Alzheimer's Disease: Prevention, Treatment, Support, and Public Engagement

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Introduction

National Alzheimer's Project Act

On January 4, 2011, the National Alzheimer's Project Act (NAPA) (Public Law 111-375) was signed into law. The Act defines "Alzheimer's" as Alzheimer's disease and related dementias (AD/ADRD) and requires the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- Create and maintain an integrated National Plan to overcome Alzheimer's disease;
- Coordinate Alzheimer's disease research and services across all federal agencies;
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease;
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease.
- Decrease disparities in Alzheimer's disease for ethnic and racial minority populations that are at higher risk for Alzheimer's disease; and,
- Coordinate with international bodies to fight Alzheimer's disease globally.

The law also establishes the Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) and requires the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain a National Plan to overcome AD/ADRD.

NAPA offers a historic opportunity to address the many challenges facing people with AD/ADRD and their families. Given the great demographic shifts that will occur over the next 30 years, including the doubling of the population of older adults, the success of this effort is of great importance to people with AD/ADRD and their family members, caregivers, public policy makers, and health and social service providers.

Alzheimer's Disease and Related Dementias

Alzheimer's disease (AD) is an irreversible, progressive brain disease that affects as many as 5.3 million Americans.[1] It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living (ADLs) and self-care).[2] In 1906, Dr. Alois Alzheimer first documented the disease when he identified changes in the brain tissue of a woman who had memory loss, language problems, and unpredictable behavior. Her brain tissue included abnormal clumps (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main pathological features of AD.[3] However, other pathologic features occur commonly in the brain of older Americans diagnosed with AD and these are thought to also contribute to the burden of dementia in the United States.[4,5]

In addition to AD, this National Plan addresses Alzheimer's Disease-Related Dementias (ADRD) consistent with the approach Congress used in NAPA. ADRD include frontotemporal dementia (FTD), Lewy body dementia (LBD), vascular cognitive impairment/dementia, and mixed dementias -- especially Alzheimer's mixed with cerebrovascular disease or Lewy bodies. It is often difficult to distinguish between AD and ADRDs in terms of clinical presentation and diagnosis. Some of the basic neurodegenerative processes have common pathways. People with these forms of dementia and their families and caregivers face similar challenges in finding appropriate and necessary medical care and community-based services. As such, many of the actions described in this plan are designed to address these conditions collectively.

The first symptom of AD, and sometimes ADRD, is often memory impairment. However, in ADRD, poor attention and executive function, behavioral disorders, visual disturbances, sleep disruption or motor

symptoms can often be the presenting symptoms. As the disease progresses, memory can decline, and other functions like language skills and decision making become more difficult. Personality and behavior changes often occur. Over time, a person with the disease may no longer recognize family and friends. Eventually, persons who survive with AD/ADRD are completely reliant on others for assistance with even the most basic ADLs, such as eating.[6,7]

In more than 90% of people with AD/ADRD, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of AD/ADRD are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors.[6] The importance of any one of these factors in increasing or decreasing the risk of developing AD/ADRD may differ from person to person. In rare cases, known as early or younger-onset dementia, people develop symptoms in their 30s, 40s, or 50s. A significant number of people with Down syndrome develop dementia in their 50s, often placing increased burden on their families and caregivers.

AD/ADRD is a major public health issue and will increasingly affect the health and well-being of the population. Unless the diseases can be effectively treated or prevented, the number of Americans with AD/ADRD will increase significantly in the next two decades. The Bureau of the Census estimates that the number of people age 65 and older in the United States will almost double, to 88 million by 2050. The prevalence of people with AD/ADRD doubles for every 5-year interval beyond age 65. Without a preventive treatment or cure, the significant growth in the population over age 85 that is estimated to occur between 2015 and 2050 (from 6.3 million to 19 million) suggests a substantial increase in the number of people with AD/ADRD.

Significant emotional, physical, and financial stress is placed on individuals with AD/ADRD and their family members. Unpaid caregivers, such as family members and friends, provide the majority of care for people with AD/ADRD in the community. Unpaid caregivers often do not identify themselves as such; they may be a wife, daughter, husband, parent, son, or friend helping a person whom they care about. However, the intensive support required for a person with AD/ADRD can negatively impact the caregiver's emotional and physical health and well-being, and their ability to work. Unpaid caregivers often report symptoms of depression and anxiety, and they have poorer health outcomes than their peers who do not provide such care.[7]

Dementia care costs are significant and often a burden to families and others providing unpaid care. Recent estimates from one nationally representative study found that paid and unpaid care costs for people older than age 70 with dementia in the United States in 2010 were between $159 billion and $215 billion. These figures include direct medical expenditures, costs for long-term services and supports (LTSS) including institutional and home and community-based services (HCBS), and two different estimates of the value of unpaid care provided by family members and friends. These costs could rise dramatically with the increase in the numbers of older adults in coming decades. Care costs per person with dementia in 2010 ranged from $75,000 to $83,000 depending on how unpaid care costs were estimated.[8] These national dementia care costs are comparable to, if not greater than, those for heart disease and cancer.[9]

Caring for people with the disease also strains health and long-term care systems. Individuals with AD/ADRD use a disproportionate amount of health care resources; for instance, they are hospitalized 2-3 times as often as people of the same age who do not have the disease.[10] Similarly, estimates from national data show that nearly seven out of ten residents in assisted living residences have some form of cognitive impairment.[11] As the number of people with AD/ADRD grows over the next three decades, these diseases will place a major strain on these care systems as well as on Medicare and Medicaid, the major funders of institutional, clinical care, and HCBS. Although Medicaid, a program for eligible low income Americans, covers long-term care such as nursing home care and HCBS, Medicare does not. Most Americans underestimate the risk of disability and the need for long-term care. More than half of older adults turning 65 today will develop a disability such as AD/ADRD serious enough to require LTSS, although most will need assistance for less than 2 years. About one in seven will have a disability for more than 5 years. On average, an American turning 65 today will incur $138,000 in future LTSS costs.

Families will pay about half of the costs themselves out-of-pocket, with the rest covered by current public programs and private insurance.[12]

The Challenges

The National Plan was designed to address the major challenges presented by AD/ADRD:

1. While research on AD/ADRD has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the diseases.

2. While HHS and other groups have taken steps to develop quality measures to assess dementia care and to improve the training of the health and long-term care workforce -- for both paid and unpaid caregivers -- there is room for improvement.

3. Family members and other unpaid caregivers, who take on the responsibility of caring for a loved one with AD/ADRD, also need services and supports. The majority of people with AD/ADRD live in the community, where their families provide most of their care. The toll of caregiving can have major implications for caregivers and families as well as population health, with about one-third of caregivers reporting symptoms of depression.[11,13]

4. Stigmas and misconceptions associated with AD/ADRD are widespread and profoundly impact the care provided to and the isolation felt by people with AD/ADRD and their families and caregivers.

5. Public and private sector progress is significant but should be coordinated and tracked. In addition, data to track the incidence, prevalence, trajectory, and costs of AD/ADRD are limited.

Framework and Guiding Principles

The enactment of NAPA provided an opportunity to focus the Nation's attention on the challenges of AD/ADRD. In consultation with stakeholders both inside and outside of the Federal Government, this National Plan represents the blueprint for achieving the vision of a nation free of AD/ADRD.

Central to and guiding the National Plan are the people most intimately impacted by AD/ADRD -- those who have the diseases and their families and other caregivers. Individuals with AD/ADRD and their caregivers receive assistance from both the clinical health care system and long-term care including HCBS, legal services, and other social services. Both the clinical care and community/support environments need better tools to serve people with AD/ADRD and their unpaid caregivers. Ongoing and future research seeks to identify interventions to assist clinicians, supportive service providers, HCBS providers, persons living with dementia, and caregivers. All of these efforts must occur in the context of improved awareness of the diseases and its impacts, and the opportunities for improvement. The Plan aims to address these key needs. HHS is committed to tracking and coordinating the implementation of NAPA and making improvements aimed at achieving its ambitious vision.

The National Plan continues to be guided by three principles:

1. ***Optimize Existing Resources, and Improve and Coordinate Ongoing Activities***. The first step in developing the National Plan was to set up a federal interagency working group and conduct an inventory of all federal activities involving AD/ADRD. In creating the Plan, HHS and its partners sought to leverage these resources and activities, improve coordination, and reduce duplication of efforts to better meet the challenges of AD/ADRD. The activities included in the inventory comprise ongoing work and new opportunities created legislation and authority. The federal working group process continues to improve coordination and awareness throughout the

Federal Government and set in motion commitments for further collaboration. Further, this process has allowed for identification of non-AD-specific programs and resources that may be leveraged to advance AD/ADRD care and prevention.

2. ***Support Public-Private Partnerships***. The scope of the problem of AD/ADRD is so great that partnerships with a multitude of public and private stakeholders are essential to making progress. The original National Plan began the partnership process by identifying areas of need and opportunity. The plan continues to rely on the Advisory Council in particular to identify key areas where public-private partnerships can improve outcomes.

3. ***Transform the Way We Approach Alzheimer's Disease and Related Dementias***. The National Plan recognizes that this undertaking will require continued, large-scale, coordinated efforts across the public and private sectors. With principles 1 and 2 above, as well as the ambitious vision that the Federal Government has committed to through this plan, HHS and its federal partners seek to take the first of many transformative actions that will be needed to address these diseases. Through an ongoing dialogue with the Advisory Council, the Federal Government continues to identify the most promising areas for progress and marshal resources from both within and outside the government to act on these opportunities.

Goals as Building Blocks for Transformation

Achieving the vision of eliminating the burden of AD/ADRD starts with concrete goals. Below are the five that form the foundation of the National Plan:

1. Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025.
2. Enhance Care Quality and Efficiency.
3. Expand Supports for People with Alzheimer's Disease and Related Dementias and their Families.
4. Enhance Public Awareness and Engagement.
5. Track Progress and Drive Improvement.

2017 Update

This is the 2017 Update to the National Plan. In order to create a focused and accessible document, agencies have provided narrative descriptions of activities that were completed in 2016, as well as some which are ongoing and have updates. This provides a clear report of progress that was made since the last plan update in August 2016. For more information about ongoing or previously completed projects, please consult Appendix 3: Implementation Milestones.

The activities outlined in this National Plan Update vary in scope and impact, and include:

- Immediate actions that the Federal Government has taken and will take;
- Actions toward the goals that can be initiated by the Federal Government or its public and private partners in the near term; and
- Longer-range activities that will require numerous actions by federal and non-federal partners to achieve.

The National Plan was never designed to be a "Federal Plan". The 2017 Plan Update includes a number of activities and projects submitted by non-federal partners. These items have been organized according to the Goals and Strategies in the Plan. Active engagement of public and private sector stakeholders is critical to achieving these national goals. In the case of many of the long-range activities, the path forward will be contingent upon resources, scientific progress, and focused collaborations across many partners. Over time, HHS will work with the Advisory Council and stakeholders to incorporate and update additional transformative actions.

Additionally, in an effort to clearly respond to the annual recommendations made by the non-federal members of the Advisory Council, the 2017 National Plan Update includes an appendix (Appendix 2) in which relevant federal agencies have briefly responded to the recommendations made by the Advisory Council. Fulfilling the recommendations is contingent on limitations on legislative authority, resources, and data among the federal agencies and the Federal Government, and this appendix makes clear which recommendations have been addressed and which would require congressional authority or additional resources.

Goal 1: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025

Research continues to expand our understanding of the causes of, treatments for, and prevention of AD/ADRD. Goal 1 seeks to develop effective prevention and treatment modalities by 2025. Ongoing research and clinical inquiry can inform our ability to delay onset of AD/ADRD, minimize its symptoms, and delay its progression. Under this goal, HHS will prioritize and accelerate the pace of scientific research and ensure that as evidence-based solutions are identified and quickly translated, put into practice, and brought to scale so that individuals with AD/ADRD can benefit from increases in scientific knowledge. HHS will identify interim milestones and set ambitious deadlines for achieving these milestones in order to meet this goal.

In 2016/2017, Goal 1 showed substantial progress across a spectrum of research areas, thanks to the continued support from our national leadership and the American public, the dedication of study volunteers and their families and caregivers, and the valued work of clinicians and scientists.

Federal funding devoted to AD/ADRD research has expanded over the past several years, reflecting intensified national interest in finding ways to treat these devastating diseases. The National Institutes of Health (NIH) played a lead role by redirecting $50 million in funding in fiscal year (FY) 2012 and allocating $40 million in FY 2013 to promising avenues of AD/ADRD research. Federal appropriations increases to the NIH budget by $100 million in FY 2014 and $25 million in FY 2015, primarily directed toward AD/ADRD research, were also approved. However, the biggest increases in funding came in FY 2016 and FY 2017, following Congressional passage of the Consolidated Appropriations Act 2016 (P.L. 114-113) and the Consolidated Appropriations Act, 2017 (P.L. 115-31). The FY 2016 appropriations directed an unprecedented additional $350 million toward AD/ADRD research, with an additional $400 million provided for this research in FY 2017; increasing overall NIH funding from Congress for AD/ADRD research by $912 million from FY 2012 to FY 2017. In FY 2017 alone, NIH estimates spending $1.4 billion on AD/ADRD research. This enormous infusion of resources enabled the launch and expansion of research programs and invigorated investigator-initiated research, further accelerating progress towards the Plan's ultimate research goal: finding effective interventions to treat or prevent AD/ADRD by 2025. [See https://www.congress.gov/115/bills/hr244/BILLS-115hr244enr.pdf.]

NIH was already poised to integrate the extraordinary new funds into its research portfolio. In July 2015, NIH released the first of what is now an annual professional judgment budget for Congress -- and the American people -- estimating the costs of accomplishing the research goals of the National Plan to Address Alzheimer's Disease. This report is known as a "bypass budget" because of its direct transmission to the President and subsequently to Congress without modification through the normal federal budget process. The most recent estimate, submitted in July 2017, outlines funding needs for the most promising research approaches for FY 2019. [See https://www.nia.nih.gov/about/sustaining-momentum-nih-takes-aim-alzheimers-disease-related-dementias.]

The NIH will continue to prepare these estimates through FY 2025. Only two other areas of biomedical research have previously been the subject of this special budget approach: cancer and HIV/AIDS. [See https://aspe.hhs.gov/national-plans-address-alzheimers-disease#2014Plan.]

Planning for the annual bypass budget and NIH's current AD/ADRD research portfolio are informed by research implementation milestones based on recommendations for AD/ADRD developed at a series of the NIH-convened research summits (described below). [See https://aspe.hhs.gov/napa-research-milestones; https://www.nia.nih.gov/research/recommendations-nih-ad-research-summit-2015; and https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones.]

Strategy 1.A: Identify Research Priorities and Milestones

Alzheimer's Disease Research Summit Advances Research Agenda. In February 2015, the NIH *Alzheimer's Disease Research Summit 2015: Path to Treatment and Prevention* expanded on the research agenda set in place at the first of such summits held in 2012. The 2015 gathering brought hundreds of experts in AD and other chronic diseases together to identify critical knowledge gaps and set priorities for the kinds of new resources, infrastructure, and multi-stakeholder partnerships needed to fully realize emerging research opportunities. The next Alzheimer's Disease Research Summit, taking place in March 2018 as well as a summit in 2017 to address care and services research will include national and international experts, research funders, public and private stakeholders, and members of the National Advisory Council on Aging. Summit proceedings will be open to the public and recommendations developed out of the meeting will inform priority setting at NIH and other federal agencies.

For more information, see:
- http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015
- https://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention
- https://aspe.hhs.gov/advisory-council-october-2016-meeting-presentation-summit-care-update

2016 Summit on Alzheimer's Disease-Related Dementias (ADRD) Research. NIH also hosted the *Alzheimer's Disease-Related Dementias 2016 Summit* in March 2016 to update the recommendations on national research priorities for FTD, LBD, multiple etiology dementia, vascular contributions to cognitive impairment and dementia (VCID), and health disparities in dementia that came out of the 2013 ADRD Summit. The meeting drew hundreds of experts across diverse fields of dementia research as well as advocates, patients, and caregivers. Their goals were to review and update recommendations based on scientific progress, to prioritize the important scientific questions that need to be answered to advance our understanding of these complex disorders, and to identify how federal and non-governmental organizations (NGOs) can further and most effectively collaborate to address these research priorities. Final recommendations from the meeting were approved by the National Advisory Neurological Disorders and Stroke Council in September 2016, and then were developed as ADRD prioritized research milestones, which were presented at the NAPA Advisory Council in February 2017. These milestones guide NIH's ADRD research priorities and help track progress toward the goal of preventing and effectively treating AD/ADRD by 2025.

For more information, see:
- https://www.ninds.nih.gov/News-Events/Events-Proceedings/Events/Alzheimers-Disease-Related-Dementias-Summit-2016
- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones

Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease and Related Dementias

Investigator-Initiated Research. In 2016, investigator-initiated research offered new insights into the complex molecular, biological and genetic factors that influence disease onset and progression. This work expands our basic understanding of AD/ADRD.

Collaborating on Drug Targets. Accelerating Medicines Partnership - Alzheimer's Disease (AMP-AD) is part of the Accelerating Medicines Partnership (AMP), a bold venture among the NIH, ten biopharmaceutical companies, and several non-profit organizations aiming to identify and validate the most promising biological targets of disease for new diagnostic and drug development. To date, over 100

novel candidate targets have been identified and are being evaluated in collaboration with industry partners.

For more information, see:
- http://www.nia.nih.gov/alzheimers/amp-ad
- http://www.nia.nih.gov/alzheimers/amp-ad-target-discovery-and-preclinical-validation-project

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Promising Drugs to Treat or Prevent Alzheimer's Disease. Currently over 50 National Institute on Aging (NIA)-supported clinical trials for AD/ADRD treatment and prevention are underway. In addition, NIH supports about 80 projects aiming to discover and develop new therapeutics for AD/ADRD.

Identifying Genetic Risk and Prevention Factors. NIH funds cutting-edge research into the genetic underpinnings of AD/ADRD, analyzing how genome sequences -- the order of nucleotides in a cell's DNA -- may contribute to increased risk or protect against the disease. The ultimate goal is to find new pathways for treatments and prevention.

The Alzheimer's Disease Sequencing Project (ADSP) generated three sets of data in the Discovery Phase to determine the order of all 3 billion letters of individual genomes: (1) Whole-genome sequence (WGS) for 584 participants; (2) Whole Exome Sequence (WES) for ~5,000 each of AD cases and controls; and (3) WES of an enriched sample set comprised of over 800 AD cases from multiply affected families and 171 Hispanic controls. In 2016, the ADSP completed the sequencing for the next phase of the project, the Discovery Extension Phase, which has two components: (1) the ADSP Discovery Family-Based Extension Study: To further assess the genomes in multiply affected families; and (2) the ADSP Discovery Case-Control Based Extension Study: To increase the diversity of sample sets. The total number of WGS available for analysis is now well over 4,000. Additional NIA-funded studies that are sharing their data with the ADSP bring that total close to 7,000 whole-genomes.

By 2016, using a combination of genetic analysis approaches, more than two dozen genetic regions of interest had been identified that play a role in AD risk. The specific regions are now being closely examined to determine what genes and cellular pathways are involved.

The NIA Genetics of Alzheimer's Disease Data Storage Site (NIAGADS) was established to share genetic/genomic and phenotypic data with the research community. In 2016, they responded to data requests from 60 labs at 43 institutions in order to facilitate the sharing of sequence data with the genetics community. NIAGADS has established several data and information technology resources for the research community at-large, and provides a web user interface that integrates AD/ADRD genetic findings with other genetic data for rapid analysis of the sequence data.

Also in 2016, NIA funded the Genomic Center for Alzheimer's Disease (GCAD). The mission of this Center is to identify genetic variants that cause or influence risk, or protect against AD, and to identify the underlying genes affected by these variants. Its goals are to facilitate AD gene discovery, harmonize all ADSP sequence and genetic and phenotypic data, and to coordinate ADSP data analysis. To date the sequence data for more than 4,000 subjects has been quality control checked and harmonized.

For more information, see:
- https://www.niagads.org/adsp/content/home
- https://www.niagads.org/
- http://www.adgenomics.org/

Genes for Healthy Aging. In 2016, a group of NIH-supported scientists found that genes that promote cognitive health may also help protect against chronic disease of old age, including AD. The "Wellderly" study focused on exceptional individuals from across the United States aged 80-105 who had not developed any chronic medical condition or diseases, including heart disease, cancer, stroke, stroke, AD,

Parkinson's disease, or diabetes. In genome-wide association study analyses, two of the top three hits associated with healthy aging were genes previously linked to cognitive function, suggesting that protection against cognitive decline contributes to healthy aging. This is the first large WGS study to focus on health rather than disease. Future studies of this kind will likely reveal additional genes and drug targets that could help protect against AD and other chronic diseases of old age.

For more information, see:
- http://www.sciencedirect.com/science/article/pii/S0092867416302781?via%3Dihub

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Testing Therapies at Earliest Stages of Alzheimer's Disease. Several NIA-supported clinical trials are testing new paradigms about when the disease starts, and if intervening in symptom-free but at-risk people in the earliest stages of the disease might forestall symptoms and delay progression. In 2014, recruitment began for the Anti-Amyloid Treatment in Asymptomatic Alzheimer's study, which is testing the drug solanezumab in 1,000 cognitively normal volunteers, age 65-85, who through imaging have been shown to have enough of the amyloid protein in the brain to put them at-risk for developing AD, but do not show clinical symptoms of the disease. This study is still actively recruiting participants. Another trial, the Generation Study, launched in early 2016, will test whether two drugs targeting amyloid, CAD106 and CNP520, can prevent or delay AD/ADRD symptoms in symptom-free older volunteers at high genetic risk for the disease. Recruitment continues for over 1,000 volunteers who carry two copies of the APOE e4 allele, a gene risk factor for Late-Onset Alzheimer's Disease (LOAD).

For more information, see:
- http://a4study.org/about/
- https://www.nia.nih.gov/alzheimers/clinical-trials/cad106-and-cnp520-prevent-or-delay-symptoms-alzheimers-disease

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A Genetic Connection between Immunity and Alzheimer's. In 2016, a group of researchers supported by the NIH found that Alzheimer's disease shares biological mechanisms with autoimmune diseases. The team used a new genetic approach to analyze data from 17,008 people with AD and 37,154 age-matched controls from four consortia in Europe and North America. The team identified two autoimmune disease-linked genetic alterations that increased AD risk. The first alteration has been linked to psoriasis, while the second has been linked to both Crohn's disease and inflammatory bowel disease (IBD). The genetic variation linked to Crohn's and IBD correlated with a 50% faster rate of cognitive decline in people with AD, mild cognitive impairment (MCI), and in healthy controls. This discovery adds to the mounting evidence that the immune system plays a key role in the development of AD.

For more information, see:
- http://jamanetwork.com/journals/jamaneurology/fullarticle/2514054

Lifestyle Alzheimer's Disease Prevention. NIH is studying whether lifestyle interventions, such as diet, exercise, and cognitive enrichment, may be preventive interventions for cognitive decline and AD. Currently, a number of NIH-funded clinical trials are underway to test whether exercise can influence AD onset and progression. For example, one active study is currently recruiting participants and using brain imaging and cognitive measures to investigate the effects of cycling on cognition and hippocampal volume.

NIA has recently funded the Exercise in Adults with Mild Memory Problems (EXERT) trial to test whether moderate/high aerobic exercise and stretching can slow the progression of MCI to AD in adults over 65. This 18-month long trial is actively recruiting participants.

For more information, see:
- https://clinicaltrials.gov/ct2/show/NCT01954550
- https://clinicaltrials.gov/ct2/show/NCT02814526

Discovering the Molecular, Cellular, and Genetic Causes of Alzheimer's Disease and Related Dementias. NIH funds a broad range of research to understand the underlying causes of dementia, which is an important first step for developing new treatments and prevention strategies. To better understand the vascular contributions to AD/ADRD, NIH launched the *Molecular Mechanisms of the Vascular Etiology of Alzheimer's Disease Consortium* (M^2OVE-AD) in March 2016. The 5-year, $30 million program brings together over a dozen research teams working on five complementary projects. Scientists from diverse fields using the latest methodologies will work collaboratively towards shared goals: to dissect the complex molecular mechanisms by which vascular risk factors influence AD/ADRD and identify new targets for treatment and prevention.

In the fall of 2016, NIH added a new team to the *M^2OVE-AD Consortium* to zero in on the how sex differences impact the trajectory of the disease; with the largest current study of gene expression mechanisms in postmortem human brains in AD. It is hoped that this closer look at the sex differences in disease progression can provide major insights related to the overall understanding of AD biology, and help direct us toward new drugs targeted specifically for women or men at-risk for dementia.

Recently, NIH-funded scientists have found links between cerebrovascular diseases, cognition, and brain aging by using data from large population studies, and are exploring new targets and strategies to reduce FTD-related pathologies. In addition, researchers identified a role of tau pathology in LBD, and are developing animal models to study genetic causes of LBD.

In addition to continuing support for investigator-initiated research, in 2016, NIH released requests for applications (RFAs) to stimulate research on how to better study and diagnose small vessel disease in the brain as it relates to cognitive decline and dementia, and created a new cross-disciplinary program to investigate the molecular mechanisms of tau toxicity in FTD. In 2017, NIH released a new ADRD funding opportunity to create the FTD Sequencing Consortium that would support WGS and replication studies to find and validate new risk genes for FTD.

For more information, see:
- https://www.nia.nih.gov/newsroom/2016/03/decoding-molecular-ties-between-vascular-disease-and-alzheimers
- http://grantome.com/grant/NIH/RF1-AG054014-01
- http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-15-018.html
- http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-021.html
- http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-023.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-017.html

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Bridging the Preclinical to Clinical Development Gap. In 2017, NIH launched the Model Organism Development and Evaluation for Late-onset AD, an initiative that will create the next generation of mouse models to be used in preclinical efficacy testing of candidate therapeutics. The new models will be based on newly identified LOAD risk genes and will undergo extensive molecular, pathological and clinical staging to align the pathologic features in mice with corresponding stages of human disease.

For more information, see:
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-16-014.html

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Addressing Health Disparities. Race and ethnicity, and socioeconomic status can influence AD/ADRD risk and outcomes. To identify and better understand biological, behavioral, sociocultural and environmental factors that influence health differences, NIH is supporting several new research efforts:

some researchers will focus on improved recruitment and cognition assessment tools for health disparities, while others examine disparities in access to and use of LTSS, which includes institutional care and HCBS, for persons with dementia. A primary goal is to develop treatment and prevention strategies that are effective and culturally appropriate among diverse populations.

One recent study, for example, looked at possible genetic influences that might explain differences in AD prevalence among African Americans and non-Hispanic Whites. Researchers found an increased genetic risk for AD in African Americans due to variations in a gene for the brain's system for clearing out beta-amyloid protein fragments. The team confirmed that this deletion mutation was associated with increased AD risk in two large African American populations, but found the mutation virtually absent in samples from over 3,000 non-Hispanic Whites.

For more information, see:
- http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html
- https://www.ncbi.nlm.nih.gov/pubmed/27231719

NIA Enhances Information on Alzheimer's Clinical Trials Participation. NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through our Alzheimer's Disease Education and Referral (ADEAR) website portal; clinical trials listing and monthly e-alert to more than 35,000 subscribers; social media messages through Facebook and Twitter; promotion of the Recruiting Older Adults into Research (ROAR) toolkit of customizable materials for aging services and public health professionals to use in community settings and social media in English, Spanish, and Chinese, and collaboration with the Administration for Community Living (ACL), Centers for Disease Control and Prevention (CDC), Food and Drug Administration (FDA) and the Patient-Centered Outcomes Research Institute (PCORI)-funded Alzheimer's and Dementia Patient/Caregiver-Powered Research Network to encourage research participation among older adults.

For more information, see:
- http://www.nia.nih.gov/alzheimers
- http://www.nia.nih.gov/alzheimers/volunteer
- https://www.nia.nih.gov/health/publication/roar-toolkit
- http://pcornet.org/patient-powered-research-networks/national-alzheimers-dementia-patient-caregiver-powered-research-network-phase-ii/

Developing a National Recruitment Strategy. With substantial community and stakeholder involvement, NIA is leading efforts to provide practical approaches to help study sites and researchers overcome the challenges and barriers in recruiting and retaining the right volunteers, at the right times, in the right studies. In facilitation with the Alzheimer's Association and collaboration with government, private, and academic stakeholders, NIA is developing the National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research. In 2017, NIA convened a workshop for experts from academia, communications, advocacy, and clinical care and research to identify the best strategies for engaging a range of audiences, including minority and underrepresented groups, in the clinical research enterprise.

VA Targets Dementia Research. The U.S. Department of Veterans Affairs (VA) Office of Research and Development (ORD) has ongoing specialty AD RFAs for biomedical laboratory or clinical research to include FTD, LBD, and/or VCID in addition to AD/ADRD.

VA Collaborates with NIA. VA/ORD and NIA have initiated the Strategic Partnership to Advance Research and Knowledge, which is a joint VA-NIA cooperative partnership of shared dementia research

priorities with the goal to develop and implement a sustainable framework to facilitate supportive resources and co-funding.

Frontotemporal Degeneration Disorders Registry. The FTD Disorders Registry LLC (FTDDR) is an independent non-profit entity co-founded by the Association for Frontotemporal Degeneration (AFTD) and the Bluefield Project for the Cure. The shared vision for a patient registry to serve the frontotemporal disorders community was realized with the formal design, build, and beta testing of the web interface occurring throughout 2016. The FTDDR is a Contact and Research Registry, where research recruitment is initially focused in the United States and Canada, while Contract Registry enrollment is international. The Registry welcomes persons diagnosed with FTD, their caregivers, family and friends to join. Research participation is primarily comprised of data collection via online surveys; de-identified data will be cultivated, aggregated and analyzed. This dynamic online database will function as the central resource for the lay community and the research/development community with overriding objectives to support research, clinical trial recruitment, and drug development. Spring 2017 marks the formal FTDDR public launch.

For more information, see:
- http://www.ftdregistry.org

Treat Frontotemporal Degeneration. In May 2016, the Alzheimer's Drug Discovery Foundation (ADDF) and AFTD launched the Treat FTD Fund to support clinical trials testing novel or repurposed drugs for FTD and related disorders (bvFTD, PPA, PSP, CBD, FTD/ALS). The Treat FTD Fund will build on recent successes of both foundations in early-stage drug discovery and biomarker development, and leverages new ongoing efforts under development by AFTD such as the recently launched FTDDR and a $5 million FTD Biomarker Initiative. Running clinical trials in FTD patients will help investigators learn how best to target this unique patient population and will employ advances in biomarkers as they develop. Through this partnership, ADDF and AFTD propose to invest $10 million over 10 years to fund at least five innovative clinical trials subject to review by an appointed Joint Steering Committee.

For more information, see:
- http://www.theaftd.org/wp-content/uploads/2016/09/Treat-FTD-RFP.pdf
- http://www.theaftd.org/research/the-treat-ftd-fund

Lewy Body Dementia Patient Engagement. The Lewy Body Dementia Association (LBDA) launched a new initiative to help drive participation in clinical research studies. This multi-pronged initiative included a webinar about participating in clinical trials, a new section on LBDA's website about new studies and clinical trials, and social media and email campaigns.

For more information, see:
- http://www.lbda.org/content/research

Patient-Powered and Caregiver-Powered Research. UsAgainstAlzheimer's has partnered with the Mayo Clinic, University of California, San Francisco, and University of Florida in the Alzheimer's Disease Patient and Caregiver-Powered Network (AD-PCPRN), funded by PCORI. The project's goal is to accelerate development of effective treatments of AD/ADRD. It is intended to connect patients, caregivers and researchers focused on developing, conducting and disseminating patient-centered dementia research. Through the GALAXY platform developed with UsAgainstAlzheimer's, the AD-PCPRN provides potential clinical trial participants a brief assessment aid powered by Roobrik to map a course of action and a trial matching service, powered by Antidote. The AD-PCPRN is governed by a Governance Council of leaders in AD, advocacy, caregiving and other areas. Providing insights to the Governance Council are four Advisory Councils, whose nearly 45 members include leaders in the AD patient/caregiver community, communications and outreach, diversity outreach and research, and registries/clinical trials.

Screening for Dementia in Persons with Intellectual and Developmental Disabilities (IDD). The National Institute on Disabilities, Independent Living, and Rehabilitation Research (NIDILRR) is funding a study, led by Dr. Peter Blanck of Syracuse University that is examining cognitive status of older African Americans with IDD with a goal of learning more about the impact of dementia on long-term outcomes and quality of life. In addition, Dr. Matt Janicki and his colleagues at the University of Illinois, Chicago's NIDILRR funded Research and Training Center on Aging with Developmental Disabilities, have produced a rich body of knowledge about cognitive decline and dementia in persons with IDD. Their work includes a useful instrument for detecting early-onset and presence of dementia in persons with IDD.

For more information, see:
- http://bbi.syr.edu/projects/Community_Living_DRRP/index.html
- https://aadmd.org/sites/default/files/NTG-EDSD-Final.pdf

Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias

Strengthening Clinical Trials with Neuroimaging. The Alzheimer's Disease Neuroimaging Initiative (ADNI), initially launched by NIH in 2004 as a landmark public-private partnership, looks at how evolution of clinical symptoms and neurocognitive testing in healthy controls, people with MCI, and people with mild AD, correlates with changes in multiple biomarkers reflecting disease development. In 2016, ADNI moved into a critical new phase of discovery with ADNI3. With $40 million in NIH funding support over the next 5 years, plus an anticipated $20 million in private sector investment, the new effort will add brain scans that detect the amount and location of tau protein tangles -- a second hallmark of AD -- with ongoing collection of initial study neuroimaging and biofluid biomarkers.

For more information, see:
- https://www.nia.nih.gov/research/dn/alzheimers-disease-neuroimaging-initiative-adni

Collaborating on Biomarker Research. One of the primary goals of the previously-noted AMP is to identify and characterize biomarkers and targets for intervention. The AMP-AD Biomarkers Project is a consortium of three NIA-supported Phase II/III secondary prevention trials testing several anti-amyloid therapies. Imaging and fluid biomarker panels already included in these trials will be supplemented with tau PET imaging and novel fluid biomarkers. Screening and baseline data from the trials will be made broadly available through the Global Alzheimer's Association Interactive Network collaborative platform. Trial data and biological samples will also be shared after completion of the trials.

For more information, see:
- http://www.nih.gov/science/amp/index.htm
- http://www.nia.nih.gov/alzheimers/amp-ad-biomarkers-project
- https://www.gaaindata.org/partners/online.html

Identifying Biomarker Trajectories Over Time. In late 2015, NIH launched a new initiative to identify biomarkers and track the progression of AD in people with Down syndrome. Costing an estimated $37 million over 5 years, the NIH *Alzheimer's Biomarker Consortium-Down Syndrome* is supporting teams of researchers using brain imaging, including amyloid and tau PET, fluid and tissue biomarkers, as well as neuropsychological measures in research that may one day lead to effective interventions for all people with dementia. Two research teams are working collaboratively to identify and track AD-related changes in the brain and cognition of over 500 Down syndrome volunteers, aged 25 and older.

For more information, see:
- https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds

Discovering Biomarkers for Alzheimer's Disease and Related Dementias. In addition to its ongoing support of several large collaborative projects and consortia that seek to discover biomarkers for FTD, NIH is supporting three programs that aim to discover and/or develop biomarkers for small vessel disease in the brain and LBD:

- In 2016, NIH established a small vessel *VCID Biomarkers Consortium* (MarkVCID), which consists of seven biomarker development project sites and one coordinating center across the United States, to develop and validate candidate human biomarkers for small vessel disease in the brain. The 5-year program's overall goal is to deliver high-quality biomarkers ready for use in clinical trials.
- NIH is supporting longitudinal studies that leverage the existing Parkinson's disease Biomarkers Program (PDBP) infrastructure to discover biomarkers for LBD. These studies began enrollment in March 2017 and will enroll 590 participants with clinical follow-up and biospecimen collection.
- In 2017, NIH solicited LBD projects that could lead to early diagnosis, improved differential diagnosis, and/or discovery of new therapeutic targets. Funded projects would utilize existing data and biospecimens from the PDBP and ADNI/National Alzheimer's Coordinating Center databases to study unique clinical or biological characteristics of LBD patients.

For more information, see:
- https://www.nia.nih.gov/newsroom/2014/10/nih-announces-grants-frontotemporal-degeneration-research
- https://markvcid.partners.org/
- https://pdbp.ninds.nih.gov/projects-we-support
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-016.html

Early Detection of Cognitive Impairment, including Dementias, in Everyday Clinical Settings. Diagnostic tools for AD/ADRD that are accurate and reliable are crucial not only in guiding clinical care and developing a long-term care plan, but also in facilitating clinical research and recruiting the right subset of participants to clinical trials. To address the unmet need for early detection of cognitive impairment and dementia when a patient, relative, or care provider voices a concern in primary care settings, NIH released a new funding opportunity in early 2017 to develop easy-to-use diagnostic tests or tools that are standardized and take 5 minutes or less to administer in everyday clinical settings.

For more information, see:
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-012.html

Frontotemporal Degeneration Biomarkers Initiative. In January 2017, AFTD proudly announced the recipients of the first six awards funded through its major new funding opportunity, the FTD Biomarkers Initiative. Through 2018, AFTD anticipates awarding up to $5 million to support innovative approaches to the discovery and development of biomarkers that differentiate FTD from other neurodegenerative disorders, discriminate between FTD subtypes, identify underlying molecular pathologies, confirm pharmacodynamic modulation of disease pathways and track disease progression. A key feature of the initiative is the requirement for award recipients to commit to the open exchange of data and results. The FTD Biomarkers Initiative has been made possible by a generous multi-year donation from the Samuel I. Newhouse Foundation.

For more information, see:
- http://www.theaftd.org/research/ftd-biomarkers-initiative

Comprehensive Lewy Body Dementia Symptoms Checklist. LBDA's free, downloadable *Comprehensive LBD Symptoms Checklist* was used in a recent study by researchers at Newcastle University in the United Kingdom to tease out what symptoms of dementia with Lewy bodies (DLB) may aid in the early diagnosis during the MCI stage. Ten early symptoms were identified, with a score of 2 or more strongly suggesting MCI-DLB.

For more information, see:
- http://www.lbda.org/node/3577

Strategy 1.D: Coordinate Research with International Public and Private Entities

Innovative Planning Tool Expanded. The International Alzheimer's Disease Research Portfolio (IADRP) -- a free, searchable database providing a global overview of AD research and funding -- is an invaluable tool for assessing and planning AD research projects. Funding organizations, researchers, and advocates are discovering IADRP's merits to help them coordinate strategies, leverage resources, avoid duplication, and identify promising areas of growth. Since NIH launched the database in 2012, in collaboration with the Alzheimer's Association, IADRP has amassed data on nearly 7,000 unique projects from 2008 through 2016, reflecting more than $5.7 billion in research funding worldwide. The number of contributors is growing, too. During the past 5 years, more than 35 funding organizations across 11 countries have joined the IADRP effort. The Common Alzheimer's Disease Research Ontology used in IADRP is also undergoing a significant update to the topic and themes that are used to categorize AD and ADRD funding data. The changes will reflect current research investment, as well as highlight emerging areas of science.

For more information, see:
- http://iadrp.nia.nih.gov/

Dementia with Lewy Bodies Consortium Annual Meeting. The first annual meeting of the newly created *Dementia with Lewy Bodies (DLB) Consortium* was held in early 2017. The funding for the consortium comes from NIH, NIA and the National Institute of Neurological Disorders and Stroke (NINDS), and the annual meeting is funded by the LBDA. This Consortium fills a vital gap in LBD research infrastructure.

For more information, see:
- https://pdbp.ninds.nih.gov/Dementia_with_Lewy_Bodies_Consortium_U01

Late-Stage Alzheimer's Drug Pipeline. In March 2016, the UsAgainstAlzheimer's network ResearchersAgainstAlzheimer's (RA2) released an analysis of AD drugs in Phase 3 clinical trials and, in September 2016, an analysis of Phase 2 drugs. These reports described to patients, caregivers and researchers the drugs that could potentially reach the market in the next 5 years and explored whether our health care system would be ready for them. RA2 presented an updated report on Phase 2 and Phase 3 drugs in development at the Alzheimer's Association International Conference (AAIC) in London in July 2017.

Global Alzheimer's Platform Updates. In October 2016, the Global Alzheimer's Platform (GAP) Foundation fully implemented its novel recruitment model to increase referrals to the University of Kansas Alzheimer's Disease Center (KU ADC) through the establishment of the Memory Strings Kansas City Alliance. The model strives to develop and support a community-wide culture to support AD trials and continually drive appropriate referrals to research centers in the GAP network. Key local Alliance members include committed principal investigators; health care professionals and health insurers; community-based organizations that support African Americans and Latinos; federal, state and local

government officials; leaders of commercial entities, non-government organizations, and respected individuals; and those interested in funding local research efforts. The Alliance focus on primarily activating primary care physicians has produced encouraging results: Q4 2016 referrals were up 200% at KU ADC and enrollments were up 150% when compared to Q4 2015 results. GAP has committed to roll-out this model in four more communities is 2017. GAP is building a global network of optimized clinical trial sites -- now numbering nearly 50 -- that are certified to meet industry-accepted quality and performance criteria.

Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs

Reporting Research Findings. NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. The ADEAR Center educates the public about the latest research findings and clinical trial participation via free, evidence-based information available online and in print. In addition, NIA disseminates research findings through the media, social media, and annual research progress reports.

For more information, see:
- http://www.nia.nih.gov/alzheimers
- https://www.nia.nih.gov/about/sustaining-momentum-nih-takes-aim-alzheimers-disease-related-dementias

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Resources for the Dementia Services Community. The interagency ROAR (NIH, ACL, CDC) group hosted an update in the popular webinar series in 2017 for professionals on AD/ADRD resources that drew 500+ participants and offered continuing education credit. Free continuing education is available to professionals who need it when they view recorded webinars from 2017 and earlier series. This continuing education is available through 2018.

For more information, see:
- https://www.nia.nih.gov/alzheimers/announcements/2017/02/2017-alzheimers-and-dementia-webinars-professionals
- http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx#resources

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Exploring the Evidence for Prevention. In 2015, NIH initiated a project involving the Agency for Healthcare Research and Quality (AHRQ), and the National Academies of Sciences, Engineering, and Medicine (NASEM), to conduct a systematic review of the evidence on prevention of clinical AD-type dementia, MCI, and age-related cognitive decline (AHRQ), and to shape these findings into a set of recommendations for public health practice and research (NASEM). This effort is driven by the intense interest in recent years -- in the United States and internationally -- to identify ways to reduce the risk for cognitive decline and AD/ADRD. Ultimately, the effectiveness of 13 interventions was explored by the Minnesota Evidence-based Practice Center (supported by AHRQ). While most interventions showed no evidence of benefit to delay cognitive decline or AD; some forms of cognitive training were found to improve performance on specific tasks, though the transfer of benefits to other cognitive areas may be limited. A review of the available evidence also showed that some types of physical activity, and vitamin B12 plus folic acid may benefit cognitive performance in some areas for adults with normal cognition. A report from NASEM detailing recommendations for public health messaging based on these findings was released in June 2017.

For more information see:
- https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=2417
- https://www.nationalacademies.org/dementia

Goal 2: Enhance Care Quality and Efficiency

High-quality care for people with AD/ADRD requires an adequate supply of culturally-competent professionals with appropriate skills, ranging from direct care workers to community health and social workers, to HCBS providers, to primary care providers and specialists. High-quality care should be provided from the point of diagnosis onward in settings including doctor's offices, hospitals, people's homes and nursing homes. Person-centered quality should be measured accurately and inter-operably across all settings of care, coupled with quality improvement tools. Further, care should address the complex care needs that persons with AD/ADRD have due to the physical, cognitive, emotional, and behavioral symptoms of the disease and any co-occurring chronic conditions. High-quality and efficient care often depends on: (1) smooth transitions between care settings; (2) coordination among health care and LTSS providers; and (3) dementia-capable health care.

Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care

Person-Centered Counseling Training Program. HHS promotes person-centered planning and self-direction, where people receiving HCBS are empowered to have more control and direction over the HCBS they receive. ACL completed its development of a six-course training program for person-centered planning and counseling. The program addresses cognitive disabilities and dementia in each of the following courses:

1. Introduction to the "No Wrong Door" System.
2. Introduction to Person-Centered Planning.
3. Person-Centered Planning and Implementation.
4. Introduction to the Long-Term Services and Supports System.
5. Who We Serve.
6. Protection and Advocacy.

Each of these courses trains front line Person-Centered Counseling Professionals in the skills necessary to assist older adults who need supports and people with disabilities in reaching their goals for community living in a respectful and dignified manner. Each course teaches the learner how to use specific tools to interact with each person in a way that gives him or her control over the goal-setting process, and helps foster the development of meaningful and trusting relationships. Pilot-testing of the training program is occurring in 2017 in 13 states.

For more information, see:
- http://directcourseonline.com/pcc/

Dementia-Specific Guidelines and Curricula. Completed in November 2015, the Health Resources and Services Administration (HRSA) created and disseminated a repository of dementia curricula and practice guidelines for providers across the care continuum, including physicians, nurses, social workers, psychologists, other health care professionals, direct care workers, and informal caregivers. The repository is hosted on the HRSA website.

For more information, see:
- https://bhw.hrsa.gov/grants/geriatrics

Healthy Brain Initiative. The CDC Healthy Brain Initiative (HBI) began in 2005 through a congressional appropriation that established the AD-specific segment of the Healthy Aging Program. The HBI addresses cognitive health from a public health perspective to catalyze action at the state and local level. The *Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*, the

second in the Road Map series, was released in 2013. This Road Map, which was designed to complement the National Plan, identifies 35 actions that state and local public health agencies and their partners can implement to promote cognitive health and address cognitive impairment and the needs of caregivers. CDC's funded partners are integral to accomplishing these actions, the Alzheimer's Association, the Balm in Gilead, and the Healthy Brain Research Network (HBRN) (a consortium of six Prevention Resource Centers). The *2013-2015 Interim Progress Report*, and the corresponding *Dissemination Guide*, released in late 2015, highlight selected HBI Road Map accomplishments and future directions.

For more information, see:
- http://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf
- http://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative-interim-report.pdf
- http://www.cdc.gov/aging/healthybrain/roadmap.htm
- https://www.cdc.gov/aging/healthybrain/research-network/index.html

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Implemented Road Map Actions in States. CDC supported a successful collaboration with the Alzheimer's Association in September 2015-September 2020 to implement a Road Map for action on care and services in several states. In FYs 2014-2017, CDC provided supplemental funds to support cognitive decline and caregiver surveillance through the Behavioral Risk Factor Surveillance System (BRFSS) in states. In 2015 and 2016, 51 states and territories participated in the cognitive decline module and 40 with the caregiver module. CDC also supported the Association of State and Territorial Health Officials and the National Association of Chronic Disease Directors to implement priority action items from the HBI Road Map of particular significance to their constituencies in select states across the United States. A major focus of CDC's efforts to support the actions of the HBI Road Map and the Healthy People 2020 objectives related to dementia is to "educate and empower the nation." To meet that challenge, CDC initiated a number of special interest projects within the CDC Prevention Research Center (PRC) program.

For more information, see:
- http://www.alz.org/publichealth/data-collection.asp

Public Health and Economic Costs. CDC funded a project designed to promote public health understanding regarding the economic costs associated with AD/ADRD by examining different economic models to estimate community and inpatient care, as well as the societal costs associated with losses of productivity and quality of life by persons living with AD/ADRD and their caregivers. The University of Washington PRC began conducting a review of the literature and will examine de-identified data from the Group Health Cooperative to calculate costs and make recommendations for improvement to allow states and localities to better forecast dementia care costs.

Curriculum for Use in Schools of Public Health. CDC supported the development of *A Public Health Approach to Alzheimer's and Other Dementias*, a new curricular resource developed by the Centers for Technical Assistance and Training in the Emory University's Rollins School of Public Health. This flexible, introductory curriculum will help faculty prepare undergraduates for careers in which they need to apply public health approaches to address AD as a multi-layered, growing public health challenge. The Centers mapped the curriculum to established competencies.

The modular design enables use in entirety or as stand-alone modules. Each module has a slide set and faculty guide with learning objectives, list of relevant competencies, talking points, and teaching aids. Microsoft Office formats enable users to adapt materials for integration into existing undergraduate courses or other educational offerings.

For more information, see:
- http://www.alz.org/publichealth/curriculum.asp

Oregon Dementia Training for Alzheimer's Disease and Related Dementias Staff. With funding from an ACL Alzheimer's Disease Supportive Services Program (ADSSP) grant, Oregon was able to provide dementia training for over 600 statewide Aging and Disability Resource Center (ADRC) Information and Assistance and Options Counseling staff. Nine online modules were developed to address ADRC staff roles in addressing issues including person-centered care for people with dementia, communication, information and referral options, decision support for people and families, care transitions, advance planning, and specific needs for people with IDD. The training is part of Oregon's efforts to increase dementia-capability of its ADRC system and statewide LTSS.

Educate Health Care Providers. HRSA, in collaboration with the HHS Office on Women's Health (OWH), supported the development of a Medscape continuing education course on assessing, managing, and treating AD/ADRD in the context of multiple chronic conditions. This educational offering, titled "Bidirectional Impact of Alzheimer's Disease and Common Comorbid Conditions" was released in September 2016. A total of 7,107 learners accessed the site in the first 6 months.

In FY 2015, HRSA combined and redesigned its four geriatrics programs into the Geriatrics Workforce Enhancement Program (GWEP). The GWEP supports transforming clinical training environments by developing a health care workforce that maximizes patient and family engagement to improve health outcomes for older adults by integrating geriatrics with primary care. The GWEP aims to provide the primary care workforce with the knowledge and skills to care for older adults by collaborating with community partners to address gaps in health care for older adults through individual, system, community, and population-level changes. In addition, the GWEP also supports training of patients, families, caregivers, direct care workers, health professions providers, students, residents, and fellows who will provide health care to older adults, and the faculty who train these individuals.

All GWEP awardees identified significant needs for dementia training. In FY 2017, HRSA supported 44 GWEP awardees totaling approximately $38.7 million; $5.978 million was used to provide dementia education and training. In FY 2015, GWEP awardees provided 402 continuing education offerings and trained 43,148 participants on AD/ADRD.

IHS Workforce Partnerships. The Indian Health Service (IHS) initiated a series of partnerships to increase workforce skills and competency in caring for individuals with dementia and their families. IHS has met with HRSA GWEP grantees to discuss opportunities for training in IHS, Tribal, and Rural Indian Health programs. IHS partnered with the VA to introduce VA's Rural Interdisciplinary Team Training (RITT) in small, rural IHS and Tribal facilitates; eight sites were trained in FY 2016- FY 2017 and RITT training will be provided to clinics serving the Aleutian and Pribiloff Islands in August 2017. In October 2015, IHS collaborated with ACL in support of the Banner Alzheimer's Institute Inaugural National Conference on Alzheimer's Disease/Dementia in Native American Communities, bringing together clinical staff, Tribal aging services staff, Tribal leadership, and researchers. In April 2016, IHS held a web-based course on AD/ADRD as part of the IHS Clinical Rounds series. In November 2016, the Banner Institute partnered with ACL, IHS, and the Centers for Medicare & Medicaid Services (CMS) to provide both professional and para-professional training in AD/ADRD as part of a national conference on *Tribal Long-Term Services and Supports* in Minneapolis, Minnesota.

VA Geriatric Scholars Toolkit. VA's Geriatric Scholars staff training program has created a Geriatric Scholars Toolkit covering 12 clinical topics in geriatrics, including dementia. Each topic contains two sections: (1) clinical assessment, management, and treatment; and (2) educational materials for patients and their caregivers. More than 2,800 toolkits have been disseminated to VA rural clinics, community living centers (CLCs), program participants, and local and national VA leaders in geriatrics. In addition, more than 330 toolkits have been made available to the public through the federal library system. Toolkit

pages or links to information are also available for downloading online; the Toolkits have been viewed over 900 times to date.

For more information, see:
- http://www.gerischolars.org

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VA Rural Interdisciplinary Team Training. The RITT program is a component of the VA Geriatric Scholars Program, through which VA has been delivering on-site education to rural VA clinics since 2010. The VA Employee Education System sponsors accreditation for Continuing Medical Education (CME) credits/Continuing Education Units (CEU). The curriculum focuses on: (1) efficiency and teamwork in primary care to care for older patients; (2) recognizing geriatric syndromes and red flags; (3) distinguishing dementia, delirium and depression; and (4) brief evidence-based tools for cognitive assessment. With funding from the VA Office of Rural Health, 20 sessions will be completed in 2017 and over 100 rural VA Community-Based Outpatient Clinics have participated.

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IHS Rural Interdisciplinary Team Training. The RITT program is a component of the VA Geriatric Scholars Program, which VA has been delivering on-site to IHS and Tribal Health Program (THP) clinics since 2016. The VA Employee Education System sponsors accreditation for CME/CEU, and IHS/THP clinicians are able to receive continuing education credits through the TRAIN platform for interagency sharing of training products. The curriculum focuses on: (1) efficiency and teamwork in primary care to care for older patients; (2) recognizing geriatric syndromes and red flags; (3) distinguishing dementia, delirium and depression; and (4) brief evidence-based tools for cognitive assessment. So far, in 2017, five sessions have been scheduled or completed and others are being planned. The activity is funded by the VA Office of Rural Health.

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Staff Training in Assisted Living Residences-VA in VA Community Living Centers. STAR-VA is an interdisciplinary behavioral approach to managing challenging behaviors among VA CLC (i.e., nursing home) residents with dementia, adapted from Dr. Linda Teri's Staff Training in Assisted Living Residences (STAR) program. The STAR-VA intervention entails four core components: (1) Creating realistic expectations of individuals with dementia; (2) Promoting effective communication with individuals with dementia; (3) Identifying and changing activators and consequences of challenging behaviors (ABCs); and (4) Increasing personally relevant pleasant events through a structured process. In STAR-VA, a CLC mental health professional and registered nurse are trained to train the entire CLC team to collaborate on behavioral assessment and care planning. Between 2010 and 2017, 83 VA CLCs have participated in STAR-VA training. Evaluation outcomes include significant decreases in the frequency and severity of target behaviors and decreased symptoms of depression, anxiety, and agitation among participating veterans.

For more information, see:
- https://www.nhqualitycampaign.org/files/STAR-VA_Manual_2016.pdf

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VA Psychotropic Drug Safety Initiative. VA aims to ensure veterans have access to high-quality, evidence-based pharmacological treatments for mental health and substance use disorders. To this end, in December 2013 the VA's Veterans Health Administration (VHA) launched the Psychotropic Drug Safety Initiative (PDSI), a nationwide psychopharmacology quality improvement program at VA medical facilities. PDSI supports facility and Veterans Integrated Service Network quality improvement initiatives by providing quarterly scores on 35 prescribing performance metrics; informatics tools that identify actionable patients with opportunities for improvement in their care, updated daily; a virtual learning collaborative; technical assistance for quality improvement implementation; and training and educational resources. PDSI Phase 2 (October 2015-June 2017) focused on improving evidence-based prescribing among older veterans in both outpatient and long-term care settings. The four aims for Phase 2 include: (1) improving the quality of prescribing among veterans with dementia by decreasing inappropriate use of

antipsychotics and benzodiazepines; (2) decreasing benzodiazepine and sedative hypnotic use; (3) increasing metabolic monitoring among older veterans prescribed an antipsychotic; and (4) decreasing use of highly anticholinergic medications.

Strengthen State Aging, Public Health, and Intellectual and Developmental Disability Workforces. HRSA GWEP awardees are collaborating with 30 Area Agencies on Aging (AAAs) and 15 Quality Improvement Organizations (QIOs) to strengthen state aging, public health, and IDD workforces. HHS will coordinate with states to develop a workforce in aging, public health, and IDD that is AD-capable and culturally-competent. For example, the Gateway GWEP is partnering with the AAAs throughout Missouri to provide training statewide in Cognitive Stimulation Therapy for individuals with mild-to-moderate dementia. Group participants take part in a number of engaging activities to help stimulate the brain and interact with others in a group atmosphere. An example of a collaboration with a QIO is at the University of Iowa's GWEP, known as the Interprofessional Strategic Healthcare Alliance for Rural Education (iSHARE). iSHARE partners with Telligen, which is providing quality facilitators who document patient outcomes data for iSHARE in the clinics of their primary care partners. Telligen has access to CMS data across several states, and iSHARE and Telligen are working together to determine whether it is possible to promote cross-GWEP partnerships by working on dementia training. If successful, regional/national collaboration may be undertaken as a pilot project.

Develop and Disseminate a Unified Primary Care Alzheimer's Disease Curriculum. HRSA worked with federal partners at ACL, CDC, CMS, OWH, and VA on a contract to develop a Dementia Curriculum for Health Care Professionals. The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. A Technical Expert Panel (TEP) consisting of dementia experts, HRSA and the federal partners identified module topics. Specifically, 16 core modules along with 13 caregiving modules have been developed and pilot-tested. The core modules were built upon the ACT on Alzheimer's preparing Minnesota communities training materials and address various high-priority issues related to the detection, management and treatment of AD. The developed materials are appropriate for guided teaching by faculty in academia and continuing education programs and are appropriate for interprofessional clinical audiences. The caregiver modules development was supported by the OWH. Thirteen modules were produced, four targeted to providers as a means to enhance their interaction with and integration of the caregiver in the medical care team and the remaining nine targeted to family caregivers to encourage and refer them to resources to support them in maintaining their own health, safety and well-being while providing care for someone with AD/ADRD.

The materials can be found on the HRSA website. GWEP awardees and other educators will use these materials and adapt them as needed to meet local needs.

For more information, see:
- http://www.actonalz.org/dementia-curriculum
- https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

Public Health Live Webcasts on Dementia Care. "Public Health Live" is a monthly webcast series designed to provide continuing education opportunities on public health issues. In 2015, the New York State Department of Health (NYSDOH), in conjunction with the State University of New York and Albany Medical College, offered the webcast "Alzheimer's Disease and Advanced Directives: A Primer for Primary Care Physicians." Offerings for 2017 include "Clinical and Ethical Indications for Cognitive Impairment Screening in Primary Care" and "Healthy Communities: An Assessment and Implementation Framework to Achieve Inclusion of Persons with Disability."

For more information, see:
- http://www.albany.edu/sph/cphce/phl_0915.shtml
- http://www.albany.edu/sph/cphce/phlchron.shtml

Dementia Friendly America Provider Tools. Dementia Friendly America (DFA) is a multi-sector, national collaborative of cross sector organizations and individuals seeking to foster communities across the United States that are equipped to support people living with dementia and their caregivers. Dementia-friendly communities foster the ability of people living with dementia to remain in the community and engage and thrive in day to day living; basic things like going to the store or the bank. The community also buoys the caregiver by adding extra supports such as respite programs. DFA has developed provider tools and resources that support timely and accurate diagnosis, education for families after a diagnosis of AD/ADRD, offers dementia care guidelines, fosters safe transitions of care, and advances coordinated and integrated health and longer services and supports. Links to the resources can be found at the DFA website.

For more information, see:
- http://www.dfamerica.org
- http://www.dfamerica.org/provider-tools-1/

Resources for Clinicians. NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals.

For more information, see:
- https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals

Improvements in the Home Care Workforce. CMS took steps in 2016 to outline strategies states can use to stabilize the Medicaid home care workforce, an important element of dementia care.

For more information, see:
- https://www.medicaid.gov/federal-policy-guidance/downloads/cib080316.pdf

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Linking the Public to Diagnostic and Clinical Management Services. ACL has new educational opportunities for family members of and service providers for persons with IDD about changes that may indicate the onset of dementia. Two webinars and an issue paper became available in 2015.

For more information, see:
- https://nadrc.acl.gov/sites/default/files/uploads/docs/IDD-and-Dementia%20Paper%20July%202015.pdf

Gerontological Society of America Report. A report is available that summarizes the discussion of a workgroup convened to outline the pathway from detection to diagnosis to management using evidence-supported tools. These tools can be integrated into clinical work flow, including the assessment opportunity created by the inclusion of cognitive impairment detection as a required element of the Medicare Annual Wellness Visit (AWV). The workgroup involved a team of experts that the Gerontological Society of America assembled from across the public, private, and academic sectors.

For more information, see:
- http://www.geron.org/ci

Strategy 2.C: Educate and Support People with Alzheimer's Disease and Related Dementias and Their Families upon Diagnosis

Educate Physicians and Other Health Care Providers About Accessing Long-Term Services and Supports. One barrier to counseling and support is that health care providers are not aware of available services and how to access them. To address this need, HRSA is collaborating with federal partners, public and private entities, the health care provider community, and community-based organizations to effectively educate primary care providers and other health care practitioners, direct services workers, and patients, families, and caregivers about and services and supports available to assist persons living with dementia, as well as their caregivers. All 44 GWEPs provide this training and 32 GWEPs partner with the Alzheimer's Association. For example, the Alzheimer's Association in St. Louis, Missouri, is providing Baseball Reminiscence Leagues for persons with a dementia diagnosis. The Gateway GWEP, which created the original Baseball Reminiscence League for veterans, now refers persons with a dementia diagnosis and an interest in baseball to these specialized support groups as part of their current GWEP/Alzheimer's Associations partnership.

Massive Online Open Course on Coursera - Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies. This free course involves five self-paced modules which examine the psychological, social, and economic impacts on persons and their families as well as society at-large. Health professionals and students, family caregivers, friends of and affected individuals, and others interested in learning about dementia and quality care will benefit from completing the course. Led by Drs. Nancy Hodgson and Laura Gitlin, participants will acquire foundational knowledge in the care of persons with AD and other neurocognitive disorders. The course will move to an open access format such that it will be continuously offered. It will be available on Coursera in the summer of 2017.

For more information, see:
   • https://www.coursera.org/learn/dementia-care#

New York State Programs for Alzheimer's Disease and Other Dementias. In 2015, NYSDOH's Alzheimer's Disease Program implemented a new $25 million strategy to support people with AD/ADRD and their caregivers, and the programs continue to make progress into 2017. This initiative represented the single largest state investment in these services in the state's history and made a significant difference in the lives of the targeted population. The initiative is based on evidence that demonstrates that providing an array of caregiver services in the community helps avoid unnecessary hospitalizations and emergency room visits, delays nursing home placement, and improves caregiver burden and mental health outcomes. All of the projects within the initiative are participating in a comprehensive evaluation to measure the impact on caregivers throughout the state.

For more information, see:
   • https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/county/

Association for Fronto-Temporal Dementia Travel Grants. AFTD offers modest financial assistance for people with FTD and caregivers interested in attending an FTD education conference. In FY 2016, AFTD awarded 60 Comstock Travel Grants to help people defray the costs of travel and lodging to attend an FTD focused education conference.

For more information, see:
   • http://www.theaftd.org/wp-content/uploads/2012/07/Comstock-Travel-Grant_and_Letter.pdf

Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings

National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers. Under the auspices of the NAPA Advisory Council, planning is fully underway for a *National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers*. The goal of this research summit is to identify what we know and what we need to know in order to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, their families, and other caregivers. The Summit is focused on research that is needed to improve quality of care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers.

Cross-cutting themes of the Summit include:
- Diversity (SES, race, ethnicity, culture, language, literacy, geographic locations)
- Disparities
- Etiologies and Disease Stages
- Care Settings (home, community, assisted living, nursing home, and medical/health care settings)
- Training and Workforce Issues
- Technology
- Differential Impact on Women

Anticipated outcomes of the Summit 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.
- Spread of information to the public including people living with dementia and their caregivers.

The Summit will be held on October 16-17, 2017 at NIH.

For more information, see:
- https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers

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Clarify and Disseminate Information on Privacy, Autonomy, and Safety Issues for Physicians. Based on the recommendation of the Advisory Council to clarify information on privacy, HHS will develop information for physicians on privacy, autonomy, and safety issues. This resource will help providers better understand these issues and the balance between safety, privacy, and autonomy. HHS will disseminate this information through the trainings provided by the GWEP awardees in Strategy 2.A.

Elder abuse and elder justice are important topics, especially for persons living with dementia. Sixteen GWEPs have produced training materials for primary care providers on this important topic. For example, the University of Washington's Northwest GWEP has produced two online modules: Elder Mistreatment and Elder Investment Fraud to address these critical issues.

For more information, see:
- http://www.nwgwec.org/activities/geri-series/elder-mistreatment/
- http://www.nwgwec.org/activities/geri-series/elder-investment-fraud/

Dementia Caregiving Network. The Dementia Caregiving Network (DCN) is an interprofessional Hartford Change AGEnts Initiative working to achieve improvements in services, supports, and care for

persons with dementia and their family caregivers, supported by the John A. Hartford Foundation. Since January 2014, DCN has identified core concepts that define or influence practice change activities in dementia caregiving. One project involves developing a database of existing caregiver support interventions for agencies to access to determine which programs to adapt. Another project involves identifying ways to modify electronic records to identify families of persons with dementia. Yet another project involves evaluating and critiquing existing measurement sets. Finally, another project involves advancing a model for care management through managed care organizations.

For more information, see:
- http://www.changeagents365.org/

Home and Community-Based Services Quality. Measuring quality in HCBS settings, where few endorsed measures exist, has become increasingly important in the new cross-setting health care paradigm, especially as Medicaid funding continues to shift from institutional to cost-effective community-based care. CMS recently received CAHPS® endorsement for its HCBS Experience of Care Survey.

For more information, see:
- https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/cahps-hcbs-survey/index.html.

Improved Care in the Nation's Long-Term Care Facilities. CMS issued a final rule in 2016 that made major changes to improve the care and safety of the nearly 1.5 million residents in the nation's 15,000 long-term care facilities (nursing homes) that participate in Medicare and Medicaid. The policies in the final rule help to reduce unnecessary hospital readmissions and infections, improve quality, and strengthen safety measures for residents. The rule also strengthens staffing provisions, requires person-centered care, includes a specific requirement for dementia training, betters discharge planning, and updates infection prevention and control protocols.

For more information, see:
- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Nursing-Homes.html.

VA Dementia Care Recommendations. VA's VHA Dementia Steering Committee Recommendations have been updated and are now posted online. The recommendations provide guidance to improve the health and well-being of veterans by increasing access to best practices in care for veterans living with dementia, their families, or other caregivers. The recommendations, which are not themselves formal VHA policy or mandates, are interdisciplinary, VA-specific, and comprehensive; combine published evidence with VA experts' experience; and address dementia recognition, diagnosis, treatment at different stages, care coordination, administrative matters, research, and education.

For more information, see:
- http://www.va.gov/Geriatrics/GEC_Data_Reports.asp

VA Clinician Fact Sheet on Detection of Cognitive Impairment. VHA's National Center for Health Promotion and Disease Prevention (NCP) Clinician Fact Sheet, *Detection of Cognitive Impairment*, has been updated and is now posted online. VHA does not recommend routine screening for cognitive impairment in asymptomatic older adults (those presenting with no signs or symptoms of cognitive impairment). Instead, it recommends that VHA Primary Care clinicians should be alert to early signs or symptoms of cognitive impairment and evaluate as appropriate. The NCP Clinician Fact Sheet includes lists of warning signs that clinicians may notice or that patients and caregivers may report, plus elements of a structured diagnostic evaluation if warning signs are present.

For more information, see:
- http://www.prevention.va.gov/docs/NCP_CPS_Factsheet_Cognitive_Impairment.pdf

Factors Influencing the Progression of Disability in Older Adults. Information about the health and disability status of older adults at a point in time is known, but information on how this changes over time at the person level is more limited. For example, how do physical limitations change over time? How rapidly does someone go from needing only assistance with bathing to needing help with other self-needs? We know that women tend to live longer than men, but are there differences in how rapidly disability progresses once it begins? The HHS Office of the Assistant Secretary for Planning and Evaluation's (ASPE's) project uses the National Health and Aging Trends Study (NHATS) data from 2011 to 2015 to study the progression of disability and the implications for caregiving needs. Outcomes data are being tabulated each year (death, long-stay nursing home admission, residential care admission, continued or increased use of informal/paid care). Those who develop dementia after 2011 would be studied, but most cases would already have dementia or symptoms in 2011, and the course of their condition would be followed through 2015. The effects of demographic characteristics (age, sex, race, marital status, income, education) on the incidence of disability and their effect on its progression are being studied as well.

Trends in Residential Care Settings for Older Adults. Most long-term care for older Americans is provided by family and friends in the home. When the needs become greater than home care can provide, nursing home admission is often used. However, increasingly older Americans are relying on care in an array of facility-based settings, such as assisted living facilities. ASPE's project is analyzing trends in residential care, using data at various points in time from several data sources, including the Medicare Current Beneficiary Survey (MCBS), NHATS, and the National Study of Long-Term Care Places (NSLTCP). This project will present the estimates, explain why they would be expected to differ across sources, and analyze the resulting trends. The sources also contain some information on the characteristics of facilities and residents. This information is being analyzed to further determine the role such places play in the long-term care system, and to better understand the reasons for differences in the estimates across sources.

Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease and Related Dementias

Alzheimer's Disease Supportive Services Program. ACL continues to support state grantees and their partners in the implementation of dementia-capable LTSS systems. The grantees are lead dementia agencies within their states, in direct response to recommendations from the Advisory Council. Grantees are: (1) developing a "no wrong door" service system; (2) ensuring access to comprehensive, sustainable services for people with dementia and their family caregivers; and (3) implementing evidence-based or informed interventions as part of their programs. In 2016, ADSSP expanded to include two new states -- Texas and Michigan. This program's focus on dementia-capability and direct services through evidence-based interventions and targeted training is in direct response to the recommendations of the Advisory Council. ACL anticipates continuation of the ADSSP with new grants in 2017.

Alzheimer's Disease Initiative-Specialized Supportive Services. ACL continues to support 32 Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) grantees and their partners, which are located across the country and in Puerto Rico. The grantees are operating within dementia-capable systems and implementing new programs designed to provide more effective services to: (1) individuals living alone in the community with dementia; (2) individuals with IDD who have or are at-risk of developing dementia; (3) caregivers who need behavioral symptom management training or expert consultations to help them care for family members; and (4) provision of effective care/supportive services for individuals living with moderate to severe AD/ADRD and their caregivers. Grantees include a broad

range of existing dementia-capable public and private entities. Grantees have tailored their programs to address service gaps in the communities they serve, including implementation of evidence-based and evidence-informed interventions. ACL anticipates the continuation of the ADI-SSS program, with new funding in 2017.

ACL National Alzheimer's and Dementia Resource Center. ACL continues to fund a resource center that supports ACL grantees, their partners, and the larger Aging and Disability Networks in developing and implementing dementia-capable programs, dementia-friendly communities, specialized supportive services, and evidence-based programs. In addition to providing technical assistance, the National Alzheimer's and Dementia Resource Center (NADRC) manages an annual webinar series that is open to the general public, writes issue briefs on program-related topics, and evaluates and summarizes program results. NADRC staff also manages and facilitates grantee learning opportunities that result in resources that are beneficial to program activities and also made available to the general public. The NADRC website is home to numerous resources developed both in house and through agency grant programs.

For more information, see:
- http://www.nadrc.acl.gov/

Examining Models of Dementia Care. ASPE has completed a study examining dementia care models across settings using a framework to understand what providers are doing to provide care to individuals living with dementia and their families. The project is intended to better understand what "innovative" dementia care providers have in common and what practices may inform future understandings of quality dementia care. The project involves an environmental scan of best practices in dementia care, and a series of five case studies conducted across the country and in a range of dementia care settings. The results will inform future research related to developing quality measures and standards. ASPE has also conducted additional work to review the literature on outcomes of models or programs for dementia care to better understand how effective they are at improving the quality of life or health for people living with dementia and/or their caregivers.

For more information, see:
- https://aspe.hhs.gov/report/examining-models-dementia-care-final-report

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Georgia Alzheimer's and Related Dementias State Plan. The Georgia Alzheimer's and Related Dementias (GARD) State Plan Advisory Group continues to meet to implement the GARD State Plan and to create a more dementia-capable Georgia. In June 2016, the Georgia Department of Human Services Division of Aging Services hired the very first GARD State Plan Coordinator. There are currently six workgroups made up of stakeholders from various sectors including health care, social services, and public policy. These workgroups include: Workforce Development; Service Delivery; Public Safety; Outreach and Partnerships; Policy; and Healthcare, Research and Data Collection. The current initiatives of GARD are focused on improved dementia education and training, implementation of person-centered care, and early and accurate diagnosis of dementia.

Minnesota: Dementia-Capable State. Minnesota is building a dementia-capable state through the synergistic efforts of a host of dementia collaborations including:

- The ACT on Alzheimer's® Collaborative's many accomplishments include: (1) Dementia-Friendly Communities now at 40 and counting; (2) Dementia Curriculum developed by leading experts in Minnesota; and (3) culturally infused Provider Practice Guidelines, 1,500 physicians and care coordinators have trained in these dementia care best practices. In Minnesota, the Health Care Summit advanced the adoption of the practice guidelines in health care systems with three major health care organizations leading the way and more in the wings. The state's Caregiver initiative

lead to the funding of the Dementia Grants program where culturally sensitive caregiver education and services are targeted.

- National Family Caregiver Support Program Act -- Minnesota has developed a statewide network of over 100 dementia-capable caregiver consultants who have or are completing the Minnesota culturally infused Caregiver Consultation training and Advanced Dementia-Capability training online and in-person training. Also, through Minnesota's current ADI-SSS grant the Resources for Enhancing Alzheimer's Caregivers' Health (REACH) Community is being embedded as a routine caregiver consultation service.

- The State of Minnesota ADI-SSS grant being implemented through 2017 delivers culturally infused Dementia-Capability training to the statewide network of aging services and health care providers via a Learning Management System that combines online and in-person training. Courses are tailored for the learner at three levels based on their prior knowledge, skills and job function. The Dementia-Capability training also addresses those with IDD and persons with dementia living alone. Cultural Consultants provide guidance and education to aging service providers and communities to increase understanding of the norms and values of diverse clients with dementia and their caregivers. Physician and care coordination training is delivered in collaboration with ACT Dementia-Capable Communities.

West Virginia Coordinated Action, Response, Education and Support about Families Living with Dementia. The initiative's aim is to help organizations and individuals in non-profit, law enforcement, faith, business and other communities learn about dementia so they can assist and enhance the quality of life for individuals living with dementia. In addition, West Virginia Coordinated Action, Response, Education and Support (WV CARES) will connect individuals and families living with dementia to national, state and local resources for education and support. The Blanchette Rockefeller Neurosciences Institute is leading the effort along with key partners throughout the state including AARP, Alzheimer's Association-West Virginia Chapter, the Claude W. Benedum Foundation, the Manahan Group, the West Virginia Bureau of Senior Services, and the West Virginia Sheriff's Association.

Outcomes for Phase I of this initiative are: (1) educate West Virginians about the prevalence, early warning signs and symptoms of AD/ADRD, as well as the economic impact of the disease; (2) establish dementia-friendly faith communities that are a safe, supportive and welcoming environment for people with dementia; (3) establish dementia-friendly financial/legal services as legal and financial advisors may be the first to identify cognitive decline; (4) encourage dementia-friendly businesses that are meeting the needs of customers and employees; and (5) ensure dementia awareness among emergency response and law enforcement personnel.

WV CARES is part of the DFA network as the only statewide initiative of the network's six pilot sites.

For more information, see:
- https://www.facebook.com/WestVirginiaCARES/

Supported Decision Making Resource Center. ACL is promoting supported decision making (SDM) because it is a valuable option in helping people with dementia and others who may have cognitive issues exert control over choices made in their lives. SDM can also improve current guardianship arrangements for older adults and people with disabilities who need support. SDM is a more inclusive alternative than guardianship that uses trusted friends, family members and advocates to assist people with disabilities understand and make their own choices. SDM shows great promise for increasing self-determination and improving quality of life outcomes. ACL supports a national training, technical assistance, and resource center to explore and develop SDM as an alternative to guardianship. Among the center's projects is development of resources for professionals that include legal documents, standards for persons involved in SDM, research to discover how people use SDM, and evaluation of its effectiveness. The ultimate goal is to develop a model that will help states and individuals consider alternatives to guardianship by 2019.

For more information, see:
- http://www.supporteddecisionmaking.org

Analysis of New Payment and Service Options for Medicare-Medicaid Dual Eligible Beneficiaries. ASPE is currently engaged in a project to produce targeted research briefs on options for expanding the Programs of All-Inclusive Care for the Elderly (PACE). PACE was established as a permanent Medicare and Medicaid benefit by the Balanced Budget Act of 1997, and it attempts to help nursing home eligible older adults avoid institutional care by providing them with an appropriate, tailored mix of coordinated acute care and HCBS. PACE is designed for the frail elderly. To be eligible, participants must be 55 or older and certified by their state of residence as being eligible for nursing home level of care. The PACE Innovation Act gives the Secretary of HHS the authority to test changes to the PACE model, such as serving individuals under the age of 55, and people who do not meet the current nursing home level of care criteria, but may be at-risk of entering a nursing home. The anticipated deliverables for this project include four research briefs that address the policy implications, benefit design, and financing structure of an expanded PACE program, including a descriptive analysis of subpopulations of dual eligible beneficiaries under age 55. Nationally, nearly half (49% comp) of PACE participants have been diagnosed with dementia, therefore lessons from the PACE model may have strong applicability to the field of dementia care broadly. Reports are expected by December 2017.

Resources for Enhancing Alzheimer's Caregivers Health VA. As part of the VA's Caregiver Support Program, the Memphis Caregiver Center has been training staff since 2011 to deliver the REACH-VA caregiver program. Over 1,000 VA staff have been trained. In 2017, through a partnership between VA's Office of Care Management and Social Services and Office of Rural Health, REACH-VA is offered directly from Memphis to caregivers of veterans and veterans who are caregivers. A recent article reported that after caregiver participation in REACH-VA, caregivers are better able to manage the behavioral concerns of the person with dementia and their own stress and burden; in addition, health care costs for the person with dementia are decreased.

VA Models of Non-institutional Long-Term Care. VHA has implemented innovative programs to provide patient-centered alternatives to long-term institutional care. New models of care have included programs focusing on dementia care, care coordination, and/or caregiver support. A summary report on *Veterans Health Administration (VHA) Innovative Dementia Models of Care: Patient-Centered Alternatives to Institutional Extended Care* was posted online. The report described a number of innovative programs developed and implemented at VA medical facilities, along with some initial results and lessons learned from the projects.

VHA continues to offer a range of innovative dementia care programs in urban, suburban and rural areas that provide veteran and caregiver support through multi-media communication, education, in home services, outpatient services, and interaction with primary care teams.

Examples of some of these sustained, successful innovative programs include the following:
- The Caring for Older Adults and Caregivers at Home program is a home-based dementia care program that assists veterans and their caregivers through support, education, and referrals with the aim of delaying nursing home placement, reducing caregiver burden, and improving dementia care. The program has been recognized by VA's Office of Rural Health as a Promising Practice based on improved access, strong partnerships/working relationships, evidence of clinical impact, return on investment, operational feasibility, and customer satisfaction.
- The VA Mobile Adult Day Health Care (ADHC) program, also known as the ADHC Mobile Veteran Program, is a therapeutically-oriented outpatient program that serves to enhance veterans' quality of life and alleviate isolation and depression by maximizing their physical, mental, and social abilities and well-being. The program provides support and respite care for families and other caregivers of veterans who are functionally impaired and/or socially isolated, enabling the veteran to maintain residence in a supportive home environment. VHA establishes

community partnerships, usually with Veteran Service Organizations, that donate the use of their site. VHA staff travel to the site during specified days, as agreed upon with the community partner. veterans must have a designated VA primary health care provider who provides orders while the veteran is enrolled in the program. The VA Mobile ADHC program treatment team recommendations are communicated to the primary health care provider based on the veteran's individual need.

For more information, see:
- https://www.va.gov/Geriatrics/docs/VHA_Innovative_Dementia_Models_of_Care_Sept_2015.pdf

VA Care of Patients with Complex Problems. VA is working to identify promising care models for veterans with complex medical, neurocognitive, and psychiatric comorbidities with behaviors that can be disruptive to safe and effective care across inpatient and nursing home care settings. Many of these veterans have dementia. Preliminary focus is on interdisciplinary behavioral consultation models and transitional care models to facilitate discharge to appropriate levels of care and decrease behavioral readmissions.

Medicare-Medicaid Accountable Care Organization Model. CMS announced a new model that builds on the Medicare Shared Savings Program, where Medicare Accountable Care Organizations (ACOs) that hit spending and quality targets are able to share in savings with CMS. This particular model will consider Medicaid savings, as the enrollees will be dually eligible for Medicare and Medicaid, and could include long-term care services. CMS intends to enter agreements with as many as six states.

For more information, see:
- https://innovation.cms.gov/initiatives/medicare-medicaid-aco-model

Research Continues to Seek New and Effective Ways to Improve Care. An overwhelming majority of older adults want to continue living at home as they age. In recognition, the Collaborative Aging (in Place) Research using Technology (CART) Initiative unites NIH, other government agencies, academic, and industry experts to develop and test tools that track changes in older adults' health status and activities unobtrusively in real time, so they can remain at home as long as possible. Launched in October 2016, the $9 million, 4-year project, which includes contributions from a number of NIH institutes and VA, will start with a pilot project in more than 200 homes in rural and urban communities across the United States. The potential benefits for older adults and their families and/or caregivers are many as more people could stay in their own homes as they age, comfortably and safely.

For more information, see:
- https://www.nia.nih.gov/newsroom/features/nih-initiative-tests-home-technology-help-older-adults-age-place
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-16-021.html

Translation of Care of Persons with Dementia in their Environments in a Publicly-Funded Home Care Program. This home-based intervention involves up to 12 home visits; a nurse provides education to caregivers as to common concerns (constipation, detection of pain, incontinence, hydration and importance of taking care of self), conducts a brown bag medication review, takes blood and urine from the person with dementia and does a visual inspection of skin integrity; an occupational therapist meets with families to assess abilities of person with dementia and to work with caregiver to provide strategies for managing their care challenges and educate them as to the nature of the disease and ways to support daily functioning.

Activities include:
- NIA-funded trial ongoing in Connecticut to translate this approach in Medicaid Waiver Program (Principal Investigator, Dr. Richard Fortinsky, Co-Investigator, Dr. Laura Gitlin).
- ACL-funded project to Maine's Adult Day Serves to integrate Adult Day Plus and Care of Persons with Dementia in their Environments (COPE) Intervention.
- ACL-funded project to Orange County, North Carolina to integrate COPE/Tailoring Activities for Persons with Dementia and Caregivers (TAP) into home care services.
- Australia-funded translational study of COPE in various settings (hospital to home, home care, social service agencies).
- COPE as part of the MIND model being tested under the CMS's (Innovation Center) Health Care Innovation Awards (HCIAs).
- COPE being integrated into a program for Managed Care to be delivered by Volunteers of America.

Patterns of Care and Home Health Utilization for Community-Admitted Medicare Patients. The Medicare home health payment policy for fee-for-service (FFS) has undergone several changes in the past decades. There have also been overall increases in Medicare home health utilization. Growth in utilization has been particularly strong for community-admitted users (those individuals for whom home health episodes are not preceded by a hospitalization or post-acute care (PAC) stay). MedPAC has suggested that this is indicative of the fact that some beneficiaries may be using the home health benefit as a long-term care benefit.[14] Several alternative explanations for the growth of the community-admitted users are plausible. Indeed, a recent Academy Health meeting on PAC noted that as the American population ages, those with chronic conditions will likely cycle between post-acute and chronic care services.[15] ASPE has begun a study to better understand the growth in use of the Medicare home health benefit by community-admitted users. This research will focus on detailed beneficiary characteristics and the trajectory of care of the community-admitted users to clarify the source of the growth in the benefit for this group of beneficiaries using home health, identify possible gaps in care or inefficient use of services, and inform benefit design. A report will be available later in 2017.

Strategy 2.F: Ensure that People with Alzheimer's Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems

Preventable Hospitalizations. CDC worked with partners to conduct a review of interventions related to dementia and decreasing preventable hospitalizations, as well as a systematic review of caregiver interventions. The findings from this review will help to inform the current state of evidence-based strategies and interventions related to the Healthy People topic area "Dementias, including Alzheimer's disease" and its objective "To reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer's disease and other dementias." A publication that described the results is available.

For more information, see:
- http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4310672

Initiative to Reduce Avoidable Hospitalizations Among Nursing Facility Residents. The first phase of the Initiative ended in 2016 and has shown reductions in avoidable hospitalizations. A recent *Health Affairs* article details results from 2015 evaluation and final results are expected in the fall of 2017. In 2016, Phase Two of the Initiative to Reduce Avoidable Hospitalizations among Nursing Facility Residents launched which provides enhanced payments to participating nursing facilities for the treatment of the six most common conditions associated with potentially avoidable hospitalizations: pneumonia, congestive heart failure, chronic obstructive pulmonary disease/asthma, skin infections, dehydration, and urinary tract infections. Additionally, this model includes payments to practitioners in nursing facilities that are similar to the payments they would receive for treating patients in hospitals. Practitioners also will be paid

for engaging in multi-disciplinary care coordination and caregiver engagement. The Initiative is taking place in nearly 260 nursing facilities across seven states, Alabama, Colorado, Indiana, Missouri, Nevada, New York, and Pennsylvania.

For more information, see:
- Initiative to Reduce Avoidable Hospitalizations Among Nursing Facility Residents Shows Promising Results, *Health Affairs*, March 2017, 36:3441-45
- https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/InitiativetoReduceAvoidableHospitalizations/AvoidableHospitalizationsamongNursingFacilityResidents.html

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Nursing Home Compare Improvements. In July 2016, nursing homes were required to submit daily staffing data that is traceable to an auditable source. CMS is collecting the staffing data now and plans to have new staffing measures derived from it on Nursing Home Compare (NHC) in early 2018.

For more information, see:
- https://www.medicare.gov/nursinghomecompare/search.html

Improved Care Planning for Medicare Beneficiaries. In 2013, CMS began paying separately under the Medicare Physician Fee Schedule for transitional care management services for the transition of Medicare beneficiaries back into the community following discharges from certain settings. In 2015 CMS began paying separately under the Medicare Physician Fee Schedule for chronic care management (CCM) services for beneficiaries with multiple chronic conditions. In 2017, CMS began separate Medicare Physician Fee Schedule payment for additional care management services, including payment for: complex CCM for Medicare patients with multiple chronic conditions; behavioral health integration services including services furnished using the "psychiatric Collaborative Care Model"; and cognitive and functional assessment and care planning for beneficiaries with cognitive impairment (e.g., AD/ADRD). The latter, billed under code G0505 for 2017, must be furnished by a physician or other appropriate billing practitioner (e.g., nurse practitioner or physician assistant). The service includes a cognition-focused evaluation, including a pertinent history and examination; medical decision making of moderate or high complexity; functional assessment (for example, ADLs), including decision making capacity; use of standardized instruments to stage dementia; medication reconciliation and review for high-risk medications; evaluation for neuropsychiatric and behavioral symptoms (including depression), including use of standardized instruments; evaluation of safety (for example, home safety), including motor vehicle operation, if applicable; identification of caregivers, caregiver knowledge, caregiver needs, social supports, and the willingness of caregiver to take on caregiving tasks; advance care planning and addressing palliative care needs, if applicable and consistent with beneficiary preference; creation of a care plan, including initial plans to address any neuropsychiatric symptoms (NPS) and referral to community resources as needed (for example, adult day programs, or support groups); and care plan shared with the beneficiary or caregiver with initial education and support.

Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with Alzheimer's Disease and Related Dementias

Evaluate Evidence on Care Integration. HHS continued to explore how service delivery models that integrate acute care and LTSS add value beyond that of the traditional, fragmented care system. The project will have a special focus on integrated care functions for people with disabilities and cognitive impairment, and will describe payment policies that promote integrated care. This information will help HHS compare and evaluate existing integrated care interventions and support their growth. Information from the project will facilitate the expansion of promising integrated care models to improve care for Medicare and Medicaid beneficiaries with AD/ADRD.

Alzheimer's Disease and Related Dementias Affinity Group. CMS regularly convenes its staff experts through an AD/ADRD "Affinity Group" to align and coordinate efforts, and to advance programs and policies in this important area. In 2017, the AD/ADRD Affinity Group, with the help of ACL, sponsored a 1-day training on person-centered planning for individuals with dementia and other conditions.

Long-Term Care "Rebalancing". CMS issued the annual LTSS expenditure report, which summarizes national trends in LTSS (institutional care, and HCBS) data and spending, the percent of Medicaid spending used for LTSS, the HCBS portion of total LTSS expenditures, state spending variation, population groups, and shifts in federal statutory authorities used by states to deliver HCBS.

For more information, see:
- https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015final.pdf.

New York State Centers of Excellence for Alzheimer's Disease. NYSDOH invested $4.7 million to create regional Centers of Excellence for Alzheimer's Disease (CEADs) to enhance the quality of dementia diagnoses and care across the state. Ten CEADs were designated and funded in the amount of $470,000 to provide integrative and comprehensive medical services for the diagnosis of AD/ADRD; coordinate patient care and treatment for people with AD/ADRD; support and refer patients and their caregivers to community services; promote the benefits of participation in research; demonstrate strong working relationships with community organizations and care providers; promote public awareness about AD/ADRD; and train health care providers and students in health care professions on the detection, diagnosis and treatment of AD/ADRD.

Strategy 2.H: Improve Care for Populations Disproportionately Affected by Alzheimer's Disease and Related Dementias, and for Populations Facing Care Challenges

Alzheimer's Disease Initiative-Specialized Supportive Services. ACL continues to use Prevention and Public Health Funds to support 21 ADI-SSS grantees and their partners, which are located across the country and in Puerto Rico. The grantees are operating within dementia-capable systems and implementing new programs designed to provide more effective services to: (1) individuals living alone in the community with dementia; (2) individuals with IDD who have or are at-risk of developing dementia; (3) caregivers who need behavioral symptom management training or expert consultations to help them care for family members; and (4) provision of effective care/supportive services for individuals living with moderate to severe AD/ADRD and their caregivers. Grantees include a broad range of existing dementia-capable public and private entities including AD-specific organizations, academic institutions, an organization dedicated to services for the IDD community, a health system, states and several local community organizations. Grantees have tailored their programs to address service gaps in the communities they serve and use evidence-based and evidence-informed interventions to do so. ACL anticipates the continuation of the ADI-SSS program, with new funding in 2016.

Veterans-Directed Long-Term Services and Supports. ACL and VHA continue to partner in supporting states' efforts to develop and better coordinate no wrong door systems of access to services. Together they lead the national expansion of Veteran-Directed Home and Community-Based Services (VD-HCBS) with the goal of assuring that veterans of all ages receive the care they need in their homes and communities, and are provided appropriate supports that allow them to remain there. In many cases, veterans in VD-HCBS hire individuals they are most comfortable with including family, friends and neighbors, to provide the services and supports they require. Veterans with dementia who reside in VA

and community nursing facilities have been successfully transitioned back into the community with the support of VD-HCBS.

Comparing Outcomes for Dually Eligible Beneficiaries in Integrated Care Models. ASPE has a project underway to determine the feasibility of an analysis that compares selected health outcomes and quality measures for Medicare-Medicaid dual eligible beneficiaries participating in managed care models that align Medicare and Medicaid benefits, such as Medicare Advantage Dual Eligible Special Needs Plans (D-SNPs), Medicare Advantage Fully Integrated D-SNPs, and PACE, to outcomes for dually eligible beneficiaries who are not participating in these models. Dually eligible beneficiaries are almost three times more likely to have dementia as their Medicare-only counterparts, therefore programs that serve large numbers of dually eligible beneficiaries are likely to also serve people with dementia. This study aims to better understand whether dually eligible beneficiaries fare differently in different integration models across a number of categories including but not limited to, mortality, nursing home utilization, hospital readmissions, and chronic conditions (inclusive of AD/ADRD or Senile Dementia, as identified in CMS's Chronic Conditions Data Warehouse). The project deliverables include an environmental scan of existing research comparing outcomes for dually eligible beneficiaries in Special Needs Plans and PACE to outcomes for beneficiaries who are not participating in these models, an analysis plan, and an exploratory analysis that will inform a report on the feasibility of the analysis plan given the current data available. Reports are forthcoming in 2018.

Policy Options for Medicare-Medicaid Dual Eligible Beneficiaries. ASPE has a project underway to identify policy options for using Medicare Advantage D-SNPs as a platform to integrate care for dual eligible beneficiaries. D-SNPs are a type of Medicare advantage managed care plan that enroll only dual eligible beneficiaries and are required to provide or coordinate all Medicare and Medicaid benefits for their enrollees. Twenty-two percent of older people with dementia are duals, and the number is increasing, and this population could benefit from the coordinated and aligned care offered by D-SNPs. This project produced a report detailing policy options, considerations, and challenges for using D-SNPs as a scalable platform for broader integration of Medicare and Medicaid benefits. A report is forthcoming by December 2017.

Analysis of Pathways to Dual Eligible Status. ASPE has a project underway to identify the frequency with which the various eligibility pathways to dual eligible status are utilized and to understand the circumstances and characteristics of individuals surrounding their transition to dual status. Individuals become dually eligible for Medicare and Medicaid programs through multiple pathways. They can become eligible for one of the programs before the other, based on age, disability, or income; or they may simultaneously become eligible for both programs. However, current understanding of these pathways remains limited. Differences in the pathways to dual eligibility have implications for Medicare and Medicaid spending and service use patterns. Understanding these differences can inform policy efforts to support the dual eligible population and individuals at-risk for becoming dually eligible. Nearly one-quarter (23%) of dual eligible beneficiaries over the age of 65 have AD/ADRD. A report is forthcoming in December 2017.

New York State Alzheimer's Disease Caregiver Support Initiative for Under-served Communities. NYSDOH allotted $1.5 million to fund a wide range of caregiver support and respite services for caregivers of individuals with AD/ADRD, either or both of whom are members of under-served communities. Fifteen contractors, funded at $100,000 each, provide culturally-competent support initiatives and stress reduction strategies for caregivers of diverse under-served populations across the state. Contractors provide extensive outreach, intake and assessment, referral, and at least one of the following core services: support groups, education, caregiver wellness, and joint enrichment.

Addressing Disparities in Alzheimer's Disease and Other Dementias in New York State. NYSDOH allocated $250,000 for a demonstration project with the goal of increasing AD/ADRD screenings in primary care settings for African American and Hispanic populations, to promote earlier diagnosis and treatment of AD/ADRD among these populations, and to connect those diagnosed with AD/ADRD to community support, medical services, and clinical trials. Long-term objectives include effective disease management, continued community residence, and decreased caregiver burden.

Goal 3: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families

Families and other unpaid caregivers play a central role in caring for people with AD/ADRD and may need supports beyond the care provided in settings such as doctors' offices, hospitals, and nursing homes. Supporting people with AD/ADRD and their families and caregivers includes providing access to tools that they need and helping to plan for future needs with the goal of maintaining safety and dignity. Under this goal, the Federal Government and partners will undertake strategies and actions that will support people with the disease and their families and caregivers.

Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials

National Brain Health Center for African Americans. CDC supported the development of the National Brain Health Center for African Americans (NBHCAA). The mission of NBHCAA is to raise awareness of the issues of cognitive health among African Americans by working through networks of faith-based institutions and by establishing partnerships with organizations and individuals dedicated to our mission. The three areas of focus of brain health education, mobilization and advocacy, and networking. NBHCAA serves as an information hub on the human brain that must be shared throughout all networks that reach and touch approximately 40 million African Americans living in the United States.

For more information, see:
  • http://brainhealthcenterforafricanamericans.org/

Training African American Nurses about Brain Health. With CDC support, the Balm in Gilead in partnership with the National Black Nurses Association trained African American nurses from 14 chapters of the National Black Nurses Association across the United States in 2016. Additional training are ongoing in 2017.

Alzheimer's and Dementia Training for Aging Professionals. ACL hosted Alzheimer's and dementia training workshops, including a half-day session, at a national conference of aging professionals. The sessions provided information on initiatives designed to improve community-based care for individuals living with dementia and their caregivers.

For more information, see:
  • https://nadrc.acl.gov/node/97

National Alzheimer's Call Center. Through the National Alzheimer's Call Center, ACL funds the operation of a national information and counseling service for persons with AD/ADRD, their family members and informal caregivers. The National Alzheimer's Call Center is available to people in all United States and territories, 24 hours a day, 7 days a week, 365 days a year to provide expert advice, care consultation and information and referrals nationwide, at the national and local levels, regarding AD/ADRD. The Alzheimer's Association, which received the ACL grant, is currently in the fourth year of a 5-year funding period which will end July 31, 2018.

Indian Country Aging Programs. Indian Country programs involve educational efforts and implementation of a proven caregiver support program. Education involves: consumer fact sheets on dementia in Indian Country, conference presentations, training programs, and webinars.

For more information, see:
- http://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LongTermCare.html

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Training Resources for IHS Staff. IHS completed a review of training resources for IHS nursing staff. Articles in the IHS Primary Care Provider highlighted person-centered goals and strategies for improving care for persons with dementia. IHS collaborated with HRSA to engage the HRSA-funded GWEPs in strategies to improve recognition and diagnosis of dementia.

Currently eight GWEPs partner with federally recognized Tribal populations and one collaborates with a non-federally recognized Tribal population. The nine GWEPs have developed a Native Populations Interest Group in preparation for exchanging training materials. The University of Wyoming is currently developing culturally-relevant dementia training material for Native American people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's *Know the 10 Signs: Early Detection Matters*.

Outreach and Training in Indian Country. IHS provided training at the National Meeting of the Title VI Directors (the ACL-funded Aging Network) on AD/ADRD and outreach and education at the National Indian Council on Aging Biennial Meeting. IHS, CMS, and ACL provide technical assistance in the development of LTSS through the jointly sponsored LTSS Technical Assistance website and shared Tribal models of LTSS in the monthly webinar series and co-sponsored a Tribal LTSS conference in Minneapolis, Minnesota, in November 2016, with a focus on AD/ADRD.

For more information, see:
- http://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-Technical-Assistance-Center/Overview.html

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Language to Assist with the Indian Health Care Improvement Act. IHS developed sample language to assist tribes to make use of new authorities under the Indian Health Care Improvement Act to provide LTSS and supports tribes to include specific language regarding delivery of LTSS in funding agreements.

Oregon Caregiver Training. Initial funding approved by the Oregon Legislature in 2013 was renewed in 2015 to support free statewide funding for paid and family caregivers, and for public safety workers. More than 1,400 caregivers have participated in training to date. Oregon Care Partners is a collaboration among a number of Oregon organizations that came together to support this statewide training effort. Training is offered both in-person and online, with topics addressing AD/ADRD, challenging behaviors, and geriatric medication management and safety.

For more information, see:
- http://www.oregoncarepartners.com

Cultural Infusion in Dementia Training. The State of Minnesota is creating a dementia-capability online training that is infused with culturally specific information to reflect the norms and values of diverse cultural groups. This material is developed by cultural experts who provide a series of in-person and video conference training sessions to statewide aging service providers, medical clinics and others. The presentations focus on the issues that affect the person with dementia and caregiver, as well as tips on how the aging network providers address dementia in a specific ethnic/cultural community.

New York State Alzheimer's Disease Community Assistance Program. The Alzheimer's Disease Community Assistance Program (AlzCAP), expanded in 2015 to a $5 million project, promotes effective

patient management, education and support for people with AD/ADRD, family caregivers, health care personnel, volunteers, community agencies, and first responders. New York State funds the Coalition of Alzheimer's Association Chapters, which oversees subcontracts with six New York State Alzheimer's Association Chapters across the state and CaringKind in New York City. AlzCAP provides care planning and consultation; caregiver training; support groups; 24-hour helpline; community awareness; and increased training for important constituencies.

Dementia Friendly America Supports for People with Dementia and Their Families. DFA provides communities with tools and resources that provide guidance on how each sector of the community can adopt sector-specific practices to become dementia-friendly. This includes advance planning, optimal clinical practices, dementia-friendly business practices, inclusion practices for faith communities, dementia-friendly disaster planning, first response, housing, public spaces and transportation and dementia-friendly customer relations. Communities identify and implement change goals that can result in increased supports for people with dementia and their families. This has led to respite care, new meaningful engagement opportunities and enhanced clinical and community supports. These changes can foster dignity, safety and rights of people with AD/ADRD. The cumulative desired results of this work include a safer and more welcoming environment that supports family caregivers.

For more information, see:
- http://www.dfamerica.org/toolkit-1/

Geriatric Competent Care. CMS's Medicare Medicaid Coordination Office held several webinars for its Geriatric-Competent Care series. 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 AD, and in working with their caregivers. Webinars addressed several elements of dementia.

For more information, see:
- https://www.resourcesforintegratedcare.com/GeriatricCompetentCare/2017_GCC_Webinar_Series/Series_Overview

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Comprehensive Primary Care Plus Model Payment for Dementia. Comprehensive Primary Care Plus (CPC+) is a national advanced primary care medical home model through CMS's Innovation Center that aims to strengthen primary care through regionally-based multi-payer payment reform and care delivery transformation. In 2017, CPC+ supports 2,891 primary care practices of 13,090 clinicians serving more than 1.76 million Medicare beneficiaries in 14 diverse regions. CPC+ has three payment elements: a care management fee, a performance-based incentive payment, and payment under the Medicare Physician Fee Schedule. Participating providers will receive a monthly additional fee for care management of enrolled Medicare beneficiaries with complex needs, including dementia.

For more information, see:
- https://innovation.cms.gov/initiatives/comprehensive-primary-care-plus

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Connected Care. CMS is working to raise awareness of the benefits of CCM services for Medicare beneficiaries with multiple chronic conditions. Connected Care is a nationwide effort in FFS Medicare that includes a focus on racial and ethnic minorities and rural populations, which have higher rates of chronic disease. Resources include a toolkit for providers, a partner toolkit with resources/activities, and beneficiary education, including a poster/postcard.

For more information, see:
- https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html

Latinos and Alzheimer's Disease: New Numbers Behind the Crisis. In September 2016, LatinosAgainstAlzheimer's network released a report in partnership with the University of Southern California Edward R. Roybal Institute on Aging entitled *Latinos and Alzheimer's Disease: New Numbers Behind the Crisis*. The report noted that without a medical breakthrough that prevents, cures or slows the disease progression, United States Latinos living with AD are projected to increase from 379,000 in 2012 to 1.1 million by 2030 and 3.5 million by 2060 -- an 832% increase. In addition, the report found that the cumulative direct and indirect costs of AD on the United States Latino community, including millions of family caregiver, would ultimately cost the United States economy $373 billion by 2030 and $2.35 trillion (in 2012 dollars) by 2060. The report's findings highlight the urgency of addressing the disparate impact of Alzheimer's on United States Latinos, who are 50% more likely than non-Hispanic Whites to develop the disease.

For more information, see:
  • http://www.usagainstalzheimers.org/sites/.../Latinos-and-AD_USC_UsA2-Impact-Report.pdf

"Forget Me Not" Play. In partnership with Axovant, AfricanAmericansAgainstAlzheimer's network organized educational events in six cities in 2016, through performances of the play *Forget Me Not*. The play raises awareness for AD by focusing on one African American family's struggle with the disease, through comedy and relatability. The play covers the ramifications of the disease's impact and effect on the members of the family, as they try to cope with their father's diagnosis. The events reached almost exclusively African American audiences with information about AD and opportunities to connect with local clinical trial resources, including potential trial enrollment.

Engaging Faith Leaders in Caregiver Support. In 2016, ClergyAgainstAlzheimer's network published a *Leader's Guide for Seasons of Caring*. The *Leader's Guide* provides guidance and structure for support groups based on the network's interfaith volume, Seasons of Caring: Meditations for Alzheimer's and Dementia Caregivers. Nationally renowned author and retired Reverend Dr. Richard L. Morgan based the *Leader's Guide* on more than 60 years of pastoral care for those with AD. Seasons of Caring includes 140 original meditations representing 17 faith traditions offering words of hope, encouragement and understanding.

Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being

Economic Impacts of Programs to Support Unpaid Caregivers. ASPE has begun a study on the economic impacts of programs to support informal caregivers. Informal caregiving is likely to grow in the coming decades as the baby boomer cohort ages. Not only will there likely be an increased need for caregiving, as disability increases with age, but the ratio of individuals potentially available for caregiving will decrease. For some caregivers of older adults and persons with disabilities, providing care may make it difficult or impossible to have paid employment, or if they do have employment, may make it difficult to advance their career. If they take time out of the labor force, they may face obstacles to returning to employment at all, or at a similar level of responsibility and pay than when they left. Both the direct costs in lost wages of not working, as well as the loss of seniority and retirement benefits may leave some caregivers economically vulnerable when they themselves age. In addition to the costs and benefits to caregivers, there are costs and benefits to the nation of informal caregiving. Inasmuch as unpaid caregiving replaces paid caregiving, unpaid caregivers may provide a net benefit to the country, reducing federal, state, and local caregiving expenditures. However, increased informal caregiving may also lead to reduced labor force participation, resulting in lower national economic growth as the number of individuals performing informal caregiving increases. Lack of support for informal caregivers may also

lead to burnout and placement of the care recipient in a facility that is more costly to the government than earlier support services such as HCBS may have been.

This research aims to provide a framework for policy makers to begin estimating costs and benefits of policies and programs aimed to help caregivers, including, for example, respite care, paid family leave, and workplace flexibility policies. While researchers have established a number of relationships that can help inform government policies that impact informal caregiving, there are both gaps in knowledge, and lack of a consistent consideration of policies from an economic perspective. This project will organize existing information around caregiving to better understand the economic impacts of caregiving.

Lifespan Respite Care. ACL continues to support the expansion and enhancement of state Lifespan Respite Care programs which are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs, to give them a break from the demands of caregiving. These programs are designed to reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels. Lifespan Respite Care programs work to improve the delivery and quality of respite services available to families across the age and disability spectrum, including those with dementia. Lifespan Respite Care programs advance the following objectives:

- Expand and enhance respite services in the states.
- Improve coordination and dissemination of respite services.
- Streamline access to programs.
- Fill gaps in service where necessary.
- Improve the overall quality of the respite services currently available.

Adult Day Care and Residential Care State Policy Compendia. ASPE recently updated two policy compendia examining state approaches to regulation of long-term care settings. The first compendium examines state regulation around adult day services (ADS) -- a non-residential service that provides services outside of an individual's home for less than a full day to older adults and younger adults with physical disabilities. These services also meet unpaid caregivers' need for respite in order to work, fulfill other obligations, and recover from the demands of continuous caregiving. Many caregivers who use ADS are providing care to family members with dementia who need constant supervision to ensure their safety. The second compendium examines state approaches to residential care, including assisted living. Residential care provides 24-hour supervision, meals, and assistance with ADLs. States vary in their approaches to licensure for residential care facilities.

For more information, see:
- https://aspe.hhs.gov/basic-report/regulatory-review-adult-day-services-final-report-2014-edition
- https://aspe.hhs.gov/basic-report/compendium-residential-care-and-assisted-living-regulations-and-policy-2015-edition

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Effect of Dementia on Hospitalization and Emergency Department Use in Residential Care Facilities. ASPE recently released a report examining the experiences of individuals living in residential care facilities (including assisted living) who have dementia. Understanding the availability and adequacy of these services is critical to understanding the range of options available to individuals with functional and cognitive limitations. These papers examine dementia care in residential care facilities based on analysis from the National Center for Health Statistics (NCHS)-ASPE National Survey of Residential Care Facilities. The analysis found that:

- Half of residential care facility residents aged 65+ had severe cognitive impairment.
- Nearly one-quarter of all residential care facility residents had at least one hospitalization and more than one-third had at least one emergency department visit in the past 12 months.

- Among residential care facility residents, living in a special care unit for dementia or a facility that only serves individuals with AD/ADRD decreases the risk of hospitalization.

For more information, see:
- https://aspe.hhs.gov/basic-report/what-effect-dementia-hospitalization-and-emergency-department-use-residential-care-facilities

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CMS-led Caregiver Workgroup. This workgroup is an ongoing joint effort between CMS and its partner organizations (non-profit organizations, federal partners, and others). Held quarterly in Washington, DC; the agenda topics are open for partners to present and give updates.

Reducing Caregiver Stress. We are continuing to learn more about what affects and supports caregivers, particularly a role that new technologies may be able to play. To build on new technological capabilities, in March 2017, NIH invited small business to submit applications for a new approach to caregiving -- the use of socially-assistive robots, to address the needs and conditions of caregivers to older people with AD/ADRD.

These robots, it is envisioned, could help caregivers with difficult or physically stressful tasks. Additionally, they could function as companions that may help in reducing the effects of loneliness experienced by people with dementia or offer psychosocial support by enhancing social connections and communications; provide physiological support through use of techniques like biofeedback; and assist with care management and ADLs.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-107.html

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Maintaining Caregiver Health and Well-Being. The State of Minnesota received an ACL ADSSP expansion grant in 2015 to pilot a collaboration between a medical center and an aging services provider to identify caregivers of people with AD/ADRD and connect them to an aging service provider for dementia-capable caregiver consultation including individualized dementia education, care planning and support services. A short screen included in the rooming process identifies patients who are caregivers and their level of stress. A positive screen initiates a caregiver protocol embedded in the electronic medical record. The caregiver is linked to the aging service provider (caregiver consultant) via the clinic's care coordinator. The clinic and aging service provider share information regarding the health of the caregiver and supports received through a shared release of information. After pilot completion, the goal is to roll out this protocol to the medical center's remaining clinics and showcase the project for other health care systems.

Dementia: Awareness, Screening Testing and Support of Caregivers. In 2015, the Minnesota State Legislature appropriated funds to the Minnesota Board on Aging for a competitive grant program focusing on dementia and its impact on caregivers. The goals of the grants are to increase awareness of AD/ADRD, increase the rate of cognitive testing, promote the benefits of early diagnosis of dementias, and/or connect caregivers of persons with dementia to education and resources. Twenty grantees were selected, including aging service providers, community health boards, a hospital and a major university. Fourteen of the grantees have some component of their project focused on ethnic and cultural communities including Latino/Hispanic, Somali, African American, American Indian, Lao, Korean, LGBT and Holocaust survivors. The projects include innovative ideas such as: using an online App to reach and support caregivers in an ethnic community; identifying and supporting female employees who are caregivers and work in a supermarket chain; and training staff of fitness centers about how to recognize symptoms of dementia and offer fitness services.

Testing and Scaling up the New Ways for Better Days: Tailoring Activities for Persons with Dementia and Caregivers Program. TAP is an intervention that provides activities tailored to abilities of persons with dementia and trains caregivers in their use. Pilot randomized clinical trial data suggest its efficacy in reducing behavioral symptoms and improving caregiver abilities and time spent in providing care. This approach has been tested in the home and also in hospital settings with occupational therapists as interventionists.

Activities include:
- NIA-funded trial that is ongoing in Baltimore to test efficacy.
- Australia-funded a trial in Sydney, Australia with individuals with FTD.
- The program is currently being used in Scotland (it will be part of their dementia care approach), Australia, England, Brazil, various United States. ACL has funded several sites using the program.

Access to the training program is in the form of online training modules. A face-to-face and virtual launch party was held May 26, 2016, to showcase the program. The initial training target is occupational therapists nationally and internationally. Modifications to the program are underway so that other professionals are able to use this approach.

For more information, see:
- http://learn.nursing.jhu.edu/face-to-face/institutes/NewWay-TAP/index.html

Translation and Evaluation of the Adult Day Service Plus Program. ADS Plus augments ADS with a systematic approach to supporting families. Staff of ADS (e.g., social worker, care manager, intake specialist, occupational therapist, nurse) can be trained to provide ADS Plus. Pilot data in three centers showed that ADS Plus increased the number of days using ADS, decreased nursing home placement, improved caregiver well-being including decreasing depressive symptoms, and enhanced sense of self-efficacy.

Activities include:
- Through funding from ACL, ADS sites in Maine are using ADS Plus combined with elements from TAP and COPE.
- NIA-funded study to test ADS Plus in 30 sites across the country.
- Plan to add sites and also develop an online program to train ADS staff nationally.

New York State Alzheimer's Disease Regional Caregiver Support Initiative. New York State is providing a total amount of $15 million to offer a wide range of caregiver support and respite services. Ten regional contractors, reaching every county in the state and funded at $1.5 million each, provide support services to promote the mental and physical well-being of caregivers. Services include support groups, respite services, care consultation, family consultation, and education for caregivers. Additional offerings consist of caregiver wellness programs, joint enrichment opportunities to include the person with dementia and their caregiver, and technology-based services. Contractors utilize strong community relationships and have a robust media presence to promote and connect caregivers with services.

NASEM Study on Family Caregiving for Older Adults. The study analyzed the prevalence of family caregiving and the demographic, societal, and technological trends that influence it. It also examined caregivers' roles and responsibilities, both current and expected in the future, and the impact of the caregiver role on individual health, employment, and well-being. Caregivers' unmet needs and the gap between the projected demand for caregivers and the population available to serve as caregivers was assessed and differences associated with race and ethnicity, culture, rural residence, and geography were examined. The study also reviewed the evidence of the effectiveness of potential supports for family caregivers and care recipients across a range of settings including, for example, in medical homes and other primary care settings, HCBS settings, acute care hospitals, and residential facilities. These

included, for example, models of team-based care that include the family caregiver as member; approaches to training providers regarding the caregiver role; and models for training caregivers for their various roles.

For more information, see:
- http://www.carenewengland.org/carenews/upload/carenews4-20hqp.pdf
- http://www.jhartfound.org/blog/author/gary-epstein-lubow/
- http://www.nationalacademies.org/hmd/Activities/Aging/FamilyCaregivingforOlderAdults.aspx

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Respite Grants. Since 2009, AFTD has been offering Comstock Respite Grants to help full-time unpaid caregivers get a much needed break from caring for a loved one with an FTD disorder at home. In FY 2016, AFTD awarded 132 annual grants of $500 to help FTD caregivers cover the costs of short-term respite care for a loved one or family member. There are few requirements to qualify for a Comstock Respite Grant other than caring for a loved one with a documented diagnosis of FTD at home.

For more information, see:
- https://www.theaftd.org/wp-content/uploads/2016/12/2016-Comstock-Respite-Grant-Application.pdf

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Strategy 3.C: Assist Families in Planning for Future Care Needs

Understanding How Families Find and Access Long-Term Services and Supports. Little is known about how families and older adults gather information, make decisions, and access long-term care when a loved one needs assistance such as after a dementia diagnosis. In 2015, ASPE undertook an exploratory qualitative research project to examine where families gather information, how they make decisions, how well these arrangements work, and how local factors influence this process. The project includes focus groups with caregivers in four communities in one state, as well as an environmental scan of the resources for finding LTSS in these communities.

Helping Persons with Dementia Communicate Their Care Desires. Many families face difficult care choices for their loved ones with advanced dementia who often have lost the ability to communicate meaningfully. These choices are usually made in nursing homes and other institutional settings, often with a limited amount of time to discuss and decide. To address this gap, NIH-supported researchers developed a Goals of Care (GOC) intervention, which combined a video decision aid and a structured care plan meeting for family decision makers. Their main goals were to evaluate if the GOC intervention improved quality of communication and decision making, and whether it would improve palliative care for people with advanced dementia. The study showed that the intervention improved end-of-life communication, enhanced palliative care plans, and reduced hospital transfers for nursing home residents with advanced dementia.

For more information, see:
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5234328/

Dementia Caregivers' Technology Preferences: Design Insights from Qualitative Interviews. This study by Shreve, Baier, Epstein-Lubow, and Gardner, and published in *Gerontechnology*, was intended to determine which information technology design characteristics and functionality family caregivers of adults with dementia would find most helpful. Emerging information technology may ease the burden of family caregivers, particularly those caring for adults with AD/ADRD. User-driven information technology design methods can determine which information technology design characteristics and functionality family caregivers of adults with dementia would find most helpful. Family caregivers were overwhelmingly receptive to the idea of website or smartphone technology interventions and detailed specific needs that

technology could address, including alleviating the psychological burden and social isolation inherent in caregiving, providing access to information and resources, and helping them to ensure care recipients' safety and track the progression of disease. The findings highlight potential technology solutions to address the overwhelming social isolation and stresses prevalent among family caregivers of adults with AD/ADRD. Given the unmet needs of this growing group of consumers, researchers and developers of information technology should incorporate caregiver perspectives, both during the design process and in the resulting products themselves.

For more information, see:
- http://www.gerontechjournal.net/index.php/journal/article/view/gt.2016.14.2.004.00/2357

AFTD Support Group Affiliation Initiative. The Support Group Affiliation Initiative connects volunteer support group facilitators to AFTD, and each other, for networking, education and peer support. To date, 71 facilitators from groups in 27 states have joined this growing network dedicated to providing FTD-specific support. By affiliating with AFTD, support group facilitators can: attend ongoing trainings by FTD experts as well as troubleshooting and networking calls with affiliated peers, and gain access to AFTD-branded materials to help educate group members and promote the group locally. AFTD's has always offered assistance to FTD support groups. Through this initiative, AFTD can ensure more people living with FTD and their caregivers have access to high-quality and FTD-specific support systems and services.

For more information, see:
- http://www.theaftd.org/wp-content/uploads/2015/06/AFTD-Newsletter-Fall2015.pdf
- http://www.theaftd.org/get-involved/regions

Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease and Related Dementias

Office of Long-Term Care Ombudsman Programs. ACL's Office of Long-Term Care Ombudsman Programs (OLTCOP) continues to provide training, technical assistance, and federal regulations that help states' long-term care ombudsman (LTCO) programs to better meet the needs of individuals living with dementia in long-term care facilities. These activities include a National Ombudsman Resource Center (NORC) webinar titled: *LTCOP Rule: Supporting Person-Centered Advocacy -- Complaint Investigations and Abuse Reporting*. OLTCOP continues to identify the complaint trend of improper evictions from both nursing homes and board and care settings; this has been the top complaint in nursing homes for the past 5 years and state Ombudsman programs report that persons with dementia who do not have their needs properly addressed are often at-risk of an eviction. The OLTCOP, along with other ACL staff, participate in a workgroup convened by CMS to identify systemic strategies to address this trend. In addition, the OLTCOP continues to work with states regarding the implementation of the LTCO rule, which became effective on July 1, 2016. ACL's Regional Support Centers incorporated states' LTCO rule implementation into their 2016 annual reviews and provide ongoing technical support focusing on conflict free, person-centered complaint resolution strategies. ACL will continue its evaluation of the impact of LTCO programs and practices generally, including those that affect residents living with dementia and their families.

Elder Abuse Prevention. ACL's National Center on Elder Abuse (NCEA) is dedicated to protecting all from the many forms of elder abuse, including those with dementia. NCEA has rebranded and updated its fact sheets, research briefs and training materials. Many of these materials are adaptable to assist families in crisis especially when their family member has lost the capacity to make their own decisions and may be especially susceptible to harm by others. For example, a research brief on dementia is available. NCEA also consults with Alzheimer's Association chapters on elder abuse issues.

For more information, see:
- http://www.ncea.aoa.gov/Resources/Publication/docs/NCEA_Dementia_ResearchBrief_2013.pdf
- https://www.nia.nih.gov/about/events/2015/nih-workshop-multiple-approaches-understanding-and-preventing-eldr-abuse

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Model Approaches to Legal Assistance. The Model Approaches to Statewide Legal Assistance Systems (Model Approaches) grants help states develop and implement effective approaches for integrating low cost legal mechanisms into statewide legal/aging service delivery networks in order to enhance overall service delivery capacity. One program notable achievement is in Maine, which involved the launch of a financial institutions training initiative called Senior$afe. The grantee worked with representatives from the Maine Office of Securities, Maine Bureau of Professional and Financial Regulation, Adult Protective Services (APS), the Maine Bankers Association, and the Maine Credit Union League. Maine's grantee also developed a streamlined reporting system for financial institutions who wish to make a report without a customer's consent. Nebraska established a partnership with the Nebraska Bankers' Association through the APS state office to address financial exploitation issues. Several bankers who participated in training intend to work with APS on elder abuse and financial exploitation issues.

Volunteer Representative Payee Pilot Program. The Social Security Administration (SSA) and ACL collaborated in development and testing of protocols and materials to assist in the identification and training of individuals to serve as volunteer representative payees. The materials developed include a manual for program implementation, protocol guidance relating to communications between SSA and APS, and forms for referrals. SSA is in the process of finalizing online training modules and continues to build awareness of the program through listening sessions and presentations. Once the modules are complete, SSA will conduct a media campaign to build awareness of this volunteer program.

National Partnership to Improve Dementia Care in Nursing Homes. The focus of the National Partnership to Improve Dementia Care in Nursing Homes continues to be on the improvement of comprehensive dementia care in nursing homes across the country. The Partnership's larger mission is to enhance the use of non-pharmacologic approaches and person-centered dementia care practices. In September 2014, the National Partnership, a public-private coalition, established a national goal of reducing the use of antipsychotic medications in long-stay nursing home residents by 25% by the end of 2015, and 30% by the end of 2016. Both goals were achieved and new goals are currently under development. CMS continues to monitor the reduction of antipsychotics, as well as possible consequences of the partnership, by utilizing antipsychotic measures on NHC; the agency's public reporting website. Data from NHC are also used to report progress quarterly, both nationally and regionally.

For more information, see:
- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html
- https://www.nhqualitycampaign.org/files/AP_package_20170413.pdf
- https://www.medicare.gov/NursingHomeCompare/search.html

Person and Family Engagement Strategy. CMS issued a new Strategy to enhance person and family engagement that establishes definitions and consistency for frequently used terms to help people engage more fully in their health care, and serve as a guide to support meaningful, intentional application of person and family engagement principles to CMS's policies and programs addressing health and well-being.

For more information, see:
- https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Person-and-Family-Engagement.html

Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias

Picture of Housing and Health Part 2: Medicare and Medicaid Use Among Older Adults in HUD-Assisted Housing, Controlling for Confounding Factors. ASPE and the U.S. Department of Housing and Urban Development (HUD) released a follow-up report to the 2014 *Picture of Housing and Health: Medicare and Medicaid Use Among Older Adults in HUD-Assisted Housing*. This second report *Picture of Housing and Health Part 2* analyzed health care utilization and spending, taking into account confounding factors. The first report found a high prevalence of chronic conditions and higher health care utilization for HUD-assisted Medicare beneficiaries compared to unassisted beneficiaries. The study sought to understand whether the higher utilization could be explained by the characteristics of the sample. This second report finds that after taking into account characteristics associated with health care utilization and payment, HUD-assisted Medicare beneficiaries do not consistently have higher utilization and payment for health care services than unassisted Medicare beneficiaries.

- HUD-assisted Medicare-Medicaid enrollees were generally less likely to use certain Medicare-covered services, such as acute inpatient stays and skilled nursing facility stays, and they had significantly lower Medicare FFS payments than unassisted Medicare-Medicaid enrollees.
- However, HUD-assisted Medicare-Medicaid enrollees were much more likely to use Medicaid-covered community-based supportive services such as personal care services, durable medical equipment, and HCBS, and have higher Medicaid FFS payments.

This suggests that perhaps HUD-assisted Medicare-Medicaid enrollees were more aware of Medicaid-covered community-based supportive services than unassisted Medicare-Medicaid enrollees. While this indicates that HUD-assisted beneficiaries are not using more acute health care services than unassisted beneficiaries after controlling for confounding factors, they still represent a high risk, high needs group with a high prevalence of chronic conditions and disabilities. The study demonstrates that HUD-assisted Medicare-Medicaid enrollees may still be a fruitful target group for policy interventions, but that the interventions may vary depending on the type of Medicare beneficiary and the geographic location.

For more information, see:
- https://aspe.hhs.gov/basic-report/picture-housing-and-health-part-2-medicare-and-medicaid-use-among-older-adults-hud-assisted-housing-controlling-confounding-factors

Support and Services at Home Program. ASPE and HUD continue to evaluate the Support and Services at Home (SASH) program in Vermont. Early findings show a promising model of coordinated health and supportive services within affordable housing settings. Using claims data for a sample of Medicare FFS beneficiaries, the evaluation analyzed health care utilization and expenditures among SASH participants and a comparison group of Medicare beneficiaries living in affordable housing properties in Vermont. Analysis of Medicare claims data indicated that SASH participants in the early panels -- which included 40% of the site-based participants with Medicare coverage -- had lower rates of all-cause hospital admissions compared to non-participants. However, there was no evidence that the SASH program reduced the rates of emergency room visits. Medicare claims data also showed that, among the site-based SASH participants in early panels, growth in annual Medicare expenditures was slower by an estimated $1,227 per beneficiary per year. These same beneficiaries in the early panels also had slower rates of growth for hospital and specialty physician costs. Forthcoming products will show outcomes from the first 4 years of the program.

For more information, see:
- https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-second-annual-report

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Unlicensed Care Homes. ASPE released a report examining unlicensed care homes. Unlicensed care homes provide room, board and some level of services for two or more unrelated individuals, but are not licensed or certified by the state. These homes often serve very vulnerable individuals such as individuals with serious mental illness or other disabilities, or older adults with functional limitations and limited financial resources. Some of these homes are legally unlicensed while others operate illegally. The goal of this exploratory study was to understand how unlicensed care homes function as a residential care option, the types of individuals who reside in them, their characteristics including quality and safety and the policies that influence the supply of and demand for these homes. While exploratory in nature, the findings highlight potential issues of safety, abuse and financial exploitation in unlicensed care homes.

For more information, see:
- https://aspe.hhs.gov/basic-report/understanding-unlicensed-care-homes-final-report

Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of AD/ADRD; more than 85% of people surveyed can identify the disease and its symptoms. AD/ADRD is also one of the most feared health conditions. Yet there are widespread and significant public misperceptions about diagnosis and clinical management. These issues can lead to delayed diagnosis, and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is an essential goal because it forms the basis for advancing the subsequent goals of the National Plan. A better understanding of AD/ADRD will help engage stakeholders who can help address the challenges faced by people with the disease and their families and caregivers. These stakeholders include a range of groups such as health care providers who care for people with AD/ADRD and their caregivers, employers whose employees request flexibility to care for a loved one with the disease, groups whose members are caregivers, and broader aging organizations. The strategies and actions under this goal are designed to educate these and other groups about the disease.

Strategy 4.A: Educate the Public about Alzheimer's Disease and Related Dementias

Memory Sunday: Increasing Awareness of Alzheimer's Disease in Church Congregations. CDC supported the Balm in Gilead to develop and implement Memory Sunday, the Second Sunday in June, as a designated Sunday, within congregations serving African Americans, that provides education on AD: prevention, treatment, research studies and caregiving. The purpose of Memory Sunday is to bring national and local attention to the tremendous burden that AD/ADRD are having on the African American community; to utilize the power and influence of the African American pulpit to bring awareness; to distribute the facts about AD; to encourage participation in research studies; and to support persons living with AD and their caregivers.

For more information, see:
- http://brainhealthcenterforafricanamericans.org/memory-sunday

Alzheimer's Disease Resource Information. CDC developed in 2017 Alzheimer's and Healthy Aging Program Updates, which is a monthly email sent to more than 63,000 subscribers. Material contained in the emails are primary Federal Government resources for information about AD/ADRD, research, and caregiving.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/index.htm

Cognitive Health Awareness. ACL rolled out a campaign to change the way consumers aged 60-70 think about their brains and brain health. The campaign encourages older adults to talk about their brain health and take steps to reduce associated risks. Those experiencing MCI are encouraged to seek medical attention. The *What is Brain Health?* Campaign's website is currently available and its launch focused on St. Louis and Las Vegas in 2015. Focus areas in 2016 were San Francisco and Chicago. Both years' efforts have national elements. Development of a *What is Brain Health?* Campaign for Hispanic audiences is underway in 2017.

For more information, see:
- http://www.brainhealth.gov

Alzheimer's Disease Information. NIA operates ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. The ADEAR Center educates the

public about the latest research findings and provides evidence-based information online, in print and via a call center. Information about AD/ADRD, participation in clinical trials, and caregiving is freely available. NIA promotes ADEAR's resources through outreach in the research and care communities and through the media & advocacy organizations, via weekly e-alerts to more than 50,000 subscribers, and social media outreach to more than 10,000 followers. Beginning in late 2017, NIA will also manage Alzheimers.gov to continue to expand public outreach about AD/ADRD.

For more information, see:
- http://www.nia.nih.gov/alzheimers

Public Outreach on Brain Health. The Brain Health Resource, a presentation toolkit on brain health as we age, was developed by ACL with NIH and CDC, for use at senior centers and in other community settings. Written in plain language, the evidence-based resource explains what people can do to help keep their brains functioning best. In 2016, the toolkit was expanded to include materials in Spanish and a new brain health module entitled, Medicine, Age, and Your Brain.

NIH unveiled the Mind Your Risks public health campaign to educate people with high blood pressure about the importance of controlling blood pressure in midlife (ages 45-65) to help reduce the risk of having a stroke and possibly developing dementia later in life. The website includes research highlights, such as the Northern Manhattan Study, a NIH-funded investigation of the predictors of stroke, cognitive impairment, and dementia in a tri-ethnic community that may inform future intervention programs for prevention of stroke and cognitive decline in diverse populations.

For more information, see:
- https://www.acl.gov/node/293
- https://mindyourrisks.nih.gov/
- http://columbianomas.org/study.html

Public Health Research Network. CDC created the new HBRN in 2014, a thematic network in CDC's PRCs. The Network's activities build on the mission of CDC's HBI to better understand attitudes and perceived changes in cognitive functioning over time through public health surveillance, build a strong evidence base for communication (e.g., messaging) and programmatic interventions to improve or maintain cognitive function, and help to translate that evidence base into effective public health programs and practices in states and communities. The PRCs include the University of Washington Health Promotion Research Center (Coordinating Center), Oregon Health and Science University Center for Healthy Communities; University of Arizona Prevention Center; University of Illinois at Chicago PRC; University of Pennsylvania PRC; and University of South Carolina PRC.

For more information, see:
- http://www.cdc.gov/aging/healthybrain/research-network/index.html

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Message Development and Testing. CDC funded the development and dissemination of science-based, culturally-relevant messages and strategies that promote awareness about cognition and cognitive impairment, including AD/ADRD. The University of Pennsylvania PRC will assess perceptions about cognitive health and impairment among non-Hispanic White and African American adults aged 50 or older living in the Philadelphia area. This work is now being tested across the country with different populations at HBRN sites.

Dementia Chart Book. ASPE is completing a chart book, *Older Adults with Dementia and Their Caregivers in 2015: Key Indicators from the National Health and Aging Trends Study*, which includes important information on the population of community-dwelling people with dementia in the United States and their caregivers. Dementia was more prevalent among people who were over age 80, had lower

educational attainment, and were not non-Hispanic White. Older adults with dementia were more likely than those without dementia to have multiple chronic conditions, have functional limitations, experience depressive symptoms, or to need assistance. Older adults with dementia received significantly more hours of care per month than those without dementia. They had more informal caregivers and received more hours of care from those caregivers. More information and data are available in the chart book, which will be released in fall 2017.

AFTD Educational Webinar Series. AFTD's Educational Webinar Series invites expert medical researchers, clinicians and other professionals to address issues important to all whose lives are impacted by FTD. These webinars represent both the clinical and care sides of FTD. Space is limited for people to participate live, but the recorded webinar is available to all on AFTD's website.

For more information, see:
- http://www.theaftd.org/newsroom/event-archive/webinars

Lewy Body Dementia: State of the Science. LBDA published a new report in 2016 called *Lewy Body Dementia: State of the Science*. Written for the general public and specifically the LBD community, this white paper highlights the progress made in LBD and promising areas for further study. A two page "brief" was also published.

For more information, see:
- http://www.lbda.org/StateoftheScience

USAgainstAlzheimer's 2016 Summit. The 2016 Summit expanded to include a pilot *Alzheimer's and Dementia Disparities Summit*, co-hosted by the African American and Latino Networks and Leaders Engaged on Alzheimer's Disease, co-convened by UsAgainstAlzheimer's. More than 70 diverse academic, research, industry and federal stakeholders explored ways to eliminate disparities in AD/ADRD. The convening formulated the first-ever community driven action plan to increase awareness, understanding and action on AD among communities of color.

We Won't Wait Campaign. WomenAgainstAlzheimer's network launched a campaign, We Won't Wait, with 25 organizational partners. It is the first-ever widespread effort to define AD as the 21st century's primary economic justice and health crisis for women, through collaborations with private sector companies that reach women; advocacy organizations in health, women's rights and business; and a women's leadership circle to disrupt the conversations about this disease. The campaign has five pillars: (1) multiply public funding for AD research; (2) demand sex-based research into AD; (3) alleviate the economic injustice of AD; (4) improve families' access to diagnosis, treatment and clinical trials; and (5) promote risk reduction strategies and ideas for living well with AD.

Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease and Related Dementias Awareness and Readiness across the Government

Resources for Enhancing Alzheimer's Caregivers' Health into Indian Country. IHS and ACL are partnering with the REACH-VA training team at the University of Tennessee Health Sciences Center in REACH into Indian Country, a project funded by the Rx Foundation to implement the REACH caregiver support intervention across Indian Country. The initial goal of REACH caregiver support services, to be in at least 50 Tribal communities by February 2018, has nearly been reached. IHS and ACL continue work with VA to adapt and implement the REACH-VA program of caregiver support in Tribal communities

through both public health nursing and the Tribal aging network, and are now focusing on increasing the impact of caregiver support services in those communities and on sustaining the initiative following the end of Rx Foundation funding. REACH-VA is an evidence-based translation that uses structured interventions to provide caregivers of people with dementia with tools and skills to manage ongoing caregiving challenges. VA is a source of clinical expertise in diagnosis and management of dementia for many Native veterans. IHS is building on VA work to test strategies for early recognition among family members, as well as clinical and aging services staff.

For more information, see:
- https://www.uthsc.edu/prevmed/memphis-caregiver-center/index.php
- https://www.facebook.com/REACHIndianCountry/
- https://link.springer.com/artic…/10.1007%2Fs13142-017-0505-1

Dementia Friendly America Community Toolkit. DFA offers a four phase community toolkit that convenes community leaders and supports them through a community change process that raises awareness about dementia. As communities undertake the toolkit they help foster awareness of dementia and its impact. The toolkit process provides each sector of the community with guides that help individuals in that sector interact with people living with dementia. Additionally, the Dementia Friends program is aligned with international efforts to consistently educate and raise awareness of dementia, its impact and how to interact with people living with dementia.

For more information, see:
- http://www.dfamerica.org/sector-guides-1/

Strategy 4.C: Coordinate United States Efforts with Those of the Global Community

World Dementia Research Leaders. In October 2016, representatives from NIH participated in the 24th Management Board Meeting of the European Union (EU) Joint Programme on Neurodegeneration (JPND) and delivered a presentation on the IADRP managed by NIA. Over 30 member countries participated in the meeting; focused on the overall goal of increased international collaboration.

World Frontotemporal Degeneration Awareness Week. From September 25-October 9, 2016, people whose lives have been touched by FTD took part in the second annual World FTD Awareness Week. Across the country and around the world, families hosted gatherings at local restaurants, held conferences and other cultural events, participated via social media and told their stories to raise awareness of FTD. Global collaboration can improve quality of life for people facing FTD and drive treatment toward a cure.

For more information, see:
- http://www.theaftd.org/2events/2017-world-ftd-awareness-week-september-24-october-1-2017

Global CEO Initiative Updates. In 2014, the Global CEO Initiative on Alzheimer's Disease (convened by UsAgainstAlzheimer's) joined the Organization for Economic Cooperation and Development, the government of Switzerland and Alzheimer's Disease International to host an annual global regulators and payers workshop. The 2016 workshop, the third in this series, focused on applying lessons from other diseases to AD payer and regulator challenges. Also in 2016, these meetings sparked "The Lausanne Dialogue on Alzheimer's" and spurred work at the country-level, most recently in Japan, the United States and Switzerland.

For more information, see:
- https://healthpolicy.duke.edu/events

Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding AD/ADRD and its impact on individuals, families, the health and long-term care systems, and society as a whole. Data and surveillance efforts are paramount to tracking the burden of AD/ADRD on individual and population health, and will be used to identify and monitor trends in risk factors associated with AD/ADRD, and assist with understanding health disparities among populations such as racial and ethnic minorities. HHS will make efforts to expand and enhance data infrastructure and make data easily accessible to federal agencies and other researchers. This data infrastructure will help HHS in its multi-level monitoring and evaluation of progress on the National Plan.

Strategy 5.A: Enhance the Federal Government's Ability to Track Progress

New Tool Enables Easier Tracking of NIH Research Milestones. NIH launched the Alzheimer's Disease and Related Dementias Research Implementation Milestone Database, a user-friendly web-based tool to track NIH funding initiatives and activities, targeting milestones aimed at achieving the Plan's ultimate research goal. Through the milestone database's linkage to IADRP, this resource encourages funders to coordinate and collaborate to maximize the impact of their collective investment in dementia research. It provides the public an easy-to-use but comprehensive window into the full landscape of research funded by NIH and provides a platform for other funders to also post their funding opportunities. Milestones currently track the entire AD/ADRD research landscape, including basic, translational, and clinical and health services research. The new AD/ADRD milestones from the NINDS-led summit in 2016 were added to the database in 2017.

For more information, see:
- https://www.nia.nih.gov/alzheimers/milestones

CDC Data Reports and Publications -- Increase in Alzheimer's Disease Deaths. CDC released *Deaths From Alzheimer's Disease -- United States, 1999-2014* in May 2017. The authors found that death rates for AD have increased 55% from 1999 through 2014. These increases were seen in most states, all age groups, and all racial and ethnic groups examined. This article includes a county-level map of AD deaths that shows higher rates in the Southeast and some areas of the Midwest and West.

For more information, see:
- https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm?s_cid=mm6620a1_w

Behavioral Risk Factor Surveillance System Data and Data for Action. CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiving Optional Modules, which were approved as official optional modules beginning in 2015. In 2015 and 2016, 51 states and territories collected data using the Cognitive Decline Module and 40 states collected data using the Caregiving Module. Additional states are collecting data using the Cognitive Caregiving Modules in 2017. Findings from the 2015 cognitive and caregiving data are publically available on CDC's Healthy Aging Data Portal and fact sheets and infographics were developed for each participating states. Findings from 2016 BRFSS will be released late in 2017.

For more information, see:
- https://www.cdc.gov/aging/agingdata/index.html
- http://www.alz.org/publichealth/data-collection.asp
- https://www.cdc.gov/aging/healthybrain/surveillance.htm

National Health and Nutrition Examination Survey. CDC supported the development and collection of subjective cognitive decline and cognitive functioning data from the in-person National Health and Nutrition Examination Survey (NHANES) are publically available for download and analysis. These data were collected in adults 60 years and older as part of the 2011-2012 and 2013-2014 data collection cycles. The data included in this release include results from three tests of cognitive function: (1) the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) Word Learning subtest; (2) a test of Animal Fluency; and (3) the Digit Symbol Substitution Test.

For more information, see:
- http://www.cdc.gov/nhanes
- https://www.cdc.gov/aging/healthybrain/surveillance.htm
- https://wwwn.cdc.gov/Nchs/Nhanes/Search/DataPage.aspx?Component=Questionnaire&CycleBeginYear=2013
- https://wwwn.cdc.gov/Nchs/Nhanes/Search/DataPage.aspx?Component=Questionnaire&CycleBeginYear=2011

CDC's Healthy Aging Data Portal. The portal was updated with CDC Updates Public Data Portal on the Health of Older Adults. CDC recently updated the Healthy Aging Data Portal, which provides access to a range of national, regional, and state data on older adults. This resource was developed by the National Center for Chronic Disease Prevention and Health Promotion. It allows users to examine data on key indicators of health and well-being for older Americans, such as tobacco and alcohol use, screenings and vaccinations, and mental and cognitive health.

2015 BRFSS data includes data on cognitive decline from 35 states and data on caregivers from 24 states. Portal users can retrieve CDC data by indicator or by geographic area, and then use these data to develop reports and create customized maps, charts, and graphics. Public health professionals can use the data to create a snapshot of the health of older adults in their states, which can help them prioritize and evaluate public health interventions.

For more information, see:
- https://www.cdc.gov/aging/agingdata/index.html

Needs Assessment Toolkit. CDC supported the Alzheimer's Association to develop a Needs Assessment Toolkit that serves as *Guidance and Resources for State Public Health Agencies on Comprehensive Needs Assessments Related to Alzheimer's and Other Dementias*. This document aims to increase the use of information and insights to appropriately respond to the growing public health burden associated with AD/ADRD through comprehensive needs assessments. These are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans that are focused either exclusively on AD/ADRD, or more broadly on the incorporation of cognitive health and impairment into other state public health plans. Public health agencies have a high level of expertise related to developing and conducting needs assessments. This toolkit has been developed to help states leverage their expertise in conducting needs assessments to enhance their ability to gather and use information specifically related to AD/ADRD.

For more information, see:
- https://www.alz.org/documents_custom/public-health/spotlight-assessment.pdf

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Diagnostic Coding for Dementia. HHS continues to partner with VA and other federal partners to examine AD/ADRD diagnostic codes and coding practices for federal agencies to use in analyses of administrative data to enhance reporting. The work will help prioritize research, clinical services, and caregiving resources.

Quality Measures Under Consideration. CMS publishes a list of quality and cost measures (the "MUC List") under consideration for certain Medicare quality and value-based purchasing programs annually. The current list includes MUC 16-317, Safety Concern Screening and Follow-Up for Patients with Dementia: *"Percentage of patients with dementia or their caregiver(s) for whom there was a documented safety screening in two domains of risk: dangerousness to self or others and environmental risks; and if screening was positive in the last 12 months, there was documentation of mitigation recommendations, including but not limited to referral to other resource."*

For more information, see:
- https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures/Pre-Rule-Making.html

Progress in Dementia Measure Development. Measures have been in development to examine the evidence base and measurement gaps to develop de novo electronic clinical quality measures (eCQMs) related to dementia care. CMS has worked on two measures: (1) Cognitive Impairment Assessment Among Older Adults (75 years and older) -- Cognitive Impairment; and (2) Documentation of a Health Care Partner for Patients with Dementia or MCI -- Health Care Partner. The measures are under consideration for use in CMS's Quality Payment Programs.

For more information, see:
- https://qpp.cms.gov/

Strategy 5.B: Monitor Progress on the National Plan

Healthy People 2020. CDC, in collaboration with NIH and ACL, released the midcourse review data for the Healthy People 2020 topic areas, *Dementias Including Alzheimer's Disease*.

For more information, see:
- http://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease/objectives
- https://www.healthypeople.gov/2020/data-search/midcourse-review/topic-areas

Non-Federal Items in the 2017 National Plan. The 2017 Plan Update includes a number of activities by non-federal partners. These partners were invited to contribute to the Plan Update to show progress made outside the federal agencies involved in NAPA, and to expand the focus of the National Plan more broadly to national work. These items have been organized according to the goals and strategies of the Plan. Additionally, in an effort to clearly respond to the annual recommendations made by the non-federal members of the Advisory Council, the 2017 Plan Update includes an appendix (Appendix 2) in which relevant federal agencies have directly responded to the recommendations made by the public Advisory Council members. Fulfilling the recommendations is contingent on limitations on legislative authority, resources, and data among the federal agencies and the Federal Government, and this appendix makes clear which recommendations have been addressed and which would require congressional authority or additional resources.

Appendix 1: List of Participating Departments and Agencies

Administration for Children and Families

Administration for Community Living

Administration on Aging

Administration on Intellectual and Developmental Disabilities

Agency for Healthcare Research and Quality

Alzheimer's Association

Association of State and Territorial Health Officials

Association for Frontotemporal Degeneration

Blanchette Rockefeller Neurosciences Institute

Centers for Disease Control and Prevention

Centers for Medicare & Medicaid Services

Consumer Finance Protection Bureau

Dementia Friendly America

Department of Defense

Department of Education

Department of Health and Human Services

Department of Housing and Urban Development

Department of Justice

Department of Labor

Department of Veterans Affairs

Food and Drug Administration

General Accountability Office

Georgia Department of Human Services

Gerontological Society of America

Health Resources and Services Administration

Indian Health Service

Institute of Medicine

John A. Hartford Foundation

Lewy Body Dementia Association

Minnesota Board on Aging

National Academies of Sciences, Engineering, and Medicine

National Alzheimer's and Dementia Resource Center

National Brain Health Center for African Americans

National Center for Chronic Disease Prevention and Health Promotion

National Center for Health Promotion and Disease Prevention

National Center for Health Statistics

National Center on Elder Abuse

National Human Genome Research Institute

National Indian Council on Aging

National Institute of Neurological Disorders and Stroke

National Institute on Aging

National Institute on Disabilities, Independent Living and Rehabilitation Research

National Institute on Minority Health and Health Disparities

National Institutes of Health

National Quality Forum

National Science Foundation

New York State Department of Health

Office of Civil Rights

Office of Global Affairs

Office of Intergovernmental and External Affairs

Office of the Assistant Secretary for Planning and Evaluation

Office of the Assistant Secretary for Preparedness and Response

Office of the Assistant Secretary for Public Affairs

Office of the Assistant Secretary for Health

Office of the National Coordinator of Health Information Technology

Office of the Surgeon General

Office of Women's Health

Oregon Department of Human Services

Organization for Economic Cooperation and Development

Patient-Centered Outcomes Research Institute

Social Security Administration

Substance Abuse and Mental Health Services Administration

USAgainstAlzheimer's

Veterans Health Administration

West Virginia Bureau of Senior Services

Appendix 2: 2017 Recommendations and Federal Response

Since 2012, the National Plan and its accompanying recommendations have catalyzed progress in the field of AD/ADRD.

The 2017 Recommendations from the public members of the Advisory Council, and the responses from the relevant federal agencies are presented below. As stated previously, fulfilling the recommendations is contingent on limitations on legislative authority, resources, and data among the federal agencies and the Federal Government, and this appendix makes clear which recommendations have been addressed and which would require congressional authority or additional resources.

RECOMMENDATION 1

The 2017 National Plan should continue to provide a robust, comprehensive, and transformative scientific Road Map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025.
   a. A Road Map for accomplishing the primary goal of the Plan should include input from experts in the field through research summits on AD/ADRD including a research summit on care and services.
   b. Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones.
   c. Include specific research milestones to:
   - Reduce racial/ethnic/socioeconomic disparities in AD/ADRD.
   - Re-evaluate research priorities among AD/ADRD across all research areas (e.g., from identifying disease modifying treatments to identifying effective care and services).
   - Include and prioritize specific milestones for populations at high risk for AD/ADRD (e.g., people with Down syndrome, African Americans).
   - Increased attention should be paid to person-centered and family-centered outcomes with respect to research planning and the delivery of care and services.

CMS Response
CMS has supported work led by ASPE to engage in efforts to plan research summits on ADRD, including a fall 2017 summit on care and services. Through the "Connected Care" campaign, CMS, working with HRSA, is raising awareness of the benefits of Medicare's CCM service for beneficiaries with multiple chronic conditions including ADRD, and furnishing resources for implementation across all diverse populations. CMS is driving efforts to empower beneficiaries and their providers to make decisions, take ownership of their care, and make certain they have the information they need to make informed choices.

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NIH Response
NIH will continue to engage a broad range of stakeholders, including academia, industry, NGOs, and individuals directly affected by AD/ADRD, in advancing the goals of the National Plan. This Plan focuses on identifying effective interventions and improving care and services, and its future updates will build upon research advances and emerging opportunities, and will be informed by additional research summits as well as feedback from the broader community. Upcoming summits that will provide guidance regarding future implementation of the Plan's goals include a summit focused on AD/ADRD care and services research in October 2017, and large AD and ADRD summits in 2018 and 2019, respectively.

NIH leadership and staff continues to update its specific research plans and cost estimates annually, as outlined in each year's *Bypass Budget for Alzheimer's Disease and Related Dementias*. Part of this process involves regularly updating, implementing, and tracking a broad set of specific AD/ADRD research milestones. To enable federal agencies and other organizations to track progress in reaching these milestones, NIH has made a searchable database available to the public. The Advisory Council's

recommendations regarding specific research milestones will greatly contribute to these NIH planning processes.

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For more information, see:
- https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers
- https://www.nia.nih.gov/alzheimers/milestones/
- https://www.nia.nih.gov/about/sustaining-momentum-nih-takes-aim-alzheimers-disease-related-dementias

RECOMMENDATION 2

A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.
  a. At present, the United States spends less than 0.5% of its annual care costs for ADRD on research, therefore investments in research should be increased to achieve the primary goal of the National Plan.
  b. Initial estimates suggested that $2 billion or more per year is needed and more accurate estimates can be generated by the Professional Judgment Budget.
  c. The annual professional judgment budget recommended by the Alzheimer's Accountability Act and prepared by the NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 goal of the plan.
  d. This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research.

NIH Response
As a component of HHS under the Executive Branch of the United States government, NIH cannot comment on targets for -- or algorithms that could be used to estimate -- the total research funds needed for AD/ADRD research, beyond the President's Budget and the estimate that NIH submits as part of the *Bypass Budget for Alzheimer's Disease and Related Dementias*.

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For more information, see:
- https://www.nia.nih.gov/about/sustaining-momentum-nih-takes-aim-alzheimers-disease-related-dementias

RECOMMENDATION 3

The 2017 National Plan should develop research goals aimed at the establishment of recommendations to improve uptake, spread and delivery of evidence-based and evidence-informed care and services.
  a. Enhance methodologies to effectively engage persons with dementia and families in research on care decision making and planning.
  b. Develop and implement quality care measures across all settings that include person-centered and family-centered outcomes.
  c. Identify and evaluate (non-drug) care strategies that reduce disease burden and delay disease progression and evaluate their costs and downstream effects.
  d. Study comprehensive dementia care from time of diagnosis to end-of-life and associated costs.

e. Develop and evaluate effective care programs across diverse settings (e.g., home, nursing home, assisted living, community-based programs, primary care), disease etiologies and disease trajectories to address key clinical features including NPS and functional decline.

f. Develop and evaluate technologies to link families to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status and promote home safety.

g. Convene a conference of key stakeholders to identify a meaningful pathway or pipeline for developing and testing non-pharmacological treatments, and scaling up and implementing effective approaches.

CMS Response

CMS, through its work to implement the National Quality Strategy and the CMS Quality Strategy, seeks to ensure person-centered and family-centered care across the health care landscape in partnership with beneficiaries, families, and caregivers. As one example, CMS regularly solicits nominations for TEP members for CMS measure development and maintenance contractors to provide input to the contractor on the development, selection, and maintenance of measures for which CMS measure contractors are responsible. Convening a TEP is one important step in the measure development or re-evaluation process that CMS uses to ensure transparency, and provides an opportunity to include multi-stakeholders early in the process. CMS, through its Medicaid Testing Experience and Functional Tools grants, is developing and testing electronic LTSS plans, personal health record systems, and Functional Assessment Standardized Items to use technology to better link beneficiaries, providers, and caregivers.

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NIH Response

Research on provision of care and services for individuals with AD/ADRD and their families is an important research priority at NIH; the NIA has played a key role in developing the 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers. The NIA looks forward to integrating recommendations from the 2017 Summit into its future planning and Funding Opportunity Announcement (FOA) development, following the meeting. Examples of past contributions include two FOAs (PAR-15-348 and PAR-15-351) released in September 2015 that focused on identifying, characterizing and addressing the needs of formal and informal caregivers and care recipients. Both funding announcements are open to receive applications through September 2018. In 2017, NIA released three additional FOAs aimed at research on improving care and utilizing new technologies to positively impact care (PAS-17-027: Improving Quality of Care and Quality of Life for Persons with Alzheimer's Disease and Related Dementia at the End of Life; RFA-AG-17-065: Pragmatic Trials for Dementia Care in Long-Term Services and Supports (LTSS) Settings; and PAR-17-107: Development of Socially-Assistive Robots (SARs) to Engage Persons with Alzheimer's Disease (AD) and AD-Related Dementias (ADRD), and their Caregivers. Additionally, as the number of seniors wanting to age in place continues to rise, efforts by NIH, VA, academic and industry leaders are aiming to help to achieve this goal. Through the CART Initiative launched in 2016, research investigators will be able to validate existing and new technology (e.g., sensors, Apps, robots, etc.) that could track changes in older adults' health status and activities unobtrusively in real time. NIH scientists hope CART will help elders remain independent while avoiding hospitalizations and transitions into care facilities and see the project as potentially transformative for the field of aging research and care for older adults.

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For more information, see:
- http://grants.nih.gov/grants/guide/pa-files/PAR-15-348.html
- http://grants.nih.gov/grants/guide/pa-files/PAR-15-351.html
- https://grants.nih.gov/grants/guide/pa-files/PAS-17-027.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-107.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-17-065.html
- https://www.nia.nih.gov/newsroom/features/nih-initiative-tests-home-technology-help-older-adults-age-place

- https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers

RECOMMENDATION 4

Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.
  a. A federally-led working group of thought leaders should be convened to identify existing barriers, opportunities and recommend strategies to develop consistent language for cognitive disorders among the scientists, care providers and the public.
  b. Engage all of the stakeholders around these issues to reduce the use of confusing or conflicting terminology and propose improved terminology for the benefit of persons with dementia, their family members and caregivers and the scientific and service communities.

NIH Response

NIH supports the effort to standardize language in this area of research, and devoted a special session to this topic at the recent *Alzheimer's Disease-Related Dementias 2016 Summit*, specifically to discuss issues and challenges regarding nomenclature and to gather suggestions on how to move forward. One of that Summit's draft recommendations proposed that a working group be organized to include all stakeholders and convene a workshop to develop a coherent nomenclature for all dementias. Once the NAPA Advisory Council establishes this working group, it will develop a plan for taking next steps and gathering public input on the issue. NIH recognizes that standardization is critical, but standards developed and applied for different types of stakeholders (e.g., research vs. public) may need to be interoperable rather than identical.

One of the *ADRD 20016 Summit's* recommendations, now formalized as one of the ADRD Prioritized Research Milestones (Topic 2 Focus Area 2), is to organize a working group of all dementia stakeholders and convene a meeting to develop a consistent nomenclature in dementia research and care. At the *National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers* in October 2017, there will be another session on nomenclature to discuss challenges associated with dementia nomenclature such as stigma and limited access to care and services.

This NAPA Council recommendation broadens the scope of the nomenclature issue, and emphasizes the need for a national effort that requires participation from all stakeholders and coordination across not only the Federal Government but also the entire community involved in dementia care and research. It will be crucial to bring scientists, clinicians, individuals with AD/ADRD, families, and caregivers together to be on the same page, and at the same time develop standards that can be applied for different types of stakeholders. An important part of the goal will be to increase the lay public's understanding of dementia diagnoses by using plain and clear language without sacrificing accuracy of terminology.

For more information, see:
- https://www.ninds.nih.gov/News-Events/Events-Proceedings/Events/Alzheimers-Disease-Related-Dementias-Summit-2016
- https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers
- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones

RECOMMENDATION 5

As recommended in the National Plan the United States government should support global efforts to address issues of research, care and services.
   a. United States public and private entities should acknowledge and scrutinize the work of the World Dementia Council and the World Health Organization (WHO).
   b. Continued collaborations on international research efforts should be promoted.

NIH Response
NIH communicates regularly on global efforts in a variety of forums with government representatives and many other stakeholders in the international dementia community. Staff welcome these discussions and resulting opportunities for collaborations. As one critical example, NIA and the Alzheimer's Association developed the IADRP tracking system, in order to catalog, search, and interrogate projects in this area of research supported by NIH, other United States federal and state agencies, several voluntary organizations, and many international funders. The United States welcomes additional participation in this database by governmental organizations or NGOs. IADRP currently captures more than 7,000 unique projects conducted by more than 4,000 researchers across more than 1,000 institutions -- supported by 35 public, private and international funding organizations in 11 countries: the United States, Australia, Brazil, Canada, Czech Republic, France, Italy, the Netherlands, Poland, United Kingdom, and Germany -- reflecting more than $5.7 billion in research funding worldwide. In October 2016, representatives from NIH participated in the 24th Management Board Meeting of the EU JPND and delivered a presentation of IADRP. Over 30 member countries participated in the meeting; focused on the overall goal of increased international collaboration. Additionally, multiple NIA-supported programs such as the Dominantly Inherited Alzheimer's Network, ADNI3, and the Health and Retirement Study include international sites.

In addition, NIA continues to co-host quarterly international funders conference calls with the Alzheimer's Association -- which offers an opportunity for NIH and other organizations to discuss research priorities and initiatives.

As a third example, foreign institutions are eligible to apply for funding to support research solicited in both of the FOAs for Research on Informal and Formal Caregiving for Alzheimer's Disease (PAR-15-348 and PAR-15-351), which specifically encouraged both national and cross-national population-based research, and in the Health Disparities and Alzheimer's Disease FOA (PAR-15-349). In 2017, NIH released an additional FOA aimed at Improving Quality of Care and Quality of Life for Persons with Alzheimer's Disease and Related Dementia at the End of Life (FOAs PAS-17-027), which is also open to foreign institutions.

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For more information, see:
   • http://iadrp.nia.nih.gov/
   • http://grants.nih.gov/grants/guide/pa-files/PAR-15-348.html
   • http://grants.nih.gov/grants/guide/pa-files/PAR-15-351.html
   • http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html
   • https://grants.nih.gov/grants/guide/pa-files/PAS-17-027.html

RECOMMENDATION 6

A major area of emphasis for the 2017 National Plan should include the enhancement of recruitment efforts for randomized controlled trials for AD/ADRD.
   a. A major challenge in the development of effective therapies for AD/ADRD has been the inefficient recruitment of participants in clinical trials.
   b. Emphasis should be placed on the enhancement of diversity and inclusiveness in these efforts.
   c. The documentation of recruitment goals should be required in applications for randomized controlled trials and incentives should be in place for meeting those goals.

NIH Response

With substantial community and stakeholder involvement, NIA is leading efforts to provide practical approaches to help study sites and researchers overcome the challenges and barriers in recruiting and retaining the right volunteers, at the right times, in the right studies. With facilitation by the Alzheimer's Association and in collaboration with a wide group of government, private, and academic stakeholders, NIA is developing a National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research. In 2017, NIA convened a workshop for experts from academia, communications, advocacy, and clinical care and research to identify the best strategies for engaging a range of audiences, including minority and underrepresented groups, in the clinical research enterprise. When the strategy is finalized, attention will turn to its implementation, not only for actions that can be considered by the Federal Government, but by stakeholders in government, academia, advocacy, medicine and the public with an interest in progress in AD research.

RECOMMENDATION 7

The National Plan should continue to promote early detection and diagnosis of AD/ADRD by encouraging cognitive assessment while at the same time CMS works to confirm measurement strategies to track progress through the implementation of new quality measures.
   a. Specifically, within the next year, CMS should implement the new quality measure: Cognitive Impairment Assessment Among At-Risk Older Adults. Percentage of patients age 75 years or older at the start of the measurement period with documentation in the electronic health record (EHR) at least once during the measurement period of: (1) results from a standardized cognitive impairment assessment tool; or (2) a patient or informant interview.
   b. The cognitive assessment should be conducted per the guidance provided by the Medicare Detection of Cognitive Impairment Workgroup's Recommendations: Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare AWV in a primary care setting. *Alzheimer's & Dementia*. March 2013; 9 (2)141-150.

CMS Response

Dementia: Cognitive Assessment (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, is available as an applicable measure in the new Quality Payment Program for Merit-Based Incentive Payment System physicians and groups. CMS develops and tests an array of measures for many of its quality programs that could impact beneficiaries with dementia, and continues its work as a measure developer to develop and implement performance measures for use in multiple programs across care settings. CMS has worked on developing two electronic clinical quality measures (eCQMs) to address quality of care for patients at-risk of or who have cognitive impairment: (1) Cognitive Impairment Assessment Among Older Adults (75 years and older) -- Cognitive Impairment Assessment; and (2) Documentation of a Health Care Partner for Patients with Dementia or MCI -- Health Care Partner. Next steps during the pre-rulemaking process would be inclusion in the annual CMS Measures Under Consideration (MUC) List.

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IHS Response
The IHS will continue to develop workforce training and community education strategies to enhance recognition of cognitive impairment and effective diagnosis.

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NIH Response
Given that treatments are very likely to be most effective the earlier they are instituted, NIH released a new FOA in 2017 to increase early detection of cognitive impairment, including dementia, when a patient or a caregiver voices a concern in primary care and other everyday clinical settings. The goal is to create a research consortium to develop and test clinical paradigms that utilize cognitive assessment tools (new or existing) that are simple to use, standardized, and can be quickly administered in a primary care setting. This includes addressing barriers that are unique to health disparities populations in the United States. This funding opportunity is directly responsive to one of the ADRD 2016 Prioritized Research Milestones, and aims to address the issue of under-detection of cognitive impairment by validating and standardizing cognitive assessment tools into user-friendly paradigms suitable for primary care in typical large and diverse populations in the United States.

With respect to education on early detection and diagnoses, several NIA resources are already available to support clinicians in assessing and managing patients with cognitive impairment; see the "Assessing Cognitive Impairment," "Managing Cognitive Impairment," and the "Patient Checklist" sections of the Alzheimer's and Dementia Resources for Professionals web page. Moreover, clinicians can use the "Talking with Your Patients About Cognitive Problems" chapter of NIA's new *Talking with Your Older Patient* resource to initiate conversations about these and other related issues. NIH strongly supports moving forward with an educational outreach campaign to clinicians.

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For more information, see:
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-012.html
- https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals#assessment
- https://www.nia.nih.gov/health/publication/talking-your-older-patient/talking-patients-about-cognitive-problem

RECOMMENDATION 8

CMS should annually report data by state/region and by diagnosis regarding the use of the new G0505 billing code.
   a. The new G0505 billing code provides for cognition and functional assessment using standardized instruments with development of recorded care plan for the patient with cognitive impairment, history obtained from patient and/or caregiver, in office or other outpatient setting or home or domiciliary or rest home.

CMS Response
Because it is a new service, CMS does not have information on utilization for code G0505 at present. CMS may monitor utilization data in the future.

RECOMMENDATION 9

Federal agencies should offer and support educational efforts that improve health care providers' ability to recognize early signs of dementia, including AD/ADRD, and to offer counseling to individuals and their caregivers, as well as connect them to local services and resources.
   a. A working group of health professional associations should be convened to develop competencies in delivering evidenced-based dementia care across care settings.
   b. Training related to quality dementia care should be included in curricula and continuing education sessions for health professionals.
   c. Specifically, training should enhance health care provider awareness and understanding of the Medicare AWV, knowledge of validated cognitive assessment tools, methods for reporting all dementia-related quality measures active in the Quality Payment Program, and the Cognitive Impairment Assessment and Planning Code G0505.

CMS Response

CMS continues its work with the OWH and HRSA to promote current policies and practices that improve the ability of caregivers for persons living with ADRD to manage or sustain their own health, and is helping its partners package training "modules" to educate and support caregivers. CMS continues to address (e.g., Medicare Learning Network, National Partnership to Address Dementia Care in Nursing Homes, the Long-Term Care Final Rule, and other policy issuances) dementia care training for health providers.

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NIH Response

With respect to education on early detection and diagnoses, several NIA resources are already available to support clinicians in assessing and managing patients with cognitive impairment; see the "Assessing Cognitive Impairment," "Managing Cognitive Impairment," and the "Patient Checklist" sections of the Alzheimer's and Dementia Resources for Professionals web page. Moreover, clinicians can use the "Talking with Your Patients About Cognitive Problems" chapter of NIA's new *Talking with Your Older Patient* resource to initiate conversations about these and other related issues. NIH strongly supports moving forward with an educational outreach campaign to clinicians.

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For more information, see:
   • https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals#assessment
   • https://www.nia.nih.gov/health/publication/talking-your-older-patient/talking-patients-about-cognitive-problem

RECOMMENDATION 10

The Advisory Council on Alzheimer's Research, Care and Services should devote one meeting to advancing the work ASPE has conducted with RTI International on defining best practices for comprehensive dementia care.
   a. Specific topics should include: (1) an in-depth description of the Examining Models of Dementia Care report and appendices; (2) federal agency reporting of current innovative services for persons with dementia and their caregivers; and (3) non-federal reporting from health systems and/or payers of exemplar population health solutions for dementia care. Advisory Council discussion of next steps to advance consensus definitions of best practice models, including measurement targets for clinical outcomes and value-based outcomes concerning cost and the care experience.

ASPE Response

The *Examining Models of Dementia Care: Final Report* is published and available on the ASPE and NAPA websites. As was discussed during the April 2017 NAPA Advisory Council meeting, there are a number of different directions in which to pursue future research, and ASPE would welcome the opportunity to discuss these opportunities in greater detail with the Advisory Council at-large, or with one or more of the relevant NAPA subcommittees.

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For more information, see:
• https://aspe.hhs.gov/report/examining-models-dementia-care-final-report

RECOMMENDATION 11

CMS should use the results of evidenced-based programs combined with definitions of best practices for comprehensive dementia care to provide adequate payment and incentives for providing evidenced-based care. This could include a comprehensive risk-based payment for reimbursement of comprehensive dementia care services.

a. For example, CMS should use the results of evidenced-based programs, combined with definitions of best practices for comprehensive dementia care, to create a fixed Per Beneficiary Per Month (PBPM) payment for reimbursement of comprehensive dementia care services. The first target for the PBPM payment model should be community-dwelling persons with dementia and their caregivers who are not eligible for (or do not have access to) a PACE.
b. CMS should establish a system for determining that accountable entities receiving PBPM payments have the ability to supply all essential elements of comprehensive dementia care.
c. Congress and/or federal agencies should authorize and/or designate funding to conduct large-scale evaluation of the PBPM payment model for comprehensive dementia care; and, if the evaluations replicate the value proven by CMS dementia demonstration projects, then CMS should implement the PBPM model nationwide.

CMS Response

CMS periodically offers opportunities for states and other entities to apply for demonstrations, waivers, and models and other special initiatives through the Medicaid program, and the Center for Medicare and Medicaid Innovation (the Innovation Center). States and accountable entities (such as Medicare ACOs), when applying for/implementing such opportunities, have some discretion in choosing what topics to address (e.g., AD/ADRD) within these. The Innovation Center is focused on testing new payment and service delivery models, and evaluating and sharing the results. Occasionally, there may be a path to wider adoption in a CMS program, should a model meet statutory and other criteria. Such adoption would be subject to a formal rulemaking process including opportunities for public comment. Public and private payers such as state Medicaid agencies, state and local governments, managed care plans, private insurers, and other entities are encouraged to review the results of CMS model testing and demonstration results, and adopt best practices. CMS will keep stakeholders appraised of future opportunities to provide input as models, including those that address ADRD and/or behavioral health, are developed.

RECOMMENDATION 12

Changes to national health care must ensure continuation of support that is critical to people living with dementia and their caregivers including Medicare AWVs that include cognitive assessment, protection for pre-existing conditions, funding for person-centered and family-centered research on dementia, and support for innovative models of care.

CMS Response
CMS is driving efforts to empower beneficiaries, consumers, and their providers to make decisions, take ownership of their care, and make certain they have the information they need to make informed choices.

RECOMMENDATION 13

Federal agencies, national health and aging organizations, states, and other industry stakeholders should identify ways to implement recommendations that result from the October 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers.

Combined Federal Response
The member agencies of the NAPA Advisory Council are committed to research that improves the lives of individuals with dementia and their caregivers. We will identify any and all recommendations from the Summit, and consider them as we develop and update our research milestones.

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For more information, see:
- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones

RECOMMENDATION 14

Congress, federal agencies, and states must expand efforts to address the needs of family caregivers, including caregivers from diverse racial/ethnic/socioeconomic groups, caregivers of younger adults and people with IDD, and children and youth who provide care for older adults. Particular support is needed to expand and scale effective caregiver interventions for diverse racial/ethnic/socioeconomic groups; address reimbursement, training, and HIPAA policy and practice barriers to enable health care providers to provide care planning with family caregivers; increase support for respite care; and address the financial burden to family caregivers. To accomplish this:
   a. Increase federal funding by at least 50% for ACL dementia-specific funding that supports state, Tribal, and community dementia interventions by 2020.
   b. Use results of October 2017 Care Summit to build and fund a research and translation strategy to address clinical care, and LTSS.
   c. 90% of people with AD/ADRD and their key family and friend caregivers have access to a community-based education or support program on dementia caregiving by 2025.
   d. Amend the Older Americans Act (OAA) to allow additional OAA services to be provided to younger adults with dementia.
   e. Double funding for the National Family Caregiver Support Program, including funding for tribes under the OAA Title VI, by 2020.

f.   Educate health care providers on HIPAA by 2020, including clarification on HIPAA implementation, ways to support person-centered plans and advance care planning, addressing HIPAA concerns, and the provision of care when the person may not be competent. This should be accomplished by CMS, HRSA and states.

g.   Designate the primary caregiver role in both the caregiver's own medical record, and in the care recipient/patient's medical record systems by 2020.

h.   Expand Medicare benefits to ensure individuals with AD/ADRD and their families receive information, care coordination, caregiver supports, and HCBS.

i.   Expand innovative paid and volunteer respite programs.

j.   Promote state expansion of respite care through Medicaid waiver programs or state-funded respite services.

k.   Establish tax and Social Security credits for family caregivers by 2020.

l.   Increase by at least 50% funding for Medicaid's Money Follows the Person demonstration program, self-directed HCBS programs, and caregiving options that pay friend/family caregivers.

m.   Expand the Family Medical Leave Act and state laws to expand paid family leave for family caregivers.

n.   Identify the roles, prevalence, and impact of caregiving among young children, including children in immigrant, minority, and Tribal populations, who provide care for older adults with dementia.

o.   Provide resources to states, tribes, and communities to provide outreach and support to families and children where children provide caregiving for older relatives with dementia.

ACL Response
ACL continues to make federal funding available for dementia-specific programs that support state, Tribal, and community dementia interventions. Funded programs promote development of new dementia-capable service systems across the country, expansion of existing systems, as well as caregiver education and support. Other recommendations in this section would require changes to federal law or appropriations.

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CMS Response
CMS beneficiaries may have a representative of their choosing (including an emergency contact) with access to information and participates in health care discussions with their knowledge and consent, as well as a legal representative such as an individual who has a power of attorney for health care, a guardian, or health care surrogate or proxy appointed in accordance with state law act on their behalf, if they are unable to make their own decisions. CMS regularly works with its HRSA partners, and provides education and information through a variety of venues on an array of topics (e.g., Open Door forums, Medicare Learning Network, "Grand Rounds," etc.). CMS is ushering in a new era for the federal-state Medicaid partnership where states have even more freedom to design programs that meet the spectrum of diverse needs of their Medicaid population, and is empowering states to advance the next wave of innovative solutions to Medicaid's challenges through solutions that focus on improving quality, accessibility, and outcomes in the most cost-effective manner. States, as administrators of the Medicaid program, are in the best position to assess the unique needs of their respective Medicaid-eligible citizens and to drive reforms that result in better health outcomes. CMS will continue to provide technical assistance to states that want to provide self-directed service delivery mode options and paid family caregiver options in their Medicaid HCBS programs.

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IHS Response
IHS will review the findings of the October 2017 Care Summit to inform priorities in support of spread of evidence-based services in Tribal communities. Additionally, IHS continues efforts to expand caregiver support services through the REACH intervention in Tribal communities.

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NIH Response

NIH recognizes the importance of research to understand and address caregiver needs. The REACH intervention, supported by NIH, developed the first intensive caregiver support intervention to be proven effective, through rigorous testing, in an ethnically diverse population. The REACH intervention is currently being translated more broadly through the VA, with participating centers in 15 states. The VA is also partnering with ACL, IHS, and a private foundation to adapt and implement REACH in Tribal communities. In addition, NIH is currently supporting the design, development, implementation and dissemination of numerous other ADRD-related interventions, as well as evidence-based tools and training materials to help support the many and various needs of caregivers for example, the New York University Caregiver Intervention.

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For more information, see:
- http://onlinelibrary.wiley.com/doi/10.1111/jgs.14716/epdf
- http://www.rosalynncarter.org/caregiver_intervention_database/dimentia/nyu_caregiver_counseling_and_support_intervention/
- https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers

RECOMMENDATION 15

Federal agencies, states, and health systems must take steps to increase identification of people with dementia who live alone, and to provide programs and services to meet the needs of this population.
   a. Increase by at least 50% ACL dementia funding for community Gatekeeper programs that train community partners to identify and connect at-risk and live alone individuals to community aging services.
   b. Double funding for the National Family Caregiver Support Program by 2020, including specific outreach and support to families who care for individuals who live alone.
   c. Identify existing information from federal agencies including ACL, CMS, HUD, Department of Transportation (DoT) or others, on the prevalence and housing situation for individuals who may have dementia and live alone.
   d. Identify best practices for housing and transportation services that can meet the needs of individuals with cognitive impairment or dementia who live alone.

ACL Response

ACL continues to make federal funding available for dementia-specific programs that support state, Tribal, and community dementia interventions. ACL's funded programs promote development of new initiatives designed to identify and provide supportive services to at-risk and/or under-served populations, including individuals who live alone. Other recommendations in this section would require changes to federal law or appropriations.

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CMS Response

CMS established the Medicaid Innovation Accelerator Program (IAP) with the goal of improving health and health care for Medicaid beneficiaries by supporting states' ongoing efforts related to payment and delivery system reforms through the provision of technical assistance, tools development and cross-state and national learning opportunities. In 2017, IAP launched the second "track" of the State Medicaid-Housing Agency Partnerships. The goals of the State Medicaid-Housing Agency Partnerships are to develop public and private partnerships between Medicaid and housing systems and to support states in the creation of detailed action plans that foster additional community living opportunities for Medicaid beneficiaries. Consistent with statute, CMS does not provide funds for room and board. Program support begins this fall and runs for 9 months. It will offer intensive, hands-on technical support to move state

Medicaid agencies towards building sustained collaborations with housing partners, and those from other service agencies.

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NIH Response

NIH supports research to identify people with dementia who live alone. In a recent study supported by NIA, it was estimated that of people with dementia living in the community, 14.3% live by themselves. The identification of the needs of persons living alone with dementia can lead to continued health-focused research on this vulnerable population. NIA values this population and recognizes that more research is needed in this area.

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For more information, see:
- http://content.healthaffairs.org/content/34/10/1642.full.pdf+html

RECOMMENDATION 16

Federal agencies, states, and health systems must increase efforts to assess, prevent, and manage behavioral symptoms associated with dementia through effective programs and services and improved workforce knowledge and skills.
   a. Incorporate AD/ADRD standards, including standards for effective ways to address behavioral symptoms, into all relevant clinical and LTSS quality measures by 2022.
   b. Increase by at least 50% dementia funding for training and scaling of evidence-based behavioral symptom management interventions for persons with AD/ADRD.
   c. Double HRSA funding for geriatric workforce training that includes increased dementia training to address challenging behavioral symptoms.

ACL Response

ACL continues to make federal funding available for dementia-specific programs that support state, Tribal, and community dementia interventions. ACL's funded programs promote development of new and/or expanded efforts to address behavioral symptoms attributable to AD/ADRD. All ACL AD/ADRD grant programs require inclusion of evidence-based and evidence-informed interventions in support of individuals living with AD/ADRD and their caregivers. Other recommendations in this section would require changes to federal law or appropriations.

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CMS Response

Last year CMS, with the assistance of ACL, released a set of "FAQs" that discuss strategies to ensure the health and safety of Medicaid beneficiaries at-risk of wandering, including people with ADRD. These focus on how person-centered planning can be used to identify any appropriate restrictions while facilitating individualized services and community integration. CMS also furnished guidance to states on suggested approaches to strengthen and stabilize the Medicaid home care workforce.

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IHS Response

IHS will be exploring the use of Project Extension for Community Healthcare Outcomes (ECHO) to provide both clinical consultation and training in the diagnosis and management of dementia in Tribal communities. The IHS and ACL partner in training the Tribal Aging Network in the recognition and management of ADRD in Tribal communities.

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RECOMMENDATION 17

Federal agencies, states, national health and aging organizations, and community partners must continue to expand public awareness and training, reduce stigma, and help connect people to information and available resources. Outreach should include children and youth, diverse racial/ethnic/socioeconomic groups, and people with IDD.

a. Increase and coordinate federal agency, state, and national organization funding for innovative outreach and messages, in order to reach diverse populations.
b. Increase information developed for children and youth using video and social media, and provided through school curriculum and youth-serving organizations.
c. Develop expanded partnerships to support outreach through groups such as unions, community colleges/adult education, community and faith organizations, and first responders.
d. Increase engagement of national health-related organizations (e.g., Down syndrome, heart, and diabetes) in providing information and resources addressing dementia.
e. Study ways these websites may be used to further expand outreach to diverse racial/ethnic and socioeconomic groups.

ACL Response

ACL continues to make federal funding available for dementia-specific programs that support state, Tribal, and community dementia interventions. ACL's funded programs promote outreach to and services for diverse and under-served populations, including dementia-friendly community education efforts. Other recommendations in this section would require changes to federal law or appropriations.

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IHS Response

IHS is working with the Alzheimer's Association and the National Indian Council on Aging to increase understanding and awareness of ADRD in Tribal communities.

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NIH Response

Beyond research-specific efforts, NIH is also committed to continuing to enhance and provide evidence-based information, resources, and referrals through the ADEAR Center to specific populations of people with AD/ADRD and their caregivers including younger people, non-traditional families, people with IDD, such as Down syndrome, and racial and ethnic minorities who are at increased risk of acquiring AD/ADRD. NIA plans to convene a meeting of federal communicators at agencies involved in AD/ADRD research, care and services to enhance collaboration outreach generally and in the upgrading and promotion of alzheimers.gov and brainhealth.gov for an increasingly diverse public audience.

Appendix 3: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Goal 1: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025						
Strategy 1.A: Identify Research Priorities and Milestones						
1.A.1	Regularly convene an AD Research Summit to update priorities.	Summit held 2015. Summit scheduled for March 1-2, 2018.	NIH/NIA	National & international experts, public & private stakeholders, Research Subgroup, academia, industry, professional & advocacy groups	Second Summit February 2015 Third Summit March 2018	2015 AD Research Summit http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015
1.A.2	Solicit public & private input on AD/ADRD research priorities.	Developed recommendations & milestones from 2015 AD Research Summit based on feedback from external stakeholders. Presented recommendations & milestones during IADRFC calls.	NIH/NIA		Ongoing Recommendations --March 2015 Milestones released--July 2015 Recommendations & Milestones will be updated following the next Summit in March 2018	2015 AD Summit Recommendations https://www.nia.nih.gov/research/recommendations-nih-ad-research-summit-2015 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers Updated AD Research Implementation Milestones https://www.nia.nih.gov/alzheimers/milestones
1.A.3	Regularly update the National Plan & refine Goal 1 strategies & action items based on feedback & input.	Update Goal 1 elements of the National Plan to reflect new insights & input from the community.	ASPE	Advisory Council, NIH/NIA & Research Subgroup	Ongoing	
1.A.4	Update research priorities & milestones.	Updated research priorities & milestones.	ASPE	Advisory Council, NIH/NIA & Research Subgroup	Ongoing	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.A.5	Create a timeline with milestones for achieving Goal 1.	Create & update milestone document.	NIH/NIA, NIH/NINDS		Ongoing	Updated AD Research Implementation Milestones: Full set of milestones through 2025 https://www.nia.nih.gov/alzheimers/milestones 2018 Milestones https://www.nia.nih.gov/sites/default/files/AD/FY2018-Alzheimers-Disease-Related-Dementias-Budget-Bypass-Milestones-508.pdf 2019 Milestones https://www.nia.nih.gov/sites/default/files/2017-07/FY2019-AD-ADRD-Milestones.pdf Updated the searchable AD/ADRD Research Implementation Milestones Database https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones
1.A.6	Regularly convene an ADRD Summit to review progress on ADRD research recommendations & refine & add new recommendations as appropriate, based on recent scientific discoveries.	Convene third summit in 2019.	NIH/NINDS	Research Subgroup, academia, industry, professional & advocacy groups	Second Summit Held March 29-30, 2016 Third Summit expected 2019	The updated recommendations from ADRD 2016 Summit were approved by NINDS Advisory Council in September 2016 & presented to the NAPA Council in February 2017. Final recommendations became the ADRD Summit 2016 Prioritized Research Milestones, which can be found here: https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.A.7	Convene a workshop focused on research needs related to Down syndrome & AD/ADRD.	Hold a workshop to solicit input on special research priorities & timelines AD/ADRD among people with Down syndrome.	NIH/NIA	DSRTF, RDS	Ongoing 11th Meeting of the Down Syndrome Consortium: A Public-Private Partnership	Input solicited on special research priorities related to Down syndrome research. 11th Meeting of the Down Syndrome Consortium: A Public-Private Partnership including several NIH ICs (NICHD, NCI, NHLBI, NHGRI, NIDCR, NIDCD, NIDDK, NIMH, NINDS, NIA, & NIMHD) https://downsyndrome.nih.gov/meetings/Pages/default.aspx NIA & NICHD collaborated to produce & disseminate information for people with Down syndrome & their families on the interplay of these conditions & the importance of participating in research. Efforts include a fact sheet, "Alzheimer's Disease in People with Down Syndrome", & outreach via email & social media https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome Alzheimer's Biomarker Consortium-Down Syndrome aims to identify biomarkers that indicate AD is developing or progressing & track the AD process in people with Down syndrome. https://www.nia.nih.gov/alzheimers/alzheimers-biomarkers-consortium-down-syndrome-abc-ds Additionally, the NIA is currently funding a Phase I clinical trial to investigate the safety & tolerability of an immunotherapy vaccine for treatment of Alzheimer's in adults with Down syndrome https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease and Related Dementias						
1.B.1	Expand research to identify the molecular & cellular mechanisms underlying AD/ADRD, & translate this information into potential targets for intervention.	Develop an integrated interdisciplinary basic science research agenda to enable the identification & selection of therapeutic targets.	NIH/NIA	Potential research partners in the public & private sectors	Ongoing	Ongoing & newly released NIH FOAs: • PAR-17-047: Selective Cell & Network Vulnerability in Aging & AD https://grants.nih.gov/grants/guide/pa-files/PAR-17-047.html • PAR-17-039: Comparative Biology of Neurodegeneration https://grants.nih.gov/grants/guide/pa-files/PAR-17-039.html • PAR-17-033: Integrative Research to Understand the Impact of Sex Differences on the Molecular Determinants of AD Risk & Responsiveness to Treatment https://grants.nih.gov/grants/guide/pa-files/PAR-17-033.html • PAR-17-031: Role of Age-Associated Metabolic Changes in AD https://grants.nih.gov/grants/guide/pa-files/PAR-17-031.html • PAR-17-029: Dynamic Interactions between Systemic or Non-Neuronal Systems & the Brain in Aging & in AD https://grants.nih.gov/grants/guide/pa-files/PAR-17-029.html • PAS-17-028: Mechanisms & Interactions Among Neurodegenerative Diseases https://grants.nih.gov/grants/guide/pa-files/PAS-17-028.html • PAR-16-371: Phenotypic & Functional Characterization of ApoE2 to Inform Translation Strategies for Aging-Related Conditions https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html • PAR-15-358: Capturing Complexity in the Molecular & Cellular Mechanisms Involved in the Etiology of AD (R01) http://grants.nih.gov/grants/guide/pa-files/PAR-15-358.html • PAR-15-357: Understanding AD in the Context of the Aging Brain http://grants.nih.gov/grants/guide/pa-files/PAR-15-357.html • PAR-15-350: Emerging Directions for Addressing Health Disparities in AD http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html • PAR-15-349: Health Disparities & AD http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html AMP-AD Activities are also relevant: https://www.nia.nih.gov/alzheimers/amp-ad

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.B.2	Expand genetic epidemiologic research to identify risk & protective factors for AD/ADRD.	Conduct WGS to identify areas of genetic variation that correspond to risk factors of AD/ADRD.	NIH/NIA	Potential research partners in the public & private sectors	Ongoing	Ongoing & newly released FOAs: • PAR-17-214: Limited Competition: Analysis of Data from NIA's ADSP Follow-Up Study https://grants.nih.gov/grants/guide/pa-files/PAR-17-214.html • PAR-16-371: Phenotypic & Functional Characterization of ApoE2 to Inform Translation Strategies for Aging-Related Conditions https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html • PAR-16-205: NIA LOAD Family-Based Study https://grants.nih.gov/grants/guide/pa-files/PAR-16-205.html • PAR-16-047: NIAGADS https://grants.nih.gov/grants/guide/pa-files/PAR-16-047.html • NOT-AG-16-033: Notice of Information: The ADSP Policy on the Publication of Study-Related Data https://grants.nih.gov/grants/guide/notice-files/NOT-AG-16-033.html • RFA-AG-16-002: ADSP Replication Phase Analysis Studies https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-16-002.html • PAR-16-406: Limited Competition: Additional Sequencing for the ADSP https://grants.nih.gov/grants/guide/pa-files/PAR-16-406.html • PAR-15-356: Major Opportunities for Research in Epidemiology of AD & Cognitive Resilience https://grants.nih.gov/grants/guide/pa-files/PAR-15-356.html Continue to support efforts through the ADSP, ADGC & NIAGADS. Next generation sequence Data are available for 17,588 subjects (cases, controls & family members) including phenotype & individual-level information ADSP https://www.niagads.org/adsp/content/home GCAD http://www.adgenomics.org/ ADGC https://www.niagads.org/resources/related-projects/alzheimers-disease-genetics-consortium-adgc-collection NIAGADS https://www.niagads.org/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.B.3	Increase enrollment in clinical trials & other clinical research through community, national, & international outreach.	Identify approaches & coordination points for these efforts; develop an action plan that incorporates these ideas; collaborate to increase awareness among health & social service providers.	NIH/NIA, ACL, CDC, VA	FDA, VA, CDC, HRSA, CMS, in partnership with the private sector	Ongoing	In 2016, NIA launched an effort to identify & disseminate effective approaches & best recruitment & retention practices. With facilitation by the Alzheimer's Association & in close collaboration with experts from government, private, & academic sectors, these approaches will be outlined in the still-in-development National Strategy for Recruitment & Participation in AD Clinical Studies. NIA continues to promote participation in AD/ADRD clinical trials, studies, & registries through our ADEAR website portal (http://www.nia.nih.gov/alzheimers/volunteer); clinical trials listing & monthly e-alert to more than 35,000 subscribers; social media messages through Facebook & Twitter; promotion of the ROAR toolkit of customizable materials for aging services & public health professionals to use in community settings & social media (https://www.nia.nih.gov/health/publication/roar-toolkit) in English, Spanish, & Chinese, & collaboration with ACL, CDC, FDA & the PCORI-funded Alzheimer's & Dementia Patient/Caregiver-Powered Research Network to encourage research participation among older adults.. In June 2017, NIH hosted a workshop entitled Inclusion Across the Lifespan, to examine the science of inclusion of various populations in clinical trials & studies. https://www.nia.nih.gov/about/events/2017/inclusion-across-lifespan
1.B.4	Monitor & identify strategies to increase enrollment of racial & ethnic minorities in AD/ADRD studies.	Track enrollment in NIH AD/ADRD studies; identify & implement next steps for engaging & enhancing research participation by racial & ethnic minorities; raise awareness of need for participation.	NIH/NIA, NIH/NIMHD	ACL	Ongoing	Ongoing & newly released FOAs: • PAR-15-350: Emerging Directions for Addressing Health Disparities in AD http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html • PAR-15-349: Health Disparities & AD http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html In 2016, NIA launched an effort to identify & disseminate effective approaches & best recruitment & retention practices, with a particular focus on reaching diverse communities. In facilitation with the Alzheimer's Association & in close collaboration with experts from government, private, & academic sectors, these approaches will be outlined in the still-in-development National Strategy for Recruitment & Participation in AD Clinical Studies. In 2015, the ROAR team continued to promote a toolkit of customizable materials for aging services & public health professionals to use in community settings & social media, & expanded the potential reach by translating materials into Spanish & Chinese. https://www.nia.nih.gov/health/publication/roar-toolkit In June 2017, NIH hosted a workshop entitled Inclusion Across the Lifespan, to examine the science of inclusion of various populations in clinical trials & studies. https://www.nia.nih.gov/about/events/2017/inclusion-across-lifespan

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.B.5	Conduct clinical trials on the most promising pharmacologic interventions.	Identify partnerships with private sector participants to voluntary share information about new & ongoing clinical trials. Develop partnerships to better coordinate federal & private sector review of the status & progress of the trials & emerging opportunities. Review the status & progress of clinical trials annually.	NIH/NIA	VA	Ongoing	FOAs for clinical trials have been released: • PAR-16-364: Phase III Clinical Trials for the Spectrum of AD & Age-related Cognitive Decline http://grants.nih.gov/grants/guide/pa-files/PAR-16-364.html • PAR-16-365: Pilot Clinical Trials for the Spectrum of AD & Age-related Cognitive Decline http://grants.nih.gov/grants/guide/pa-files/PAR-16-365.html • RFA-AG-17-005: Alzheimer's Clinical Trials Consortium https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-17-005.html See also AMP. Part of this initiative seeks to identify biomarkers that can predict clinical outcomes by incorporating selected biomarkers into 2 NIH-funded clinical trials, which include industry support, designed to delay or prevent disease onset. AMP-AD https://www.nia.nih.gov/alzheimers/amp-ad A list of ongoing AD/ADRD trials & information about enrolling is available as in the FY18 Bypass Budget. A newer update will be available in the upcoming bypass document set for release in the summer of 2017. https://www.nia.nih.gov/alzheimers/publication/stopping-alzheimers-disease-and-related-dementias/category-c-translational Coordination of federal, non-federal, & international AD/ADRD research, including clinical trials, can be found in the IADRP. http://iadrp.nia.nih.gov/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.B.6	Continue clinical trials on the most promising lifestyle interventions.	Conduct annual reviews of the status & progress of clinical trials.	NIH/NIA	VA	Ongoing	Trials are ongoing & planned; vehicles for inventorying trials are in place. NIA has funded the EXERT trial to test whether moderate/high aerobic exercise & stretching can slow the progression of MCI to AD in adults over 65. This 18-month long trial is actively recruiting participants. https://clinicaltrials.gov/ct2/show/NCT02814526 Ongoing & New FOAs include: • PAR-16-364: Phase III Clinical Trials for the Spectrum of AD & Age-related Cognitive Decline http://grants.nih.gov/grants/guide/pa-files/PAR-16-364.html • PAR-16-365: Pilot Clinical Trials for the Spectrum of AD & Age-related Cognitive Decline http://grants.nih.gov/grants/guide/pa-files/PAR-16-365.html • RFA-AG-17-005: Alzheimer's Clinical Trials Consortium https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-17-005.html A list of ongoing AD/ADRD trials & information about enrolling is available as in the FY18 Bypass Budget. A newer update will be available in the upcoming bypass document set for release in the summer of 2017. https://www.nia.nih.gov/alzheimers/publication/stopping-alzheimers-disease-and-related-dementias/category-c-translational IADRP facilitates tracking research efforts, including treatment studies. http://iadrp.nia.nih.gov/cadro-web/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias						
1.C.1	Identify imaging & biomarkers to monitor disease progression.	Conduct annual reviews of ADNI to identify & monitor disease progression.	NIH/NIA	ADNI Partners	Ongoing	Ongoing reporting & monitoring of ADNI activities, continuing on an annual basis, along with provision of research funding on developing & testing diagnostic tools. ADNI's activities are & will continue to be monitored & reviewed on an annual basis http://adni.loni.usc.edu/ AMP-AD https://www.nia.nih.gov/alzheimers/amp-ad Ongoing FOAs include: • PAR-15-359: Novel Approaches to Diagnosing AD & Predicting Progression http://grants.nih.gov/grants/guide/pa-files/PAR-15-359.html • PAR-15-350: Emerging Directions for Addressing Health Disparities in AD http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html • PAR-15-349: Health Disparities & AD http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html
1.C.2	Maximize collaboration among federal agencies & the private sector.	Identify additional partnership opportunities with the private sector & facilitate collaborative efforts to enhance identification of risk factors & early biomarkers.	NIH/NIA	FDA	Ongoing	NIH, FDA, 10 biopharmaceutical companies, & multiple non-profit organizations launched an unprecedented public-private partnership in February 2014. One of the main goals of this effort is to identify biomarkers for AD/ADRD. AMP http://www.nih.gov/science/amp/index.htm AMP-AD (Projects A & B) http://www.nia.nih.gov/alzheimers/amp-ad ADNI is also a public-private partnership between NIH, the Canadian government, & over 20 biopharmaceutical companies & non-profit organizations. ADNI http://adni.loni.usc.edu/about/funding/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 1.D: Coordinate Research with International Public and Private Entities						
1.D.1	Inventory AD/ADRD research investments.	International AD Research Database launched July 2012 & continually updated.	NIH/NIA		Ongoing	IADRP now includes data from over 35 public & private funding organizations across 11 countries. http://iadrp.nia.nih.gov/cadro-web/ The Common AD Research Ontology is also undergoing a significant update to the topics & themes that are used to categorize AD & ADRD funding data. The changes will reflect current research investment as well as highlight emerging areas of science.
1.D.2	Expand international outreach to enhance collaboration.	Invite international colleagues to meet & discuss AD/ADRD research priorities & collaboration through regular meetings in person & via teleconference.	NIH/NIA		Ongoing	AD Funders' meeting held during the 2016 AAIC; quarterly funders' calls led by NIA & Alzheimer's Association. Also, IADRP which includes data from over 35 public & private funding organizations across 11 countries is publicly-available for use. In October 2016, representatives from NIH participated in the 24th Management Board Meeting of the EU JPND & delivered a presentation on the IADRP managed by the NIA. Over 30 member countries participated in the meeting; focused on the overall goal of increased international collaboration.
Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs						
1.E.1	Leverage public & private collaborations to facilitate dissemination, translation, & implementation of research findings.	Disseminate research findings through various media & in partnership with organizations, particularly those involving interventions in treatment & care.	NIH/NIA	FDA, ACL, CDC, partner organizations	Ongoing	NIA continues to expand our efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis & management of cognitive impairment; training materials; a patient checklist handout in English & Spanish, & other resources, which are available online in a mini-portal of resources for professionals. https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals
1.E.2	Continue to promote use of ADEAR to educate the public about the latest research findings.	Prepare & disseminate regular reports on AD/ADRD research findings.	NIH/NIA	NIH/NIA ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations	Ongoing	NIA routinely disseminates information on ADRD research findings. See: ADEAR Center https://www.nia.nih.gov/alzheimers Progress in Alzheimer's research is also reported in the annual Bypass Budget proposal. https://www.nia.nih.gov/about/sustaining-momentum-nih-takes-aim-alzheimers-disease-related-dementias
1.E.3	Issue guidance about drugs for early-stage AD/ADRD.	Issue recommendations about standards for evaluating the effectiveness of treatments for early-stage AD/ADRD.	FDA		Ongoing	Draft Guidance for Industry: Alzheimer's disease: Developing Drugs for the Treatment of Early Stage Disease http://www.fda.gov/Training/GuidanceWebinars/ucm345077.htm
1.E.4	Expand & disseminate research on co-occurring conditions & dementias.	Literature review to be disseminated through CDC's public health network, AoA's Aging Network, & NIA research network.	CDC	ACL/AoA, NIH/NIA	Ongoing	In January 2016, CDC released the Progress Report of public health Road Map action item accomplishment & next steps. In 2017, the development process of the 3rd Road Map began that will identify action items for public health professionals related to cognitive health through 2023. The 3rd Road Map will be released in late 2018.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
1.E.5	Provide information to the public on brain health.	Develop & disseminate a brain health resource to aging, disability, & public health professionals.	ACL/AoA, NIH/NIA, NIH/NINDS, CDC	CMS, HRSA, VA, private partners	Ongoing	On February 2, 2016, NINDS launched a public health campaign on link between hypertension & cognitive decline for integration with the HHS Million Hearts Campaign. https://mindyourrisks.nih.gov/

The Brain Health Resource, a presentation toolkit on brain health as we age, was developed by ACL with NIH & CDC for use at senior centers & in other community settings. Written in plain language, the evidence-based resource explains what people can do to help keep their brains functioning best. In 2016, the toolkit was expanded to include materials in Spanish & a new brain health module entitled, Medicine, Age, & your Brain. https://www.nia.nih.gov/health/publication/brain-health-resource |
| **Goal 2: Enhance Care Quality and Efficiency** | | | | | | |
| **Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care** | | | | | | |
| 2.A.1 | Educate health care providers. | Educate providers through HRSA's GWEPs about how to: (1) work with people with the disease, & their families, (2) link people to support services in the community, identify signs of caregiver burden & depression, & (3) detect cognitive impairment & assess/diagnose AD/ADRD. | HRSA | CMS, NIH/NIA, CDC collaboration | Ongoing | HRSA, in collaboration with the HHS/OWH, supported the development of a second Medscape continuing education course on assessing, managing, & treating AD/ADRD in the context of multiple chronic conditions. This educational offering, titled "Bidirectional Impact of Alzheimer's Disease & Common Comorbid Conditions" was released in September 2016. A total of 7,107 learners accessed the site in the first 6 months.

In FY 2017, HRSA supported 44 GWEP awardees totaling approximately $38.7 million; $5.978 million was used to provide dementia education & training.

NIA continues to expand our efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis & management of cognitive impairment; training materials; a patient checklist handout in English & Spanish, & other resources, which are available online in a mini-portal of resources for professionals. https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals

NIA produced & disseminated Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients |
| 2.A.2 | Encourage providers to pursue careers in geriatric specialties. | Educate providers about opportunities through: the HRSA GWEP. | HRSA | | Ongoing | In FY 2015, GWEP awardees provided 402 continuing education offerings & trained 43,148 participants on AD/ADRD. |

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
2.A.3	Strengthen state aging, public health, & IDD workforces.	Educate the workforces through various means including online training, webinars, fact sheets & other tools.	ACL/AoA	HRSA	Ongoing	HHS will coordinate with states to develop workforces in aging, public health, & IDD that are AD-capable & culturally-competent. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network. One example is the New Jersey GEC, which provided a series of trainings to the Aging Services Network in August/September 2015. Over 2,100 health professional & caregivers from the AAAs participated in the trainings. In addition, HRSA GWEP awardees are collaborating with 32 AAAs & 15 QIOs to strengthen state aging, public health, & IDD workforces. HRSA GWEP awardees are collaborating with 32 AAAs & 15 QIOs to strengthen state aging, public health, & IDD workforces.
2.A.4	Develop & disseminate a voluntary unified primary care AD/ADRD curriculum.	Develop a voluntary curriculum for primary care practitioners.	HRSA	CMS, NIH/NIA, VA	Ongoing	HRSA partnered with federal partners at ACL, CDC, CMS, HHS/OWH, & VA on a contract to develop a *Dementia Curriculum for Health Care Professionals*. The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely & accurate detection & diagnosis, & identify high-quality dementia care guidelines & measures across care settings. The curriculum was available as of July 2017. https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
2.A.5	Ensure aging & public health network providers have access to research-based up-to-date information on AD/ADRD.	Webinars with representatives from the Aging Network, ADCs, ADEAR, the National Alzheimer's Call Center & Elder Locator, Alzheimers.gov & other federal partners to ensure aging & public health workforces receive recent, updated & culturally-competent information.	ACL/AoA, NIH/NIA	CDC, AHRQ	Ongoing	NIH initiated a project involving AHRQ & NASEM, to conduct a systematic review of the evidence on prevention of clinical AD-type dementia, MCI, & age-related cognitive decline (AHRQ), & to shape these findings into a set of recommendations for public health practice & research (NASEM). The NASEM report, detailing recommendations for public health messaging based on findings were released in June 2017. For more information see: AHRQ report https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=2417 NASEM report https://www.nationalacademies.org/dementia Free continuing education is available to professionals who need it when they view recorded webinars. This continuing education is available through 2016. http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx#resourcs The interagency ROAR (NIH, ACL, CDC) group hosted an update in the popular webinar series in 2017 for professionals on AD/ADRD resources that drew 500+ participants & offered continuing education credit. Free continuing education is available to professionals who need it when they view recorded webinars from 2017 & earlier series. This continuing education is available through 2018. https://www.nia.nih.gov/alzheimers/announcements/2017/02/2017-alzheimers-and-dementia-webinars-professionals https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals
2.A.6	Engage the public health workforce on brain health.	Conduct briefings with federal, state, & local public & private partners regarding the HBI: The Public Health Road Map for State & National Partnerships, 2013-2018.	CDC	ACL, NIH/NIA	Ongoing	CDC in collaboration with the HBRN has developed a Scholars Program to assist in the training of graduate-level students in brain health. Students engage in a variety of educational, partnership, & research activities. This program in year 2 of a 5-year funding cycle. CDC in collaboration with the Alzheimer's Association developed *A Public Health Approach to Alzheimer's & Other Dementias*. This introductory curriculum describes the role of public health in addressing the epidemic of AD/ADRD. Its 4 modules each contain a comprehensive faculty guide & slide deck. Whether you're teaching a public health course at an academic institution or delivering health education at the local level, explore how you can adapt this flexible resource to fit your needs. http://www.alz.org/publichealth/curriculum.asp

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
2.A.7	Strengthen the ability of primary care teams in Indian Country to meet the needs of people with AD/ADRD & their caregivers.	Incorporate training for AD/ADRD into the online continuing education curriculum for IHS, Tribal, & Urban program nursing.	IHS		Ongoing	Web-based course on AD/ADRD April-June 2016 IHS Clinical Rounds. On agenda of IHS Nursing Leadership meeting May 17, 2016. Clinical training on diagnosis & management of AD/ADRD for ACL/IHS/CMS LTSS conference, November 2016. Banner Alzheimer's Institute National Alzheimer's meeting October 2015. Review of online IHS nurse training resources completed. Exploring use of Project ECHO to support diagnosis & management of ADRD.
2.A.8	Develop a baseline understanding of self-reported competence & confidence of IHS, Tribal & Urban Indian Health nursing staff in care of individuals with dementia.	Assess nursing in IHS, Tribal, & Urban Indian Health programs on self-reported competence, confidence, & recent training specific to care for individuals with dementia.	IHS		Ongoing	Survey pilot-tested at 1 Tribal site.
2.A.9	Improve educational resources for primary care staff caring for individuals with dementia & their family.	Pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, & Urban Indian Health Programs.	IHS	HRSA	Ongoing	Pilot-test in 6 sites when the curriculum is available.
2.A.10	Decision Support for Clinicians.	Develop & pilot-test decision support tools for clinicians using the IHS EHR.	IHS		Ongoing	In development.
2.A.11	Interdisciplinary Team Training in recognition, assessment, & management of dementia in small rural Indian Health facilities.	Provide the VA RITT to 10 IHS & Tribal sites with a focus on dementia care.	IHS	VA	Ongoing	Eight trainings completed. Two more scheduled as well as training in Alaska in partnership with the Aleutian-Pribilof Islands Association.
2.A.12	Strengthen states' ability to provide & sustain dementia-capable HCBS.	Grants to states & technical assistance on high-quality person-centered dementia care. Develop learning collaboration & tool to evaluate dementia-capability.	ACL/AoA	CMS	Ongoing	Products in 2015 include: Tools for Screening, Identification, Referral, & Care Planning for People with AD & Their Caregivers.
2.A.13	Fill service gaps in dementia-capable systems by expanding the availability of specialized services & supports to target previously under-served populations.	Grants to states & localities.	ACL/AoA	CMS	Ongoing	This is an ongoing project assuming continuing congressional appropriations.
2.A.14	Strengthen the long-term care workforce.	Provide technical assistance to states.	DoL, CMS	HHS	Technical assistance ongoing	Final Rule issued October 2013.
2.A.15	Improve HCBS LTSS provided through state Medicaid waivers.	Hold webinars, national calls, & provide information to key stakeholders.	CMS		Ongoing	As 1 example, CMS is supporting state Medicaid agencies in community integration through HCBS. One targeted area of support is helping a select number of Medicaid agencies plan & implement quality & outcome incentives in their HCBS programs. https://www.medicaid.gov/state-resource-center/innovation-accelerator-program/community-integration-ltss/ci-ltss.html
2.A.16	Disseminate CMS Hand-in-Hand dementia training materials in VA CLCs.	Share with federal partners a summary report on implementation & evaluation of VA's dissemination of CMS Hand-in-Hand dementia training materials in VA CLCs.	VA	ASPE, ACL, HRSA	Ongoing	This is an ongoing project. Evaluation activities were underway in 2017.

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Strategy 2.B: Ensure Timely and Accurate Diagnosis						
2.B.1	Identify & disseminate a variety of appropriate assessment tools.	Identify a variety of appropriate assessment tools that can be used in a variety of outpatient settings, including the Medicare AWV, to assess cognition. Complete the development of the "toolbox" of cognitive assessment tools. Disseminate recommended tools to practitioners.	NIH/NIA	CDC	Ongoing	Searchable database of assessment tools http://www.nia.nih.gov/research/cognitive-instrument Updated fact sheet on the AWV for FFS Medicare providers http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AWV_Chart_ICN905706.pdf In 2015, NIA developed a mini-portal of resources for professionals, including the clinician quick guides "Assessing Cognitive Impairment in Older Adults" & "Managing Older Patients with Cognitive Impairment." https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals
2.B.2	Educate family members of & service providers for persons with IDD about changes that may indicate the onset of dementia.	Develop fact sheets & tools to aid in identifying the onset of dementia.	ACL/AIDD	National Task Group on Intellectual Disabilities & Dementia Practice	Ongoing	Two webinars & an issue paper were made available in 2015 Resources: Webinar: IDD & Dementia--California Webinar http://www.aoa.acl.gov/Site_Utilities/Standard_External_Disclaimer.aspx?redirection=https://youtu.be/ZCZb7aMrSMU
2.B.3	Increase awareness of AD/ADRD in Tribal & Urban Indian Communities & of the availability of services for Individuals with dementia & their families.	Pilot-test AD/ADRD awareness strategies in communities in which REACH into Indian Country is implemented, through both health care & aging services settings.	IHS	ACL	Ongoing	The focus of the REACH intervention in its final year will be on increasing awareness of ADRD in those communities served by REACH & increasing use of REACH caregiver support services.
Strategy 2.C: Educate and Support People with Alzheimer's Disease and Related Dementias and Their Families upon Diagnosis						
2.C.1	Educate physicians & other health care providers about accessing LTSS.	Increase knowledge of available resources among doctors, nurses, & hospitals.	HRSA	CMS, VA, ACL	Ongoing	One barrier to counseling & support is that health care providers are not aware of available services or how to access them. To increase knowledge of these resources among physicians, nurses, & hospitals, HRSA is partnering with federal partners, public & private entities, the health care provider community, & community organizations that provide LTSS to effectively educate physicians & other health care providers, direct services workers, & patients, families, & caregivers about support resources & services available to assist people with AD/ADRD, as well as their caregivers. These activities will continue as part of the training in Action 2.A.1. CMS is doing other work through its Innovation Center to facilitate this goal.
2.C.2	Connect American Indians & Alaska Natives to AD/ADRD resources.	As new resources become available, they will be distributed through a variety of venues to Indian Country.	IHS	ACL/AoA, NIH/NIA	Ongoing	The focus on increasing support to caregivers has been through spread of REACH into Indian Country, with the goal of offering this intervention to those with AD/ADRD & their families.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings						
2.D.1	Explore dementia care guidelines measures.	Convene meetings with public & private organizations to discuss dementia care practices; develop/identify 3-5 evidence-based guidelines of best dementia practices; include guidelines in the National Guidelines Clearinghouse; disseminate guidelines to consumer & clinical stakeholders, as well as quality measure developers.	CMS	ASPE, AHRQ	Ongoing	
2.D.2	Solicit stakeholder input on meaningful outcomes to drive quality measurement.	Convene listening sessions with relevant stakeholders.	CMS	ASPE	Ongoing	Initial target met; continuing work of reviewing literature & guidelines continues to support quality measure development & implementation.
2.D.3	Clarify & disseminate information on privacy, autonomy, & safety issues for physicians.	Develop information for physicians on privacy, autonomy, & safety issues. This resource will help providers better understand these issues & the balance between safety, privacy, & autonomy.	HRSA		Ongoing	HHS will disseminate this information through the trainings provided by GWEP awardees.
2.D.4	Training Resources for IHS Staff.	Review of training resources for IHS nursing staff highlighting person-centered goals & strategies for improving care for persons with dementia.	IHS	HRSA	Ongoing	IHS collaborated with HRSA to engage the HRSA-funded GWEPs in strategies to improve recognition & diagnosis of dementia.

Currently 8 GWEPs partner with federally recognized Tribal populations & 1 collaborates with a non-federally recognized Tribal population. The 9 GWEPs have developed a Native Populations Interest Group in preparation for exchanging training materials. The University of Wyoming is currently developing culturally-relevant dementia training material for Native American people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's "Know the 10 Signs: Early Detection Matters". |
| 2.D.5 | Understanding trends in residential care settings for older adults. | Analyze trends in residential care, using data at various points in time from several data sources, including MCBS, NHATS, & NSLTCP. | ASPE | | Ongoing | |
| 2.D.6 | Study factors influencing the progression of disability in older adults. | Use the NHATS 2011-2015 data to study the progression of disability & the implications for caregiving needs. | ASPE | | Ongoing | |

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease and Related Dementias						
2.E.1	Evaluate the effectiveness of relevant CMMI models for people with AD/ADRD.	Examine changes in care quality & care coordination among people with AD/ADRD.	CMS/CMMI	NIH/NIA	Ongoing	At this time CMS has several HCIAs that impact people with AD/ADRD & their caregivers. The evaluation results for the HCIA Round 1 awards were released in March 2017 (see Plan updates). HCIA Round 2 First Annual Evaluation Report was released in August 2016. Third Annual Evaluation Report Released in March 2017. • Disease-Specific http://downloads.cms.gov/files/cmmi/hcia-diseasesspecific-thirdannualrpt.pdf • Complex/High-Risk Patient Targeting https://downloads.cms.gov/files/cmmi/hcia-chspt-thirdannualrpt.pdf HCIA-2 First Evaluation Report was released in August 2016 https://downloads.cms.gov/files/cmmi/hcia2-yroneevalrpt.pdf
2.E.2	Evaluate the effectiveness of the Independence at Home Demonstration.	Examine whether health & functional status outcomes are improved among people with AD/ADRD in this demonstration.	CMS/CMMI		Ongoing	Year 2 Results https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-08-09.html
2.E.3	Develop a SDM model as an alternative to guardianship.	Support a national training, technical assistance, & resource center to explore & develop SDM as an alternative to guardianship.	ACL/AoA		Started in 2015, expected completion in 2019	http://www.supporteddecisionmaking.org
2.E.4	Analyze new payment & service options for Medicare-Medicaid dual eligible beneficiaries.	Produce targeted research issue briefs on options for expanding PACE.	ASPE		Ongoing	
2.E. 5	Analyze "quality dementia care" practices across settings.	Case studies conducted across settings to better understand what innovative dementia care providers are doing to provide quality care.	ASPE		Complete, report expected July 2017	
2.E.6	Analyze reimbursements for high-quality, community-based, ambulatory mental health & substance use disorder services.	Two year demonstration program of Certified Community Behavioral Health Clinics.	ASPE	SAMHSA	Ongoing	http://www.samhsa.gov/section-223
2.E.7	Studying home health utilization.	Study to better understand the growth in use of the Medicare home health benefit by community-admitted users --those individuals for whom home health episodes are not preceded by a hospitalization of PAC stay.	ASPE		Ongoing	
Strategy 2.F: Ensure that People with Alzheimer's Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems						
2.F.1	Implement & evaluate new care models to support effective care transitions for people with AD/ADRD.	Evaluate care transition demonstration programs.	CMS	ACL/AoA	Ongoing	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
2.F.2	Assess the adequacy of HIT standards to support the exchange of information at times of referrals & transitions in care for persons with AD/ADRD.	Convene partners to explore feasibility & timing.	ASPE	ONC, CMS	Ongoing	
Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with Alzheimer's Disease and Related Dementias						
2.G.1	Implement & evaluate care coordination models.	Implement & evaluate care coordination models.	CMS		Ongoing	Multiple care coordination models & guidance on care coordination continue across CMS.
2.G.2	Evaluate evidence on care integration.	Issue report on findings.	ASPE		Ongoing	
2.G.3	Assess the adequacy of HIT standards for care plans to support the needs of persons with AD/ADRD.	Convene partners to explore feasibility & timing.	ASPE	ONC	Ongoing	
Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and Related Dementias and for Populations Facing Care Challenges						
2.H.1	Create funding opportunities for organizations to improve care for these specific populations.	Fund dementia-capable systems to implement new programs designed to provide more effective services to: (1) individuals living alone in the community with dementia; (2) individuals with IDD who have or are at-risk of developing dementia; (3) caregivers who need behavioral symptom management training or expert consultations to help them care for family members; & (4) provision of effective care/supportive services for individuals living with moderate to severe AD/ADRD & their caregivers.	ACL/AoA		Ongoing	ACL awarded 11 grants in 2015. ACL anticipates awarding 10 new grants in 2016. Note that future grants are contingent on availability of funding.
2.H.2	Enhance understanding of models of family support for people with IDD as they age.	Explore promising models, release report.	ASPE		Ongoing	
2.H.3	Compare outcomes for dual eligible beneficiaries in integrated care models.	Determine the feasibility of an analysis that compares selected health outcomes & quality measures for Medicare-Medicaid dual eligible beneficiaries participating in managed care models.	ASPE		Ongoing	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Goal 3: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families						
Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials						
3.A.1	Distribute materials to caregivers.	Distribute training & education materials through federal agencies & state & local networks.	ACL	NIH/NIA, ADEAR	Ongoing	Networks serving caregivers have frequent opportunities for webinars, consultation, & grants to better serve caregivers. http://www.alzheimers.gov Fact sheets http://www.eldercare.gov/eldercare.NET/Public/REsources/Advanced_Care/Index.aspx NIA's ADEAR continues to offer free information on AD/ADRD caregiving https://www.nia.nih.gov/alzheimers/topics/caregiving
3.A.2	Utilize HIT for caregivers & persons with AD/ADRD.	Identify tools, evaluate, & disseminate findings.	AHRQ		Completion expected July 2016 Ongoing, completion expected 2019	Grant #1P50 HS 019917 awarded & used to create Elder Tree, a suite of electronic services to support older adults & their caregivers. The Elder Tree tool is being evaluated. Recruited 400 people who have used the suite, participants were surveyed. Analysis underway & results will be available by July 2016. Grant #5R18HS027836 awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD & study impact on ability of caregivers to manage family member with AD/ADRD. Recruited 60 caregivers, systems installed & caregivers trained. The recruitment goal is 100.
3.A.3	Increase awareness of the importance of brain health in culturally sensitive ways.	Increase awareness of brain health, specifically AD/ADRD & caregiving among African Americans.	CDC		Ongoing	CDC supported the development of NBHCAA. The mission of Brain Health Center is to raise awareness of the issues of cognitive health among African Americans by working through networks of faith-based institutions & by establishing partnerships with organizations & individuals dedicated to our mission. The 3 areas of focus of brain health education, mobilization & advocacy, & networking. The Brain Health Center serves as an information hub on the human brain that must be shared throughout all networks that reach & touch approximately 40 million African Americans living in the United States. http://brainhealthcenterforafricanamericans.org/ Memory Sunday: Increasing Awareness of AD in Church Congregations. CDC supported the Balm in Gilead to develop & implement Memory Sunday, the Second Sunday in June, as a designated Sunday, within congregations serving African Americans, that provides education on Alzheimer's: prevention, treatment, research studies & caregiving. The purpose of Memory Sunday is to bring national & local attention to the tremendous burden that Alzheimer's & other Dementias are having on the African American community; to utilize the power & influence of the African American pulpit to bring awareness; to distribute the facts about Alzheimer's; to encourage participation in research studies & to support persons living with Alzheimer's & their caregivers.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being						
3.B.1	Develop & disseminate evidence-based interventions for people with AD/ADRD & their caregivers.	Identify specific evidence-based interventions that can be developed into training materials or new programs; develop training materials and/or design intervention programs based on NIH/NIA research.	NIH/NIA	AHRQ, CMS, CDC, ACL/AoA	Ongoing	Resources for dissemination http://www.alzheimers.gov NIA's ADEAR continues to offer free information on AD/ADRD research & interventions https://www.nia.nih.gov/alzheimers Ongoing & newly released FOAs: • PAR-15-348: Research on Informal & Formal Caregiving for AD (R01) http://grants.nih.gov/grants/guide/pa-files/PAR-15-348.html • PAR-15-351: Research on Informal & Formal Caregiving for AD (R21) http://grants.nih.gov/grants/guide/pa-files/PAR-15-351.html • PAR-17-107: Development of SARs to Engage Persons with AD/ADRD, & their Caregivers (R41/R42) https://grants.nih.gov/grants/guide/pa-files/PAR-17-107.html • PAS-17-027: Improving Quality of Care & Quality of Life for Persons with AD/ADRD at the End of Life https://grants.nih.gov/grants/guide/pa-files/PAS-17-027.html NIA staff has had several discussions with AoA staff about interventions that might be ready for dissemination within the AoA network. NIA & AoA have jointly supported a FOA for translation of evidence-based research. NIA staff have participated in numerous meetings with AoA to share information & discuss opportunities to work together on dissemination of interventions within the AoA network.
3.B.2	Provide effective caregiver interventions through AD-capable systems.	Work with states to identify caregiver interventions for dissemination.	ACL/AoA		Ongoing	New grants are awarded each year as funding permits.
3.B.3	Collaborate to share information on LTSS with Tribal providers.	Various dissemination mechanisms such as webinars & sharing materials with relevant networks.	ACL/AoA	IHS, CMS	Ongoing	Presentations occur at Indian Country meetings & webinars. November 2016 Tribal LTSS conference in Minneapolis, MN. Ongoing webinar series through the CMS/IHS/ACL LTSS technical assistance website. A CMS-funded baseline survey of Tribal LTSS is in development.
3.B.4	Continue to promote use of the National Alzheimer's Call Center to provide information, advice, & support to people with dementia or their caregivers.	AoA will continue to contribute funding to this public-private effort.	ACL/AoA	Alzheimer's Association	Ongoing	AoA will continue to contribute funding to this public-private effort, assuming Congressional appropriations continue.
3.B.5	Make behavioral symptom management education & training available to caregivers.	Award grants.	ACL/AoA	CMS	Ongoing	2015 grants made & more anticipated in 2016.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
3.B.6	Examine technological solutions to support family caregivers.	Grant awarded--awaiting results.	AHRQ		December 2019	Grant #5R18HS027836 awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD & study impact on ability of caregivers to manage family member with AD/ADRD. Recruited 60 caregivers, systems installed & caregivers trained. The recruitment goal is 100.
3.B.7	Adapt & Implement REACH in Tribal Communities.	Working in partnership with ACL, the University of Tennessee Health Sciences Center, & the Rx Foundation implement the REACH intervention as REACH into Indian Country.	IHS	ACL/AoA. VA, University of Tennessee Health Sciences Center	Ongoing	Baseline in February 2015 was 3 communities (the REACH-VA Pilot Sites). 47 communities reached as of April 2017. Implementation began in February 2015, with 47 Communities as of December 2016. • Website Developed https://www.uthsc.edu/prevmed/memphis-caregiver-center/index.php • Brochure Developed https://www.uthsc.edu/prevmed/documents/reach/reach-indian-country-brochure.pdf Implementation in 50 Tribal communities by February 2018. Focus in final year is on sustainability.
3.B.8	Determine economic impacts of programs to support informal caregivers.	Provide a framework for policy makers to begin to estimate costs & benefits of policies & programs aimed to help caregivers.	ASPE		Ongoing	
Strategy 3.C: Assist Families in Planning for Future Care Needs						
3.C.1	Understand how families find & access LTSS.	Exploratory qualitative research project to examine where families gather information, how they make decisions, how well arrangements work, & how local factors influence the process.	ASPE		Ongoing	
3.C.2	Understand long-term care financing & service delivery models.	Development of series of long-term care financing proposals through actuarial & micro-simulation modeling.	ASPE		Ongoing	
Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease and Related Dementias						
3.D.1	Monitor, report & reduce inappropriate use of antipsychotics in nursing homes.	National Partnership to Improve Dementia Care.	CMS	ACL/AoA, NORC	Ongoing	CMS continues to make progress on the National Partnership to Improve Dementia Care. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html
3.D.2	Incorporate elder abuse awareness into Aging Network activities.	Eldercare Locator & other Aging Network & prevention programs providers to recognize warning signs of abuse.	ACL/AoA	Private partner/grantees	Ongoing	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
3.D.3	Translate & disseminate information on abuse of people with dementia.	Create & disseminate research briefs, fact sheets & webinars.	ACL/AoA	NIH/NIA, DoJ, private partners	Ongoing	In 2016, NIH published an Age Page on Elder Abuse to educate the public & disseminate information about types of elder abuse, dealing with caregiver stress, & how to help. https://www.nia.nih.gov/health/publication/elder-abuse
3.D.4	Improve the ability of legal services to address the needs of people with AD/ADRD.	Award, monitor, & report on demonstration grants. Revise NLRC website.	ACL/AoA	Legal assistance developers, NLRC	Ongoing	New contract for the National Center on Law & Elder Rights & new grants are available under the Model Approaches program.
3.D.5	Develop public-private partnerships to combat abuse & exploitation of Social Security beneficiaries.	An interagency, public-private partnership program to address abuse & exploitation of individuals who are incapable of managing their finances.	SSA	ACL/AoA, CNCS, CFPB, SSA	Ongoing	Volunteer Representative Payee Pilot Program results include the development & testing of protocols & materials to assist in the identification & training of individuals to serve as volunteer representative payees. Once the modules are complete, SSA will conduct a media campaign to build awareness of the pilot's results.
3.D.6	Educate law enforcement about interacting with AD/ADRD.	Educate law enforcement & public safety professionals about how to interact appropriately with missing persons with AD/ADRD.	DoJ		Ongoing	March 2016: Launch of 10 regional Elder Justice Task Forces. These teams will bring together federal, state & local prosecutors, law enforcement, & agencies that provide services to the elderly, to coordinate & enhance efforts to pursue nursing homes that provide grossly substandard care to their residents. https://www.justice.gov/opa/pr/department-justice-launches-10-regional-elder-justice-task-forces
3.D.7	Work with communities to develop best practices for protecting people with AD/ADRD.	A guide to educate law enforcement & inform communities, families & caregivers about best practices for protecting persons with AD/ADRD & preventing them from wandering & becoming lost.	DoJ		Ongoing	DoJ Elder Abuse Information https://www.justice.gov/elderjustice/financial/faq.html
Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias						
3.E.1	Understand use of Medicare & Medicaid funded health services among older adults in HUD-assisted housing.	Analyze health care utilization & spending among Medicare & Medicaid beneficiaries in HUD-assisted housing.	ASPE, HUD		Part 1 completed 2014 Part 2 expected 2016	Picture of Housing & Health: Medicare & Medicaid use of Older Adults in HUD-Assisted Housing https://aspe.hhs.gov/basic-report/picture-housing-and-health-medicare-and-medicaid-use-among-older-adults-hud-assisted-housing Picture of Housing & Health Part 2: Medicare and Medicaid Use Among Older Adults in HUD-Assisted Housing, Controlling for Confounding Factors https://aspe.hhs.gov/basic-report/picture-housing-and-health-part-2-medicare-and-medicaid-use-among-older-adults-hud-assisted-housing-controlling-confounding-factors
3.E.2	Evaluate SASH program.	Analyze the SASH program model of coordinated health & supportive services within affordable housing settings.	ASPE		First Report: 2014 Second Report: 2016	https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-second-annual-report
3.E.3	Understand & analyze unlicensed care homes.	Exploratory study to understand how unlicensed care homes function as a residential care option, the types of individuals who reside in them, & their characteristics including quality & safety policies that influence the supply & demand for these homes.	ASPE		Report completed 2016	https://aspe.hhs.gov/basic-report/understanding-unlicensed-care-homes-final-report

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Goal 4: Enhance Public Awareness and Engagement						
Strategy 4.A: Educate the Public about Alzheimer's Disease and Related Dementias						
4.A.1	Design & conduct a national education & outreach initiative.	Plan, fund, & implement AD/ADRD awareness activities, in racially & ethnically diverse populations.	CDC		Ongoing	CDC in partnership with the Balm in Gilead is educating African Americans about cognition & brain health through faith-based organizations & medical organizations. Additionally, HBRN is conducting a series of focus groups to test educational messages in racially, ethnically, & geographically diverse samples.
4.A.2	Enhance public outreach about AD/ADRD.	Update website & ADEAR site/publications & disseminate information through social media.	ACL/AoA NIH/NIA		Ongoing	NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, & caregiving. The ADEAR Center educates the public about the latest research findings & provides evidence-based information online, in print & via a call center. Information about AD/ADRD, participation in clinical trials, & caregiving is freely available. NIA promotes ADEAR's resources through outreach in the research & care communities & through the media & advocacy organizations, via weekly e-alerts to more than 50,000 subscribers, & social media outreach to more than 10,000 followers. Beginning in 2017, NIA will manage Alzheimers.gov to continue to expand public outreach about AD/ADRD.
4.A.3	Expand access to treatment for people with mental health & substance use disorders.	Maintain the Mental Health & Substance Use Disorder Parity Task Force. The Task Force will focus key federal agencies on the work of ensuring that Americans receive the coverage & treatment that they need.	ASPE	DoT, DoD, DoJ, DoL, VA, OPM, ONDCP	Ongoing	Presidential Memorandum--Mental Health & Substance Use Disorder Parity Task Force https://www.whitehouse.gov/the-press-office/2016/03/29/presidential-memorandum-mental-health-and-substance-use-disorder-parity
4.A.4	Dementia Chart Book.	Complete a chart book with important information on the population of community-dwelling people with dementia in the United States & their caregivers	ASPE		Release in Fall 2017	
Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease and Related Dementias Awareness and Readiness across the Government						
4.B.1	Continue to convene federal partners.	Convene to share research findings, innovative or best practices, & information about new or upcoming initiatives.	ASPE	CDC, NIH/NIA, ACL/AoA, CMS, HRSA, AHRQ, IHS, SAMHSA, OASH, VA, NSF, DoD	Ongoing	This work will continue throughout the duration of the NAPA legislation & beyond.
4.B.2	Build upon lessons learned to improve the dementia-capability of state & local service systems.	Expand Dementia-Capability Toolkit to include educational materials on identifying persons with cognitive impairment, direct links to tools, & examples of best practices in other states.	ACL/AoA	CMS	Ongoing	ADSSP learning collaborative results http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx ADSSP & ADI-SSS grantees & their Resource Center provide new & improved resources every year.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
4.B.3	Get Tribal input on AD/ADRD, & support improved coordination between IHS, Tribal, & Urban Indian Health programs & the Tribal Aging Network around 4 person-centered goals.	Convene Tribal leaders. Improve coordination between IHS, Tribal, & Urban Indian Health programs & the Tribal Aging Network around 4 person-centered goals. IHS & ACL will adapt the VA approach to dementia warning signs & pilot-test it in clinical & community-based settings. IHS & ACL will partner with AD/ADRD advocacy organizations to link state & local chapters with Tribal Senior Centers & IHS, Tribal, & Urban Indian Health Programs.	IHS ACL/AoA	ASPE, ACL/AoA, VA	Ongoing	Alzheimer's Association meetings with the United South & Eastern Tribes & with the Northwest Portland Area Indian Health Board. Tribal representation on the Alzheimer's Association/CDC Health Brain Initiatives Road Map.
Strategy 4.C: Coordinate United States Efforts with Those of the Global Community						
4.C.1	Work with global partners to enhance collaboration.	Convene global partners in collaboration with G8 Dementia Summit.	ASPE		Ongoing	United States participated in legacy meetings throughout 2014. United States hosted the final legacy meeting in February 2015, & was represented at the WHO Dementia meeting in Geneva in March 2015.
Goal 5: Improve Data to Track Progress						
Strategy 5.A: Enhance the Federal Government's Ability to Track Progress						
5.A.1	Identify needed changes or additions to data.	Work with federal partners & researchers.	ASPE	CMS, CDC, NIH/NIA, ACL/AoA, VA, IHS	Ongoing	This work will continue throughout the duration of the NAPA legislation & beyond
5.A.2	Make needed improvements to data.	Develop questions to be fielded for data collection. Add to surveys.	ASPE	CDC/NCHS, NIH/NIA	Ongoing	This work will continue throughout the duration of the NAPA legislation & beyond

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
5.A.3	Summarize data on cognitive impairment & caregiving across states.	Report on BRFSS data on cognitive decline & caregiving.	CDC		Ongoing	BRFSS Data & Data for Action. CDC worked with partners & revised the BRFSS Cognitive Decline & Caregiving Optional Modules, which were approved as official optional modules beginning in 2015. In 2015 & 2016, 51 states collected data using the Cognitive Decline Module & 40 states collected data using the Caregiving Module. Additional states are collecting data using the Cognitive Caregiving Modules in 2017. Findings from the 2015 cognitive & caregiving data are publically available on CDC's Healthy Aging Data Portal & fact sheets & infographics were developed for each participating states. Findings from 2016 BRFSS will be released late in 2017. http://www.cdc.gov/aging/agingdata/index.html http://www.alz.org/publichealth/data-collection.asp https://www.cdc.gov/aging/healthybrain/surveillance.htm CDC supported the development & collection of subjective cognitive decline & cognitive functioning data from the in-person NHANES are publically available for download & analysis. These data were collected in adults 60 years & older as part of the 2011-2012 & 2013-2014 data collection cycles. The data included in this release include results from 3 tests of cognitive function: CERAD. http://www.cdc.gov/nhanes
5.A.4	Develop & disseminate measures of awareness of AD/ADRD.	Release report on validated survey questions.	CDC		Ongoing	CDC is examining the validity of subjective cognitive questions used in national surveys by comparing self-rated perceptions of cognitive functioning to functional measures. The report will be released in 2018.
5.A.5	Summarize existing data on people with AD/ADRD & their caregivers.	Develop & release data portal.	ASPE	CDC/NCHS, NIH/NIA, ACL/AoA	Ongoing	CDC's Healthy Aging Data Portal. The portal was updated with CDC Updates Public Data Portal on the Health of Older Adults. CDC recently updated the Healthy Aging Data Portal, which provides access to a range of national, regional, & state data on older adults. This resource was developed by the National Center for Chronic Disease Prevention & Health Promotion. It allows users to examine data on key indicators of health & well-being for older Americans, such as tobacco & alcohol use, screenings & vaccinations, & mental & cognitive health. 2015 BRFSS data, including data on cognitive decline from 35 states & data on caregivers from 24 states. Portal users can retrieve CDC data by indicator or by geographic area, & then use these data to develop reports & create customized maps, charts, & graphics. Public health professionals can use the data to create a snapshot of the health of older adults in their states, which can help them prioritize & evaluate public health interventions. https://www.cdc.gov/aging/agingdata/index.html
5.A.6	Develop a consistent set of ICD-9/ICD-10 codes for AD/ADRD for federal agencies to use in analyses of administrative data.	Convene interagency group to reach consensus. Crosswalk to ICD-10 codes.	ASPE	CMS, VA, NIH, IHS	Ongoing	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2016 and 2017
Strategy 5.B: Monitor Progress on the National Plan						
5.B.1	Track plan progress.	Track progress on the plan, & incorporate measures into other efforts to monitor population health such as Healthy People 2020.	ASPE		Ongoing	This work will continue throughout the duration of the NAPA legislation & beyond.
5.B.2	Update the National Plan annually.	Release updated National Plan.	ASPE		Ongoing	This work will continue throughout the duration of the NAPA legislation & beyond.

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List of Acronyms Used

AAA	Area Agency on Aging
AAIC	Alzheimer's Association International Conference
ABC	Antecedent, Behavior and Consequence
ACL	Administration for Community Living
ACO	Accountable Care Organization
AD	Alzheimer's Disease
AD-PCPRN	Alzheimer's Disease Patient and Caregiver-Powered Network
ADC	Alzheimer's Disease Center
ADDF	Alzheimer's Drug Discovery Foundation
ADEAR	Alzheimer's Disease Education and Referral
ADGC	Alzheimer's Disease Genetics Consortium
ADHC	Adult Day Health Care
ADI-SSS	Alzheimer's Disease Initiative-Specialized Supportive Services
ADL	Activity of Daily Living
ADNI	Alzheimer's Disease Neuroimaging Initiative
ADRC	Aging and Disability Resource Center
ADRD	Alzheimer's Disease-Related Dementias
ADS	Adult Day Services
ADSP	Alzheimer's Disease Sequencing Project
ADSSP	Alzheimer's Disease Supportive Services Program
AFTD	Association for Frontotemporal Degeneration
AHRQ	Agency for Healthcare Research and Quality
AIDD	Administration on Intellectual and Developmental Disabilities
AIDS	Acquired Immune Deficiency Syndrome
AlzCAP	Alzheimer's Disease Community Assistance Program
AMP	Accelerating Medicines Partnership
AoA	Administration on Aging
APOE	Apolipoprotein E
APS	Adult Protective Services
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
AWV	Annual Wellness Visit
BRFSS	Behavioral Risk Factor Surveillance System
bvFTD	Behavioral Variant Frontotemporal Degeneration
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CART	Collaborative Aging (in Place) Research using Technology initiative
CBD	Corticobasal Degeneration
CCM	Chronic Care Management
CDC	Centers for Disease Control and Prevention
CEAD	Center of Excellence for Alzheimer's Disease
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CEU	Continuing Education Unit
CFPB	Consumer Finance Protection Bureau
CLC	Community Living Center
CME	Continuing Medical Education
CMMI	Center for Medicare and Medicaid Innovation
CMS	Centers for Medicare and Medicaid Services
CNCS	Corporation for National and Community Service
COPE	Care of Persons with Dementia in their Environments
CPC+	Comprehensive Primary Care Plus

D-SNP	Dual Eligible Special Needs Plan
DCN	Dementia Caregiving Network
DFA	Dementia Friendly America
DLB	Dementia with Lewy Bodies
DNA	Deoxyribonucleic Acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DoL	U.S. Department of Labor
DoT	U.S. Department of Transportation
DSRTF	Down Syndrome Research and Treatment Foundation
eCQM	electronic Clinical Quality Measures
EHR	Electronic Health Record
EU	European Union
EXERT	Exercise in Adults with Mild Memory Problems tial
FAQ	Frequently Asked Question
FDA	Food and Drug Administration
FFS	Fee-For-Service
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Degeneration
FTD/ALS	Frontotemporal Degeneration/Amyotrophic Lateral Sclerosis (Lou Gehrig's disease)
FTDDR	Frontotemporal Degeneration Disorders Registry
FY	Fiscal Year
GAP	Global Alzheimer's Platform
GARD	Georgia Alzheimer's and Related Dementias
GCAD	Genomic Center for Alzheimer's Disease
GEC	Geriatric Education Center
GOC	Goals of Care
GWEP	Geriatrics Workforce Enhancement Program
HBI	Healthy Brain Initiative
HBRN	Healthy Brain Research Network
HCBS	Home and Community-Based Services
HCIA	Health Care Innovation Award
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HIT	Health Information Technology
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
IADRFC	International Alzheimer's Disease Research Funder Consortium
IADRP	International Alzheimer's Disease Research Portfolio
IAP	Innovation Accelerator Program
IBD	Inflammatory Bowel Disease
ICD-9	International Classification of Diseases, 9th revision
ICD-10	International Classification of Diseases, 10th revision
IDD	Intellectual and Developmental Disability
IHS	Indian Health Service
iSHARE	Interprofessional Strategic Healthcare Alliance for Rural Education
JPND	Joint Programme on Neurodegeneration

KU ADC	University of Kansas Alzheimer's Disease Center
LBD	Lewy Body Dementia
LBDA	Lewy Body Dementia Association
LGBT	Lesbian, Gay, Bisexual, and Transgender
LOAD	Late-Onset Alzheimer's Disease
LTCO	Long-Term Care Ombudsman
LTSS	Long-Term Services and Supports
M^{2}OVE-AD	Molecular Mechanisms of the Vascular Etiology of Alzheimer's Disease
MCBS	Medicare Current Beneficiary Survey
MCI	Mild Cognitive Impairment
MUC	Measures Under Consideration
NADRC	National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer's Project Act
NASEM	National Academies of Science, Engineering and Medicine
NBHCAA	National Brain Health Center for African Americans
NCEA	National Center on Elder Abuse
NCHS	National Center for Health Statistics
NCP	National Center for Health Promotion and Disease Prevention
NGO	Non-Governmental Organization
NHANES	National Health and Nutrition Examination Survey
NHATS	National Health and Aging Trends Survey
NHC	Nursing Home Compare
NIA	National Institute on Aging
NIAGADS	National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities
NINDS	National Institute of Neurological Disorders and Stroke
NLRC	National Legal Resource Center
NORC	National Ombudsman Resource Center
NPS	Neuropsychiatric Symptoms
NSF	National Science Foundation
NSLTCP	National Study of Long-Term Care Places
NYSDOH	New York State Department of Health
OAA	Older Americans Act
OASH	HHS Office of the Assistant Secretary for Health
OLTCOP	ACL Office of Long-Term Care Ombudsman Programs
ONC	HHS Office of the National Coordinator for Health Information Technology
ONDCP	White House Office of National Drug Control Policy
OPM	U.S. Office of Personnel Management
ORD	VA Office of Research and Development
OWH	HHS Office on Women's Health
P.L.	Public Law
PAC	Post-Acute Care
PACE	Program of All-Inclusive Care for the Elderly
PBPM	Per Beneficiary Per Month
PCORI	Patient-Centered Outcomes Research Institute
PDBP	Parkinson's Disease Biomarkers Program
PDSI	Psychotropic Drug Safety Initiative
PET	Positron Emission Tomography
PPA	Primary Progressive Aphasia

PRC	Prevention Research Center
Project ECHO	Extension for Community Healthcare Outcomes project
PSP	Progressive Supranuclear Palsy
Q4	Fourth Quarter
QIO	Quality Improvement Organization
RA2	ResearchersAgainstAlzheimer's
RDS	Research Down Syndrome
REACH	Resources for Enhancing Alzheimer's Caregivers' Health
RFA	Request for Application
RITT	Rural Interdisciplinary Team Training
ROAR	Recruiting Older Adults into Research
SAMHSA	Substance Abuse and Mental Health Services Administration
SAR	Socially-Assistive Robot
SASH	Support and Services at Home
SDM	Supported Decision Making
SSA	U.S. Social Security Administration
STAR	Staff Training in Assisted Living Residences
TAP	Tailoring Activities for Persons with Dementia and Caregivers
THP	Tribal Health Program
TEP	Technical Expert Panel
VA	U.S. Department of Veterans Affairs
VCID	Vascular contributions to Cognitive Impairment and Dementia
VD-HCBS	Veteran-Directed Home and Community-Based Services
VHA	Veterans Health Administration
WES	Whole Exome Sequence
WGS	Whole-Genome Sequence
WHO	World Health Organization
WV CARES	West Virginia Coordinated Action, Response, Education and Support