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

Virtual Meeting

November 9-10, 2020

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Katie Brandt (Co-Chair), Allan Levey (Co-Chair), Venoreen Browne-Boatswain, Cynthia Carlsson, Debra Cherry, Robert Egge, Bradley Hyman, Matthew Janicki, Becky Kurtz, Carrie Molke, Maria de los Angeles Ordonez

- *Federal Members Present*: Kim Wittenberg (Agency for Healthcare Research and Quality, AHRQ), Ellen Blackwell (Centers for Medicare & Medicaid Services, CMS), Susan Cooley (Department of Veterans Affairs, VA), Bruce Finke (Indian Health Services, IHS), Richard Hodes (National Institutes of Health, NIH), Shari Ling (CMS), Erin Long (Administration on Community Living, ACL), Lisa McGuire (Centers for Disease Control and Prevention, CDC), Deborah Olster (National Science Foundation, NSF), Arne Owens (Office of the Assistant Secretary for Planning and Evaluation, ASPE), Anthony Pacifico (Department of Defense, DoD), Joan Weiss (Health Resources and Services Administration, HRSA)

- *Advisory Council Designated Federal Officer*: Helen Lamont (ASPE)

DAY 1: November 9, 2020

General Proceedings

On November 9, Co-Chair Katie Brandt called the meeting to order at 1:02 p.m.

Charge for Meeting

Co-Chair Allan Levey noted that the Coronavirus 2019 (COVID-19) pandemic has been especially stressful for patients with Alzheimer's disease and related dementias (AD/ADRD), and their families and caregivers. COVID-19 has increased patients' decline and mortality. However, increased use of telemedicine has increased providers' reach, reduced burden of transportation to care, and supported connectivity for those who have access.

Healthy Brain Initiative and Building Our Largest Dementia (BOLD) Infrastructure Act Updates

Lisa McGuire, PhD, Centers for Disease Control and Prevention

Dr. McGuire presented updates on the CDC National Center for Chronic Disease Prevention and Health Promotion's Healthy Brain and BOLD Initiatives. The Healthy Brain Initiative aims to integrate brain health into public health practice. BOLD's purpose is to create a strong public health infrastructure to support patients with dementia and their caregivers. The Healthy Brain Initiative offers funding for organizations with national scope to develop priorities and strategies, and for organizations that serve populations disproportionately affected by dementia to tailor and disseminate national messages and strategies for their clients.

BOLD grants support development public health infrastructure. BOLD supports a Center of Excellence in each of the following areas: dementia caregiving, dementia risk reduction, and early detection of dementia. The program prioritizes early detection and diagnosis, preventable hospitalizations, care planning and management, and support for caregivers, with emphasis on health disparities, rural communities, and high burden populations.

Discussion. Council members expressed appreciation for the BOLD initiative and interest in hearing grantees' accomplishments at future meetings.

Telehealth in Long-Term Care

Cari Levy MD, PhD, University of Colorado Denver, School of Medicine, Division of Health Care Policy and Research / Rocky Mountain Regional Veterans Affairs Medical Center

Dr. Levy discussed the use of telemedicine in long-term care. Telehealth can support provider training, administrative meetings, continuing medical education, and clinical services. Telemedicine is a subset of telehealth that specifically involves providing remote clinical services. Senior living communities commonly use telehealth for routine primary care, emergent health issues, mental or behavioral health care, physical therapy, speech therapy, and occupational therapy.

The VA's Video Connect program provides telemedicine infrastructure, facilitating approximately 10,000 video appointments per week as of February 2020, and 120,000 video appointments per week as of May 2020. The program distributes cellular-enabled tablets, with no charges for data usage, to veterans who do not have access to the Internet. Since COVID-19, Medicare has reimbursed telemedicine services for visits originating from patients' homes, nursing homes, and family members' homes, allowing use for emergency department visits, initial and discharge visits to nursing facilities, home visits, and therapy services. Interstate telehealth practice has expanded since the pandemic's start. More than 40 states now allow citizens to receive services from out-of-state providers who use interactive audio and visual telecommunication systems.

Facility occupancy has decreased during the pandemic. Providers can bill for telehealth services, which helps them to remain financially solvent. It is important to educate patients, families, and providers about what to expect and how to conduct a telemedicine visit. Technical difficulties are frustrating for patients, families, and providers, and can discourage patients from scheduling additional telemedicine visits. Providers must ensure patients have privacy and the necessary equipment to participate in a telemedicine visit. Providers must implement a plan for sharing information about telemedicine visits to frontline staff.

VetConnect supports veterans in VA-contracted community nursing homes in connecting to telemedicine services, including specialized care and saves approximately $150 per visit. Virtual Tours offers tours of nursing homes to veterans waiting to be discharged from the hospital to a nursing home.

COVID-19: The Use of Telemedicine in Nursing Homes During the Pandemic

Steven Handler, MD, PhD, CMD, GRECC VA Pittsburgh Healthcare System / University of Pittsburgh

Dr. Handler said the VA is participating in the Life-Sustaining Treatment Decision Initiative, a national quality improvement initiative to promote personalized, proactive, patient-centered care for veterans with serious illnesses. The initiative aims to ensure veterans’ values, goals, and life-sustaining treatment decisions are elicited, documented, and honored. Provider teams conduct interviews, review progress notes, and document in electronic medical records to determine goals of care and to ensure that providers deliver care concordant with goals established by patients with their families and those with health care power of attorney. Telemedicine can support the process.

Telemedicine can support triage before patients arrive at the emergency department, reducing risk of spreading infectious diseases such as COVID-19 and improving workflow. Forward triage expands practice of nurses and paraprofessionals to patient assessment. It allows alternate care destinations and provides clinical guidance for emergency management and notification to the receiving facility. Nurses conduct home visits to patients with COVID-19 symptoms within 2 hours of the patient contacting the call center. During the visit, the nurse collects a specimen, assesses the patient and leaves a kit to support symptom management and rehabilitation.

The VA currently is implementing post-COVID telerehabilitation, comprising home safety evaluations and home environment assessments, treatment planning, and training to use in-home rehabilitation equipment provided by a visiting nurse. The VA also is facilitating use of telemedicine for specialized health care services for nursing home residents to reduce necessity of quarantine following leaving the nursing home as well as to reduce transportation costs. A VA study is assessing feasibility of applying tablet technology for telemedicine. Researchers screen veterans for cognitive and functional impairment, and assess potential benefits of offering tablets to provide telehealth, cognitive and/or communication support, or to facilitate social/recreational participation.

Discussion. Dr. Levey asked how telemedicine should be sustained after COVID-19 is under control. Dr. Handler said telehealth allows providers to deliver much of health care where patients reside, which should continue. Dr. Levy added that telehealth supports expanding provider networks and helps to address the geriatric workforce shortage. Recording visits can serve as teaching tools. Ms. Brandt said it is important to consider how best to protect veterans' privacy during telemedicine visits from community living environments. Dr. Handler said both the provider and patient settings should be considered clinical settings.

A Team-Based Intervention for Distress Behaviors in Dementia: Lessons Learned in VA Community Living Centers

Kim Curyto, PhD, Western New York VA Healthcare System, Center for Integrated Healthcare
Michelle Karel, PhD, ABPP, VA Office of Mental Halth and Suicide Prevention
Dr. Curyto and Dr. Karel described Staff Training in Assisted Living Residences (STAR-VA), an interdisciplinary, team-based approach to help care teams understand and manage challenging behaviors among residents with dementia. A mental health professional and a registered nurse lead each team in implementing core components: realistic expectations, effective communication, basic behavioral problem solving, and facilitating pleasant events. An evaluation study demonstrated that STAR participants decreased prescriptions of antipsychotic and benzodiazepine medications for agitation and anxiety significantly more than comparison group participants. The intervention also resulted in significantly greater reduction in staff injuries than comparison facilities. Distress behaviors decreased, but not more among for intervention than comparison group participants. This may be due to comparison facility staff underreporting distress behaviors. Team support, communication, and organization culture, especially leadership support, are key factors affecting sustainability.

Discussion. Dr. Carlsson said these evaluation results show the importance of community living center staff feeling confident in their ability to manage residents' behaviors without medication, and the importance of training the workforce in this area. Dr. Lamont asked whether nursing homes outside the VA have implemented STAR. Dr. Curyto said STAR originally was designed and implemented in community living centers, then adapted for the VA. Key components of STAR are promoting curiosity regarding the reasons for behaviors rather than assuming the behavior should be stopped, often with medication, as well as collaborative problem solving. Sarah Lenz Lock of AARP asked whether there is evidence that STAR-VA affects staff retention. Dr. Curyto said there is some anecdotal evidence that this is the case and the research team plans to assess this in the future.

VA Caregiver Support Program Interventions for Caregivers: REACH VA Dementia

Jennifer Martindale-Adams, EdD
Linda O. Nichols, PhD
VA Caregiver Center Memphis / University of Tennessee Health Science Center, Department of Preventive Medicine

Dr. Martindale-Adams described the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program, which helps caregivers manage patients' behaviors and their own stress. The program comprises individual and group training sessions about the nature of dementia, safety issues, caregiver health and emotional well-being, and behavioral management. Trained VA clinical staff teach problem-solving skills, stress management, and cognitive reframing strategies. VA Caregiver Centers deliver the REACH VA program to caregivers across the United States, train VA staff to deliver REACH VA services, evaluate the program, and continually develop and implement targeted interventions for caregivers. Evaluation studies have demonstrated that REACH reduces caregiver burden, anxiety, depression, frustration, and safety concerns, and also reduces patients' undesirable behaviors.

REACH Hope serves caregivers of veterans who have dementia and a history of traumatic brain injury. The program offers REACH services with a mobile app called "Virtual Hope Box," which includes photos, videos, and recorded messages to remind users how to do things; entertaining cognitive games to ease anxiety; inspirational quotes; relaxation exercises; and coping skill exercises. The App also stores support contact information.

Dr. Nichols described the VA's Annie Caregiver Text program, an expansion of REACH. Annie provides caregivers who have VA electronic health records with texts about self-care via their cell phones. The initial text protocol targeted stress. A bereavement protocol is available to caregivers who lose their loved ones. Annie sends texts with information about COVID-19 precautions. The VA currently is pilot testing Annie to provide daily texts to provide information about dementia, stress, and behavior management for caregivers of people who have dementia. Each text provides a link to additional information.

Updates

Legislative Update

Robert Egge, Alzheimer's Association

Mr. Egge reported that Congress remains strongly committed to addressing AD/ADRD. The House of Representatives recommended modestly increased research funding, doubled BOLD funding, maintained funding for ACL programs, and appropriated $5 million for IHS dementia programs. A continuing resolution will expire in early December. There seems to be bipartisan support for addressing this issue rapidly. The

Younger Onset Alzheimer's Disease Act was reauthorized in March. The RAISE Family Caregivers Act was extended for 1 year. The Geriatrics Workforce Improvement Act reauthorized the Geriatric Workforce Enhancement and Geriatric Career Awards programs. Pending high-priority bills include the Lifespan Respite Care Reauthorization Act, Improving Hope for Alzheimer's Act, Preventing Elder Abuse Act, Concentrated and High-Value Alzheimer's Needs to Get to and End (CHANGE) Act, and the Stop the Wait Act to phase out the 2-year wait for Medicare eligibility for Social Security Disability Insurance beneficiaries.

Discussion. Dr. Janicki noted that President-elect Biden has said he will prioritize addressing AD/ADRD and asked whether the President-elect has provided any details regarding his positions. Mr. Egge said the President-elect expressed support for biomedical research and care and support services during meetings conducted while he was a presidential candidate, and appears likely to support Council priorities and to appoint staff who support these priorities as well.

Coronavirus Commission on Safety and Quality in Nursing Homes

Shari Ling, MD, Centers for Medicare & Medicaid Services, Center for Clinical Standards and Quality

Dr. Ling said that COVID-19 has revealed needs for health care quality improvement. Residents of congregate living facilities such as nursing homes as well as their families and staff are especially vulnerable to the virus. CMS appointed the Commission to make recommendations for CMS-operated nursing homes regarding preventing and controlling COVID-19. The Commission recommends collaboration between federal and state agencies and the private sector to support screening and testing capabilities, increase personal protective equipment supplies and utilization, revise cohorting practices, prioritize and manage visitation, provide guidance on communication with residents and families, strengthen the workforce ecosystem, support technical assistance and quality improvement, enhance facility design, and make data more actionable. CMS has established an online Nursing Home Resource Center, which provides the most recent information about federal guidance and resources, including the Commission's report.

Discussion. Dr. Levey asked whether the Commission had estimated the costs of implementing its recommendations. Dr. Ling said it had not. The CARES Act does provide funds for testing. However, the Commission's recommendations focus on factors that affect vulnerability to the virus.

Public Comments

- Sarah Lenz Lock of AARP and the Global Council on Brain Health invited meeting participants to visit the organization's website, which offers resources for support during COVID-19 as well as resources to support brain health. She invited participants to consider collaboration with the Global Council's prevention and care improvement efforts.

- Kristen Lees Haggerty of Education Development Center said she and co-authors Gary Epstein-Lubow and David Reuben have published an article titled, “Recommendations to improve payment policies for comprehensive dementia care” in the *Journal of the American Geriatric Society*. The article offers recommendations for improving access to comprehensive dementia care through payment reform, research, education, and a population health approach to coverage based on risk and need. The article presents six models of dementia care delivery that improve care quality and clinical outcomes without increasing costs. These models are not yet widely available. HHS should advance payment reform by continuing to examine models of dementia care, including how COVID-19 has affected best practice implementation; convene or invite at least one workgroup to address payment reform for comprehensive dementia care; and monitor and document data on how including dementia as a risk adjustment modifier in CMS hierarchical condition category coding affects definitions of populations living with dementia, the quality and types of care they receive, and their health outcomes.

- Irene Hamrick of Cincinnati VA Medical Center submitted written comments saying that primary care teams should be knowledgeable about dementia and prepared to develop care plans, and that primary care physicians should be able to conduct cognitive screens when they believe it is appropriate to do so.

- Seth Keller, neurologist and co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices, said providers do not receive adequate training to address the needs of adults with intellectual and developmental disabilities as they experience age-related decline. This population is affected by high rates of co-morbidities, family caregivers’ aging, high turnover rates of professional caregivers, poor reimbursement practices, and lack of care guidelines. This population needs appropriate assessment and diagnostics, appropriate reimbursement practices, tertiary dementia care, care providers trained to address their needs, healthy aging services, and community-based support services, but these needs are not adequately met. The Federal Government should fund efforts to meet these needs.

Adjournment

Dr. Levey adjourned the meeting at 4:02 p.m.

DAY 2: November 10, 2020

General Proceedings

Dr. Levey convened the meeting at 1:02 p.m.

Charge for Meeting

Ms. Brandt said that Day 2 of the meeting would focus on long-term services and support (LTSS). She said COVID-19 necessitates physical separation between residents of nursing homes and their families, which is emotionally challenging. Frontline caregivers offer critical emotional support for patients during this time.

Expanding Access to LTSS for People Living with AD/ADRD and their Caregivers

Debra Cherry, PhD, Alzheimer's Los Angeles

Dr. Cherry said people with AD/ADRD need affordable, high-quality LTSS. Service needs range from supports to retaining autonomy for patients with mild cognitive impairment, such as transportation services, to residential skilled nursing facilities. Intermediate services include in-home personal care and assistance with errands, and community day care programs. LTSS availability, cost, and quality vary greatly. About 80% of people with AD/ADRD live at home with informal caregivers, without whose support living at home would not be safe. Informal caregivers generally receive little training, compensation, or recognition. Ideally, health care providers should identify caregivers and assess their needs for services and supports, then engage in person and family-centered care planning, provide culturally competent education and support at the appropriate literacy level, and connect the caregiver to appropriate community-based resources. Major barriers to accessing LTSS are inadequate workforce training and compensation, inadequate service availability and quality, and affordability. Public programs are not available to most middle-class families, and private services are often expensive. Available services often are not culturally or linguistically appropriate, or are not at the appropriate literacy level. Lack of access to technology is often a barrier to care. Medicare does not cover long-term care. Medicaid covers care for people at or near poverty. Most middle-class families cannot afford long-term care insurance. As the population ages and the availability of informal caregivers decreases, reliance on informal caregivers for LTSS may not be sustainable. There is a movement to shift Medicaid spending on LTSS from institutional care to home and community-based care.

Learning from the Past to Inform Future Recommendations

Lived Experience

Venoreen Browne-Boatswain

Ms. Browne-Boatswain discussed her experience as a caregiver for her husband who had frontotemporal dementia. At the time he was diagnosed at age 53, Ms. Browne-Boatswain did not know what the disease was and could not accept that it was possible for a person who was so young. She joined a support group, which helped her to understand the gravity of the diagnosis and financial implications. Most services are targeted for people of retirement age, not adults in their 50s. Her husband had the disease for 6 years before he qualified for government support. When he did qualify for financial support, none was available for his family. Ms. Browne-Boatswain was forced to withdraw from her retirement account and pay a tax penalty for early withdrawal. It was difficult to learn which resources were available. Health care providers should be prepared to refer caregivers to appropriate services, which should be easier to access. Services should be available to younger families affected by AD/ADRD.

Past Efforts to Expand Access to LTSS

Gretchen Alkema, PhD, SCAN Foundation

Dr. Alkema said most milestones in United States policy relevant to aging have focused on income security and health, not LTSS. The American Taxpayer Relief Act of 2012 authorized the Commission on Long-Term Care to create a plan to establish, implement, and finance a comprehensive, coordinated, high-quality LTSS system with availability ensured for older adults, people with substantial cognitive or functional limitations, people requiring assistance with activities of daily living, and people planning to address future needs. The Commission estimates more than 12 million Americans need LTSS. Nearly half of people who need services are younger than 65 years old. Most of them live at home, and most are assisted by family caregivers. Most retirees are not adequately prepared for the cost of LTSS. The Commission calls for an increase in workforce capacity and compensation, and improved workforce training and care delivery.

LTSS is often difficult to access and lacks coordination. As the population ages, need for LTSS will increase, straining federal and state budgets. The number of Americans who need long-term care will more than double from 2010 (about 12 million) and 2050 (about 27 million). Strategies for meeting LTSS need include care integration, using technology, innovative workforce strategies such as changing scope of practice, and creative financing solutions. In addition, the United States needs a more accessible and sustainable safety net. The Commission’s vision for a future LTSS system includes service delivery that is person and family-centered, outcomes-focused, integrates medical and non-medical services, and is financially sustainable. The Commission advises balancing public and private financing, and protecting against catastrophic costs. It advises adequately preparing and supporting the LTSS workforce.

The Commission recommends incentivizing states to balance home and community-based care with institutional care, integrating care delivery, and implementing a standardized assessment tool to support care plan development. Access should have “no wrong doors.” The field should develop LTSS quality measures. Payment should be based on services rather than setting. Medicaid should be more uniform across states and should support LTSS that help people with disabilities to remain employed. Medicare should eliminate the requirement to stay in a hospital for at least 3 days prior to staying in a skilled nursing facility and should reconsider the requirement that people be homebound in order to receive home health care. People should be able to establish Section 529 savings funds for LTSS.

States are the primary sources of LTSS delivery and financing. AARP, the Commonwealth Fund, and the Scan Foundation collaborate to issue state LTSS scorecards. Scorecards assess affordability and access, choice of provider and setting, quality of life and care, family caregiver support, and care transitions. States have made some improvement since 2017, but long-term care insurance policy enrollment has declined significantly, and significant unmet need for affordable, accessible housing continues.

Discussion. Ms. Kurtz said most states do not have a “no wrong door” policy for nursing home admissions and asked how this could change. Dr. Alkema said caregiver support organizations can help people to consider care options. Medicare Advantage care coordinators can help to identify complex care needs and functional limitations and help members to address social determinants of health. Ms. Brandt said it is critical for caregivers to be aware of what LTSS are available.

Ellen Blackwell asked how COVID-19 is likely to affect LTSS over the long term. Dr. Alkema said federal and state regulatory flexibilities have potential to transform care, especially those increasing access of virtual care. The emergency has inspired creativity regarding care access and has shown that older people are able to use digital technology.

Effective Administration for Community Living-Funded Models for Increasing Access to Home and Community-Based Services for Ethnically Diverse People Living with AD/ADRD and Caregivers

Maria Ordonez, DNP, Administration for Community Living
Dr. Ordonez said that ACL funds many AD/ADRD programs that offer culturally tailored services in diverse communities across the United States.

Tete-a-Tete: A Faith-based Memory Café

Madeline Michel, DNP, Florida Atlantic University, Louis and Anne Green Memory and Wellness Center
Dr. Michel described the Tete-a-Tete program, which is tailored for Haitian Creole people living with dementia and their caregivers. The program works in partnership with a church. Program staff conduct home visits to assess dementia and family needs. The program offers education about dementia and how to manage it, exercise classes, and support group sessions. Trust development is a core goal, partly due to the stigma associated with dementia in this community. Program staff have established social connections with community members and connected them with services. More than 95% of participants have reported that the program has improved their quality of life, increased their knowledge about ADRD and related topics, and improved their social support.

Promotoras Program for a Better Quality of Life.

Constantina Mizis, Latino Alzheimer's and Memory Disorders Alliance

Ms. Mizis reported that the number of Latinx Americans with AD/ADRD is expected to increase between 2012 and 2060 from 379,000 to 1.1 million. Lower education and income levels increase likelihood that Latinx people will delay treatment and receive inadequate care. Promotoras are trusted bilingual community members who are familiar with community organizations and who are skilled communicators. They can serve as patient advocates, educators, outreach workers, and translators. Promotoras can raise community awareness of AD/ADRD and serve as liaisons between health care and community service providers. The Promotoras program aimed to increase access to high-quality bilingual dementia support services in Cook County, Illinois, and to increase the number of AD/ADRD programs targeted to serve Latinx communities. Promotoras informed people about a program that offered memory screenings, education, and physician referrals. Promotoras provided educational sessions about resources and symptom management for Latinx caregivers. In addition, promotoras shared awareness information through traditional and social media. Target audiences included people living with AD/ADRD and people who live alone. Evaluation results demonstrate that the program has increased participants' knowledge about risk factors for developing dementia, disease management skills among caregivers and people living alone with dementia, and cultural competence and linguistic appropriateness of services for caregivers. Program developers recommend expanding the program nationally with the support of partners.

Panel Discussion: Current Status of States and Plans for the Future

Carrie Molke (facilitator), Mark Cohen, PhD, Kitty Purrington, Martha Roherty, Jennifer Rosen

Learning from New State Initiatives in Financing LTSS

Dr. Cohen described his study of six States' efforts to initiate LTSS financing reform with the aim of financing services without Medicaid support. Participating States were in varying stages of success ranging from passing legislation to building coalitions. Reform aims to control Medicaid expenditures, move from a welfare to a social insurance basis, and provide protection against medical bankruptcy. These goals have bipartisan appeal. Common obstacles to reform include costs, securing legislative support, and disagreement with the reform coalition. Study results show the importance of a broad stakeholder coalition with formalized processes and structures, and of identifying legislative champions. Results show that reform takes time and that actuarial data and studies are critical for education about the nature and scope of the problem. It is important for advocates to apply a policy framework and establish linkages between stakeholders and policy makers. COVID-19 is straining state finances and capacity, and has increased burden on families and caregivers, providing impetus for financial reform.

Discussion. Ms. Roherty said fear of aging is preventing Americans from discussing it or planning for it, which makes system change difficult. Ms. Rosen said some legislators will not discuss any Medicaid expansion, which is a major barrier to finance reform. She said states are more likely to make a policy change after another state has succeeded, so Washington's success is important.

Ms. Purrington said COVID-19 has decimated state tax revenues, providing an opportunity to prioritize finance reform and demonstrate the value of social insurance. Ms. Roherty said one-third of adult day care programs have closed, though they are a critical support for caregivers with jobs outside the home.

Ms. Molke asked whether panelists knew of promising programs and practices. Ms. Rosen said that Missouri passed legislation to create a structured family caregiver program to improve access to home and community-based services and provide reimbursement for family caregiving tasks. Ms. Purrington said state waivers offer flexibility and nurture innovation. States offer programs that support and educate family caregivers, sometimes specifically caregivers of people with AD/ADRD. In response to regulatory flexibilities for COVID-19, states are paying family caregivers to deliver care. Ms. Roherty said forming broad coalitions of stakeholders is critical for implementing strategic plans on aging. Ms. Molke said Wisconsin's Dementia Care Specialist Program offers evidence-based programs for caregivers of people with dementia and is currently being tailored for specific diverse race/ethnic communities. All panel members emphasized the importance of engaging consumers in coalitions.

Dr. Alkema asked Ms. Purrington how the field can benefit from lessons learned while states apply regulatory flexibility during the pandemic. Ms. Purrington said data such as Medicaid utilization information, Healthcare Effectiveness Data and Information Set quality measures, and consumer satisfaction surveys can provide information about effects of regulatory flexibility on care utilization and quality. Ms. Roherty said analysts should assess which options for flexibility states did and did not employ, and why.

Future Directions for LTSS

Gretchen Alkema, PhD, SCAN Foundation

Dr. Alkema said the Scan Foundation conducted a poll about aging and family caregiving during COVID-19. Results showed that Americans' most common concerns about growing older were loss of independence, loss of memory and other cognitive abilities, care costs, having to move to a nursing home, being a burden on family, not planning adequately to get needed care, being alone, and leaving debt to family. Most Americans aged 65 years and older (52%) need support for at least two activities of daily living. Dr. Alkema made recommendations to consider in national agenda development: (1) Appoint a White House leader on aging to ensure AD/ADRD is a priority at the highest levels; (2) Every governor should develop a master plan for aging that emphasizes relevance of aging and AD/ADRD in all areas of state and local policy; (3) Communities should build dementia-friendly infrastructure to link families with services; (4) Policy makers should promote person-centered, value-based care delivery and payment, which can include leveraging regulatory flexibilities implemented to address COVID-19, accelerating Medicaid and Medicare integration, expanding supplemental benefits, and expanding virtual care; and (5) Policies should focus on employment security for family caregivers, and retirement security for all caregivers.

Concluding Remarks

Dr. Lamont said the Council's next meeting will be held in January and will focus on research. She adjourned the meeting at 4 p.m.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.