that demonstrates similar efforts.

  - Alzheimer's Disease Initiative - Specialized Supportive Services will fund both new and current grantees:
    - Highlight -- Minnesota: Cultural Awareness in Dementia care effort will make consultants available to racial/ethnic minority communities.

- ACL published a policy brief on promoting community living for older adults, with a special emphasis on those with dementia. Available in the dementia section at: http://www.acl.gov/Get_Help/BrainHealth/Index.aspx.

- ACL also issued continuation funding for the National Alzheimer's Call Center (Alzheimer's Association is grantee) for the next budget period (from August 1, 2016 to July 31, 2017).

- Several webinars and webinar series have taken place to increase awareness and promote improvements for persons with dementia.
  - On July 20, 2016, ACL hosted a webinar on the benefits of legal planning, obstacles, and supported-decision-making to ensure that legal choices made reflect the wishes of the person with dementia.
  - ACL, CDC, and NIA host a free webinar series to provide information to an audience of aging and disability, public health, and research professionals on promoting awareness of research participation opportunities and improving coordination of federal resources available to assist people with dementias, including Alzheimer's disease, and their family caregivers. The fifth event in the series is upcoming.
  - VA and ACL hosted a webinar on May 5, 2016, to provide information to aging network partners about a new VA model, Mobile Adult Day Health Care, which involves community partnerships to provide meeting space for a mobile team to provide adult day health care to veterans, including those with dementia.
  - HRSA and ACL hosted a webinar on June 22, 2016, to describe HRSA's approaches to workforce development, including identifying ways for efficient dementia case finding, learning about lifestyle interventions for persons living with dementia, developing effective communication strategies

across all levels of care, and learning about inter-professional health care teams that include community service partners.

- Several efforts are continuing to enhance quality:
  - ACL continues to work with states as they implement the Long-Term Care Ombudsman Rule, which was effective July 1, 2016. Regional Support Centers are incorporating Rule implementation into the 2016 state annual reviews.

  - CMS' project to define home and community-based services (HCBS), examine quality measurement in HCBS, and identify gaps in HCBS measurement (http://www.qualityforum.org/Measuring_HCBS_Quality.aspx) is ongoing:
    - National Quality Forum (NQF) recently issued a third interim report.
    - Public comment closed in late July and a public webinar is to be held on Thursday, August 4, 2016.

  - CMS issued a final rule on Medicaid managed care (April) (https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/managed-care/managed-care-final-rule.html).

  - In July 2016, CMS issued the annual LTSS expenditure report which summarizes national trends in LTSS data and spending, the percent of Medicaid spending used for LTSS (institutional and community-based), the HCBS portion of total LTSS expenditures, state spending variation, population groups, and any shifts in federal statutory authorities used to deliver HCBS (https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-2014.pdf).

- Funding of research projects continues with several interventions awarded support, including (but not limited to):
  - **Interventions**:
    - (1R01AG049895-01A1): EPIC: A Group-based Intervention for Early-stage Alzheimer's Disease Dyads in Diverse Communities.
    - (1R01AG048931-01A1): The Residential Care Transition Module.
    - (1R01AG049692-01A1): Improving Outcomes for Family Caregivers and Older Adults with Complex Conditions: The Adult Day Service Plus Program.
    - (1R01AG052495-01): A Mindfulness Based Stress Reduction for Family Caregivers of Dementia Patients.

  - **Enable family caregivers to continue to provide care while maintaining their own health and well-being**:
    - (1RF1AG050609-01A1): Transitions to Family Caregiving and Its Impact on Health Indicators.

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- o **Tools and training**:
  - – (9R44AG053936-02): Tools for Coordination among Caregivers of Patients with Alzheimer's Disease and Other Dementias.
  - – (1R43AG051303-01A1): Caregiver training app to maintain independence in persons with Alzheimer's.

- o **Maintain the dignity, safety and rights of people with Alzheimer's disease**:
  - – (1R21AG052763-01): Strategies for Managing Persons with Dementia in Assisted Living.

Clinical Services

Ellen Blackwell provided an update from the Clinical Services workgroup.

The NQF Neurology Standing Committee issued a draft report for public comment that closed July 27. It evaluated 26 measures against NQF's standard evaluation criteria: nine measures were recommended for endorsement and one measure was recommended for Approval for Trial Use:

- 2111 Antipsychotic Use in Persons with Dementia (Pharmacy Quality Alliance): Recommended:
  - o **Description**: The percentage of individuals 65 years of age and older with dementia who are receiving an antipsychotic medication without evidence of a psychotic disorder or related condition. This process measure was originally endorsed in 2013 and is planned for use in accountability programs including Medicare Part D.

- 2872 Dementia-Cognitive Assessment (Physician Consortium for Performance Improvement): Recommended for Approval for Trial Use:
  - o **Description**: Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least once within a 12 month period. This new process eMeasure was reviewed for consideration in the NQF Approval for Trial Use Program. It is currently in use in the CMS Physician Quality Reporting System and Meaningful Use Stage 2.

- In May 2016, CMS published the second annual independent evaluation reports from the first round Health Care Innovation Awards.

- In May 2016, CMS held kick-off webinars with selected states and one territory (Nevada, New Hampshire, New Jersey, Puerto Rico, and Washington) as part of Medicaid's Innovation Accelerator Program on Physical-Mental Health Integration.

- In April 2016, CMS announced Comprehensive Primary Care Plus, a five-year multi-payer model that begins in January 2017 and will include more than 20,000 clinicians. The states and regions selected for the model were announced in August 2016.

- In July 2016, CMS issued proposed 2017 changes to the Physician Fee Schedule (PFS), in response to feedback received from physicians and others. There are many proposed and several relate to dementia (https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/PFS-Federal-Regulation-Notices-Items/CMS-1654-P.html). Council members are encouraged to comment. Changes include:
    - The Diabetes Prevention Program.
    - A PFS billing code set that more accurately recognizes the work of primary care and other cognitive specialties to accommodate the changing needs of Medicare beneficiaries.
    - Separate payments for certain existing Current Procedural Terminology (CPT) codes describing non-face-to-face prolonged evaluation and management services.
    - Revaluation of existing CPT codes describing face-to-face prolonged services.
    - Separate payments using new codes to describe the comprehensive assessment and care planning for beneficiaries with cognitive impairment (e.g., dementia).
    - Advance Care Planning delivered through telehealth.
    - Separate payments using new codes to pay primary care practices that use interprofessional care management resources for beneficiaries with behavioral health conditions -- some codes describe integrated services like the Collaborative Care model that involves care coordination between a behavioral health specialist and the primary care clinician.
    - Separate payments using new codes to recognize the increased resource costs of furnishing visits to beneficiaries with mobility-related impairments, relevant for Medicare-Medicaid enrollees.
    - Separate payments for codes describing Chronic Care Management for beneficiaries with greater complexity.
    - Changes to reduce administrative burden associated with furnishing/billing the Chronic Care Management codes.
    - Comment period closes September 6, 2016.

- The National Partnership to Improve Dementia Care began in 2012, and since then there has been a 28.8% reduction in the national use of antipsychotic medications among long-stay nursing home residents. In 2012, 23.9% of long-stay residents were on antipsychotic medications. By the end of 2015, the percentage dropped to 17.0%.

- Following a recommendation from the Council, HRSA developed an Alzheimer's disease and Related Dementias Curriculum that is expected to be released in

October 2016. HRSA will also be releasing a Medscape Article "*Bidirectional Impact of Alzheimer's Disease and Common Comorbid Conditions: Managing Patients*" targeting primary care providers (expected release is September 2016).

- Medicaid agencies have weekly teleconferences that feature a variety of topics. Recently, CMS and ACL led a webinar during one of these teleconferences on wandering and exit-seeking behavior. Interested parties can contact Jane Tilly for more information.

Research

Dr. Richard Hodes updated the Council on the status of the NIH Bypass Budget. He reviewed the previously described processes involved in bypass budget development, including strategic meetings, milestones creation, and budget formulation.

- Thirteen NIH institutes provided input into the bypass budget. The eight Common Alzheimer's Disease Research Ontology categories provide the framework for the FY2018 Alzheimer's Disease Bypass Budget and description.

- The baselines estimate for FY2017 for Alzheimer's disease and related dementias is estimated at $991 million dollars.

- The proposed increases for FY2018, based on an assumption of flat-level funding compared with 2017, reflect a healthy increase that is aligned with the needs and goals identified in the National Plan. The increases proposed total over $414 million and include (*Note: some numbers are rounded*):
  - Molecular Pathogenesis a Physiology of Alzheimer's Disease ($83 million).
  - Diagnosis, Assessment, and Disease Monitoring ($58.1 million).
  - Translational Research and Clinical Interventions ($118.6 million).
  - Epidemiology ($33.3 million).
  - Care and Caregiver Support ($28 million).
  - Research Resources ($50 million).
  - Alzheimer's Disease-Related Dementias ($40.2 million).
  - Staff Needs, Supports, Miscellaneous ($3.3 million).

- Several database tracking tools are available to monitor funding awards and research progress:
  - International Alzheimer's Disease Research Portfolio (http://iadrp.nia.nih.gov/).
  - https://www.nia.nih.gov/alzheimers/milestones.

- The VA just completed its most recent Merit review cycle and five awards will be funded from the 18 applications that were reviewed. The VA expanded the Request for Application to include FTD, LBD, and Vascular Contributions to Dementia.

- In July 2016, Eliezer Masliah, M.D. assumed the role of Director of NIA's Division of Neuroscience, from Acting Director Dr. Tony Phelps.

Discussion

- There was appreciation by the Council for the amount of work required to assess the needs and existing funding levels in order to propose increases for next year.

- Council members discussed the possibility of receiving the full amount of proposed funding, even if the actual FY2017 budget differs from what is anticipated. Due to the inclusion of multi-year milestones within each bypass budget, as well as indication on how milestones can be accelerated in the context of increased funding, it is expected that funding could still be received.

- With budget increases, increased staffing also may be necessary. NIA and National Institute of Neurological Disorders and Stroke are working hard to expand the workforce; resources are sufficient and the recruiting process is difficult but is proceeding appropriately.

Update on National Plan

Rohini Khillan updated the Council and public on the status of the National Plan. She also shared that the Advisory Council and ASPE team received the Secretary's Award for Meritorious Service earlier this year. Ms. Khillan also acknowledged the efforts of Kumari Devarajan, a summer intern from Wellesley College who supported ASPE and National Alzheimer's Project Act this summer. During this presentation, Ms. Khillan and other Council members shared some key updates that are included in the final National Plan.

The full set of recommendations and the federal responses, are included in the meeting materials, as well as the National Plan appendix.

- The National Plan has been cleared and is awaiting final signature. A draft version has been posted on the ASPE website, and the final official version will be distributed to Council. The Plan contains: Updated Implementation Milestones, items from members of the Council *and* other national partners, recommendations from the Advisory Council, and formal responses from federal agencies (included in an appendix).

- State-level efforts from Minnesota, New York, Oregon, and West Virginia were highlighted:
  - In Minnesota, efforts to expand dementia-capable and dementia-friendly communities has continued. Additionally, a focus on addressing cultural competence and relevance to dementia services was highlighted.

- o In New York, partners are working to expand Alzheimer's disease programming.
  - o In Oregon, ACL funding supported state-wide training for their Aging and Disability Resource Connection staff, reaching approximately 600 people. Caregiver training has also been supported by the state.
  - o In West Virginia, the Dementia-Friendly American initiative is being piloted through existing organizations and a large training is scheduled for September 2016. They are engaging legal, financial, law enforcement, and other communities to advance the initiative.

- Several new research projects were submitted for inclusion in the Plan:
  - o Translation of Care of Persons with Dementia in their Environments in a Publicly-Funded Home Care Program (funded by NIA).
  - o WeCareAdvisor^{TM} (a digital app that provides caregiver support and guidance).
  - o NAS Study on Family Caregiving for Older Adults.
  - o Hospice Referral after Inpatient Psychiatric Treatment of Individuals with Advanced Dementia from a Nursing Home.

- The World Dementia Council, which grew out of the G7 Summit, was supported by the British government until December 2015. The Council has expanded from approximately 12 members to 24 and now includes low and middle-income countries. Currently, the Council plans to meet twice annually in an attempt to influence dementia work being conducted worldwide.

- The Lewy Body Dementia Association launched the *Lewy Who?* Campaign as a cohesive awareness campaign. There is much work to be done to make LBD more widely known, but the campaign has had an impact thus far.

- The Alzheimer's Association published a Care and Support Milestones journal article, the findings of which were discussed during the January Council meeting.

- Ms. Khillan described the Council recommendations and formal federal responses, all of which are contained within an appendix to the National Plan.

Discussion

- With respect to describing progress toward milestones, actions were noted in terms of completion and with context (e.g., the description of an action and to what degree it has progressed, even if ongoing).

- In future meetings, the Council would appreciate the opportunity to review the federal responses to the recommendations so that a robust discussion can take place. Council members did not have the opportunity to review prior to this meeting, as the documents were recently finalized.

Update on Care Summit

The National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers steering committee co-chairs, Dr. Laura Gitlin and Katie Maslow, presented an update on the planning for the two-day summit.

- The goal of the summit is to accelerate the development, evaluation, translation, implementation and scaling up of strategies to improve quality of care and outcomes across settings, including quality of life and the lived experience of persons with dementia, family members, and caregivers.

- The Executive Committee members include Dr. Ronald Petersen, Dr. Linda Elam, and Ms. Rohini Khillan.

- Special attention is being paid to diversity (socioeconomic status, race/ethnicity, locations, and literacy), disparities, etiologies, and disease stages.

- Potential outcomes are still being developed and considered by the steering committee, and may include:
  - Recommendations for research priorities to inform federal agencies, foundations, and other private sector organizations.
  - Identification of evidence-based programs, strategies, and approaches that can be used now to improve care and services.
  - Research milestones to track and guide acceleration and advancement of evidence-informed care and services.

- Stakeholder groups will be led by steering committee and/or Council members to focus on caregivers, persons with dementia, service providers, and states/payors.

- Work on logistics and financial planning is underway; however, no updates are available yet.

- Dr. Elam described the role of the Federal Government in this effort. Currently, a quasi-logistics contract is in development to determine what resources need to be developed in advance and help organize the planning meetings and materials. ASPE has written a scope for a potential contract and the draft scope has been moved forward. ASPE is pleased to have the opportunity to support the summit and advance efforts to secure logistics components.

- Pre-summit activities have been proposed to promote alignment of summit participants and ensure that the actual summit is as up-to-date and efficient as possible. Pre-summit activity criteria include:
  - Activity should be "naturally occurring" and have their own funding source(s).

- o Activity should focus on topic of high relevance to Research Summit.
- o Activity will contribute a research report or publication to serve as background materials for the Research Summit.
- o Activity will potentially contribute to or inform a panel or nominate speakers for the Research Summit on topic covered.
- o Activity will generate recommendations, guidelines for future research addressing care and services.

- One approved pre-summit activity was the July 2016 Alzheimer's Association International Conference Featured Research Symposium focused on accelerating development, testing and dissemination of home-based dementia care interventions.
  - o Chairs: Constantine G. Lyketsos, MD, MHS, Johns Hopkins Medicine; Diane Bovenkamp, Brightfocus Foundation.
  - o Dr. Gitlin -- Status of the field: clinical trials evaluating home based dementia care.
  - o Dr. Samus -- Clinical trial example: "Maximizing Independence at Home" for people with dementia: design, outcomes, and future directions.
  - o Dr. Kales -- Clinical trial example: "WeCare Advisor" a clinical trial of a caregiver focused, iPad administered algorithm to manage behavioral symptoms.
  - o Dr. Callahan -- Dissemination science: Addressing challenges to the widespread use of evidence-based, home dementia care.
  - o A final report will include recommendations for the Summit concerning home-based dementia care interventions and ways to assure acceleration of proven approaches.

- Additional ideas for pre-summit activities include: epidemiology and demographics for persons with dementia and family and other caregivers (Patient Centered Outcomes Research Institute-led effort), methodological challenges including pipeline for interventions, next generation of interventions, international research/activities concerning care and services, and the role of technology.

- The structure of the summit is still being discussed; however, Ms. Maslow shared a preliminary overview with the Council. The current plan is to host the summit in the fall of 2017, over two full days, and spanning six main sessions. Draft main summit sessions include:
  - o **Family caregiving** (e.g., what we know and what we need to know to provide effective care and services).
  - o **Persons with dementia** (e.g., what we know and what we need to know to provide effective care and services).
  - o **Implementation and scaling up** (e.g., needed research on translation and scaling of effective care and services).
  - o **Research methodology** (e.g., measurement issues and approaches for involving persons with dementia and family caregivers in research;

measurement of quality of life, outcomes; pragmatic trial and other adaptive designs for rapid research).
- o **Technology to provide/support care and services** (e.g., use of technologies for service delivery, monitoring).
- o **Setting-specific care delivery issues** (e.g., home and community services, including care coordination; residential care, including assisted living and nursing home).

- The summit steering committee meets every six weeks, and the co-chairs meet weekly with each and periodically with ASPE. Currently, pre-summit activities are being planned, stakeholder groups of persons with dementia and caregivers are currently being organized, and ways to obtain input from other stakeholder groups (service providers, payors, and states) are being considered.

Discussion

- The focus on caregivers is inclusive of paid and unpaid caregivers.

- The service provider stakeholder group could be populated from some organizations that helped create the Alzheimer's Association practice recommendations several years ago.

Update on Alzheimer's Association International Conference

Harry Johns shared his perspectives on the conference, which was held in Toronto, Canada in July 2016.

- Approximately 5,200 people, primarily researchers, from around the world were present at the meeting, where "resilience" was a primary area of focus. Many young researchers were present and there was a fair degree of media coverage. There were numerous ancillary meetings that hosted large numbers of people and reflected the strong interest from the field.

- While there were no "blockbuster" research findings presented, many important findings and developments were shared by meeting participants.

- A plenary session on traumatic brain injury, genomics, the growing body of evidence in support of exercise as a useful prevention and treatment tool for dementia.

Discussion

- The research on underlying dementia pathology tends to focus on amyloid and tau proteins versus other mechanisms. During this conference, there was a mix of topics -- the overall balance with respect to a specific etiology was not clear.

Tau did receive greater attention than in previous years, in part, due to a newly available Tau imaging approach.

- The caregiver track was integrated into the meeting this year, while previous years it was somewhat separate. This change was noticed and appreciated and will help to promote a focus on the importance of caregiver research.

International Work Update

Dr. Petersen shared highlights of Alzheimer's disease and related dementia developments outside of the United States.

- The World Health Organization (WHO) is developing a Global Dementia Observatory that will observe member states on the "State of the State" of dementia. During a meeting in Tunisia in July 2016 in which Dr. Petersen participated, pilot data (e.g., dementia care, research, terminology) from 22 member states were reviewed and discussed. The WHO will engage the remaining member countries and assess their data in an attempt to create a worldwide inventory of dementia.

Concluding Remarks

Chair Dr. Ronald Petersen thanked all participants for their attendance and discussion.

The next Advisory Council meeting will take place on October 31, 2016, in Washington, D.C.

The meeting adjourned at 3:41p.m.

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