National Plan to Address Alzheimer's Disease: 2016 Update

U.S. Department of Health and Human Services

National Plan to Address Alzheimer's Disease: 2016 Update

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Introduction

Vision Statement

For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer's disease is a pain they know all too well. Alzheimer's disease burdens an increasing number of our Nation's elders and their families, and it is essential that we confront the challenge it poses to our public health.

-- President Barack Obama

National Alzheimer's Project Act

On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA) (Public Law 111-375). 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.
- 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, 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 5.2 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 contribute to the burden of the illness due to 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 degeneration

(FTD), Lewy body dementia (LBD), vascular dementias, 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 preventative 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.

The disease places enormous emotional, physical, and financial stress on individuals who have it 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 are 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 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 the 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 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 two decades, these diseases

will place a major strain on these care systems as well as on Medicare and Medicaid, the major funders of institutional 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.

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 -- 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 support. 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.[11,12]

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 Alzheimer's disease and related dementias (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 by the Affordable Care Act. 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.

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 will be 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 is committing 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 has and continues to identify the most promising areas for progress and marshalling 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.

2016 Update

This is the 2016 Update to the National Plan. In order to create a more focused and accessible document, agencies have provided narrative descriptions of those activities that were completed in 2015, as well as some which are ongoing and have important updates. This is an attempt to provide a clear report of progress that was made since the last plan update in July 2015. 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:

1. immediate actions that the Federal Government has taken and will take;
2. actions toward the goals that can be initiated by the Federal Government or its public and private partners in the near term; and
3. 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 2016 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 2016 National Plan Update includes an appendix (Appendix 2) in which relevant federal agencies have directly 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. This goal 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 2015/2016, Goal 1 advanced on a number of fronts, thanks to a research community galvanized by a series of National Institutes of Health (NIH)-hosted summits on AD/ADRD and a ramp-up of federal funding for dementia research.

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. 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 were approved, with the expectation that a significant portion of the funds would be aimed at AD/ADRD research. As a result, spending at the NIH on AD research increased by roughly 30% from FY 2011 through FY 2015.

In December 2015, Congress passed the Consolidated Appropriations Act, 2016 (P.L. 114-113) that called for an unprecedented additional $350 million in 1 year towards AD/ADRD research (subject to the scientific opportunity presented in the peer review process) -- a boost that will further accelerate progress towards the Plan's ultimate research goal: finding effective interventions to treat or prevent AD/ADRD by 2025. This new funding invigorated and expanded investigator-initiated studies, the mainstay of NIH-funded efforts to learn more about AD/ADRD, as well as those conducted by dedicated NIH staff scientists. [See https://www.congress.gov/bill/114th-congress/house-bill/2029/text.]

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. 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 estimate outlined funding needs for the most promising research approaches for FY 2017. The NIH bypass budget for FY 2018 is anticipated to be released in the summer of 2016. NIH will prepare these estimates through FY 2025. Only two other areas of biomedical research have been the subject of this special budget approach: cancer and HIV/AIDS. [See https://aspe.hhs.gov/national-plan-address-alzheimers-disease-2014-update.]

Planning for the annual bypass budget and NIH's current AD/ADRD research portfolio are informed by research implementation milestones based on recommendations for Alzheimer's and related dementias 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 http://www.ninds.nih.gov/funding/areas/neurodegeneration/workshops/adrd2013/ADRD_2013_Recommendations_NAPA_508comp.pdf.]

Strategy 1.A: Identify Research Priorities and Milestones

2015 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 Alzheimer's 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. In response to goals and objectives discussed at the 2015 summit, NIH issued ten Funding Opportunity Announcements (FOAs) in the fall of 2015 inviting new grant applications on topics covering a broad spectrum of AD research. These funding announcements offered an array of opportunities for investigators, covering studies of epidemiology, basic molecular and cellular mechanisms, diagnosis and prediction, health disparities, caregiving, clinical trials, and brain aging, among others. The research community responded robustly to these new opportunities, and the first set of awards will be made before October 2016.

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

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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 progress 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 will be released, following approval by the National Advisory Neurological Disorders and Stroke Council and the NAPA Advisory Council later in 2016.

For more information, see:

- https://meetings.ninds.nih.gov/Home/Tab2/11958
- http://www.ninds.nih.gov/funding/areas/neurodegeneration/workshops/adrd2013/

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

Expanding Basic Understanding of Alzheimer's Disease. Investigator-initiated research reported in 2015 offered new insights into the complex molecular, biological and genetic factors that influence disease onset and progression.

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. In early 2015, the *AMP-AD Target Discovery and Preclinical Validation Project* launched a data portal with innovative analytical tools to the wider research community to shorten the time between the discovery of potential drug targets and the development of new drugs.

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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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 Discovery phase of the Alzheimer's Disease Sequencing Project (ADSP) determined the order of all 3 billion letters in the individual genomes of 580 participants. It also generated whole exome sequencing data (focused on the proteins influencing the disorder) of an additional 11,000 volunteers -- 6,000 with Alzheimer's compared to 5,000 controls. In 2015, investigators began to identify variations in the genomes of families where three or more family members are affected by the disease. The specific regions are now being closely examined to determine what genes are involved. The ADSP also initiated the Discovery Extension Phase of the study with whole genome sequencing on over 430 more family members.

Two NIH-funded entities are collaborating on managing and making available to the genetics research community the massive amounts of ADSP data: the Genetics of Alzheimer's Disease Data Storage Site (NIAGADS) and the Database for Genotypes and Phenotypes. In 2015, NIAGADS released genotypic data generated on more than 11,500 subjects and responded to data requests from 30 labs at 26 institutions in order to facilitate the sharing of sequence data with the genetics community. NIAGADS 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.

Promising Drugs to Treat or Prevent Alzheimer's Disease. Currently 38 National Institute on Aging (NIA)-supported clinical trials for AD/ADRD treatment and prevention are underway. In addition, NIH supports over 70 projects aiming to discover and develop new therapeutics for AD/ADRD.

Identifying Ways to Keep Neurons Healthy. As animals, including humans, age or develop brain diseases such as Alzheimer's, their brain cells may not produce enough energy to remain fully functional. Scientists using a new mouse model discovered that an enzyme, SIRT3, may protect brain cells against stresses believed to contribute to energy loss. They also found that physical exercise increases the expression of SIRT3 -- found in mitochondria, the cells powerhouse -- which helped to protect the brain against degeneration in the mice. The findings suggest that bolstering mitochondrial function and stress resistance by increasing SIRT3 levels may offer a promising therapeutic target for protecting against age-related cognitive decline and brain diseases such as Alzheimer's.

For more information, see:
- http://www.cell.com/cell-metabolism/abstract/S1550-4131(15)00529-X

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* (A4) trial, 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. 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 is underway for over 1,000 volunteers who carry two copies of the APOE e4 allele, a gene risk factor for late-onset Alzheimer's.

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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Alzheimer's Pathology in the Oldest-Old. The brains of people who live to age 90 and older -- the oldest-old -- usually have a mix of pathologies associated with dementia. AD/ADRD-related brain changes are the most common, but other pathologies often found at autopsy include infarcts, Lewy bodies, hippocampal sclerosis, and white-matter disease. For the first time, NIH-funded researchers examined the relationship between the number of pathologies found at autopsy and the severity of dementia in the oldest-old. They found the more pathologies present in the brain, the more severe the dementia, and that Alzheimer's pathology alone was less damaging to cognition than mixed pathologies. These findings point to the need to target multiple pathologies to reduce the burden of dementia.

For more information, see:
- http://www.ncbi.nlm.nih.gov/pubmed/26180144

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/ADRD. Currently, five NIH-funded clinical trials are underway to test whether exercise can influence Alzheimer's 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.

Being obese or overweight in middle age has been linked to increased risk of dementia. NIH staff scientists discovered that being obese or overweight at midlife -- as measured by body mass index (BMI) at age 50 -- may also predict earlier age of onset of Alzheimer's. The investigators found that in study participants who developed Alzheimer's, each unit increase in BMI at age 50 accelerated onset by nearly 7 months, that a higher midlife BMI was associated with greater levels of neurofibrillary tangles and amyloid -- hallmarks of the disease -- in the brain. The findings suggest that maintaining a healthy BMI at midlife might be considered as one way to delay the onset of Alzheimer's.

NIA has recently funded a Phase III randomized controlled trial designed to test the effects of a 3-year intervention of a hybrid of the Mediterranean and DASH diets, called MIND, on cognitive decline. This intervention will be tested among 600 individuals 65+ years of age without cognitive impairment who are overweight and have suboptimal diets that may place them at risk for developing dementia.

For more information, see:
- https://clinicaltrials.gov/ct2/show/NCT01954550
- http://www.ncbi.nlm.nih.gov/pubmed/?term=Chuang%2C+Y-F%2C+et+al.%2C+Midlife+adiposity+predicts+earlier+onset+of+Alzheimer's+dementia%2C+neuropathology+and+presymptomatic+cerebral+amyloid+accumulation
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9081135&icde=29784664&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC

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 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.

NIH-funded scientists developed imaging tools that are enabling a deeper understanding of how Lewy bodies form and contribute to neurodegeneration in mouse models of LBD. Additionally, they created animal and cell models with FTD-causing C9orf72 mutations to investigate how these mutations cause disease, and identified specific molecules in brain blood vessels that regulate beta-amyloid clearance.

In 2015, NIA supported a $21 million initiative to stimulate research on the immune and inflammatory mechanisms contributing to or mediating the development and progression of AD/ADRD. Scientists are studying the brain innate immune system and its crosstalk with the peripheral immune system to give greater insight into pathological processes underlying the disease.

In addition to continuing support for investigator-initiated research, in 2016 NIH released a request for applications (RFAs) to stimulate research on how vascular changes can cause disease within white-matter (areas of densely packed nerve fibers that carry information between brain regions), and plans to create a multi-center, interdisciplinary Center without Walls to investigate the molecular mechanisms of tau toxicity in FTD.

For more information, see:

- https://www.nia.nih.gov/newsroom/2016/03/decoding-molecular-ties-between-vascular-disease-and-alzheimers
- http://www.sciencedirect.com/science/article/pii/S2211124715001023
- http://www.nature.com/neuro/journal/v18/n7/full/nn.4025.html
- 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

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Addressing Health Disparities. Race, 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 formal LTSS for those with dementia. A primary goal is to develop treatment and prevention strategies that are effective among diverse populations.

For more information, see:

- http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html

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NIA Enhances Information on Alzheimer's Clinical Trials Participation. NIA's the Alzheimer's Disease Education and Referral (ADEAR) Center developed a web mini-portal in 2015 for encouraging participation in Alzheimer's research. The portal features information on participating in Alzheimer's research, a newly upgraded AD/ADRD searchable clinical trial finder with user-friendly trial descriptions, and an infographic and social media messaging. ADEAR sends out monthly e-alerts to nearly 35,000 subscribers announcing new recruiting trials and featuring registries and matching services, such as the Alzheimer's Prevention Registry and Brain Health Registry.

In 2016, NIA joined a collaborative effort with Food and Drug Administration (FDA) and the PCORI-funded Alzheimer's and Dementia Patient/Caregiver-Powered Research Network to encourage research participation. The shared goal is to amplify the patient and caregiver voice in Alzheimer's and related dementias research and to broaden recruitment, especially among minorities.

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

Recruiting Older Adults into Research Expands Recruitment Tools. Research cannot be conducted without the volunteers and their caregivers who make clinical trials possible. It is estimated that some 70,000 volunteers with Alzheimer's, mild cognitive impairment (MCI), or normal cognition are needed for clinical trials and studies; researchers will need to screen at least half a million potential volunteers to reach this goal. To address this need, the NIA, Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) collaborate on Recruiting Older Adults into Research (ROAR), a program to promote research participation through outreach and messaging at the national, state, and local levels.

In 2015, the ROAR team continued to promote a toolkit of customizable materials for aging services and public health professionals to use in community settings and social media, and expanded the potential reach by translating materials into Spanish and Chinese. In addition, the group hosted a fourth annual webinar series for these professionals on Alzheimer's and caregiving resources, current research studies, and caregiver support programs that drew record attendance (500+ participants for each of three webinars) and offered continuing education credit.

For more information, see:
- https://www.nia.nih.gov/health/publication/roar-toolkit

VA Targets Dementia Research. The U.S. Department of Veterans Affairs (VA) Office of Research and Development (ORD) has updated the wording in its specialty Alzheimer's Disease RFAs for biomedical laboratory or clinical research to include FTD, LBD, and/or VCID and dementia in addition to AD/ADRD.

VA Collaborates with NIA. VA ORD is working with NIA to increase funding opportunity collaboration, including collaborating more closely on dementia research (e.g., recruitment/retention of participants in clinical trials; data sharing; biorepository use; and use of VA's electronic health records (EHRs) in research studies).

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

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.

For more information, see:
- http://www.nih.gov/science/amp/index.htm
- http://www.nia.nih.gov/alzheimers/amp-ad-biomarkers-project

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Tracking Biomarker Trajectories Over Time. In late 2015, NIH launched a new initiative to identify biomarkers and track the progression of Alzheimer's in people with Down syndrome. The NIH Alzheimer's

Biomarker Consortium-Down Syndrome is supporting teams of researchers using brain imaging, as well as fluid and tissue biomarkers, in research that may 1 day lead to effective interventions for all people with dementia. Costing an estimated $37 million over 5 years, the goal is to develop biomarker measures that signal the onset and progression of Alzheimer's in people with Down syndrome. Two research teams are working collaboratively to identify and track Alzheimer's-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/newsroom/2015/11/nih-supports-new-studies-find-alzheimers-biomarkers-down-syndrome

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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 established two new biomarker efforts in 2015:

- Small Vessel VCID Biomarkers Consortium will develop candidate biomarkers for small vessel disease in the brain.
- NIH is soliciting longitudinal studies that would leverage the existing Parkinson's disease Biomarkers Program infrastructure to discover biomarkers for LBD.

For more information, see:
- http://www.ninds.nih.gov/news_and_events/news_articles/pressrelease_FTD_grant_10232014.htm
- https://www.rarediseasesnetwork.org/cms/create
- http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-020.html
- http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-022.html

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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 Alzheimer's research and funding- is an invaluable tool for assessing and planning Alzheimer's 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 2015, reflecting more than $4.7 billion in research funding worldwide. The number of contributors is growing, too. During the past 3 years, 35 funding organizations across ten countries have joined the IADRP effort.

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

Efforts Intensify to Establish Global Goals for Dementia Research and Care. The HHS Deputy Assistant Secretary for Planning and Evaluation Dr. Linda Elam and NIA Director Dr. Richard J. Hodes joined health ministers, leading scientists, and advocates from around the world March 16-17, 2015 in Geneva, Switzerland, to advance planning on dementia research and care on a global scale. The agenda at the *Ministerial Conference on Global Action Against Dementia*, hosted by the World Health Organization (WHO), reflected shared goals that are gaining momentum worldwide: to raise awareness of dementia's socioeconomic impact, and discuss ways to advance scientific research, foster the availability of new treatments and improved care, and finding ways to reduce the risk of neurodegenerative disorders.

For more information, see:
- http://www.who.int/mental_health/neurology/dementia/en/

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:
- https://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/introduction

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Resources for the Dementia Services Community. Since 2012, the NIA and ACL have co-hosted an annual webinar series on AD/ADRD to educate professionals and improve coordination of federal resources between the research and aging services communities. In 2014, CDC joined as a sponsor and Continuing Education credits were made available for participants. In 2014, a key focus of the series was how to forge successful community collaborations serving people with AD/ADRD, as well as updates on resources and research. Free continuing education is available through 2016 to professionals who need it when they view recorded webinars.

For more information, see:
- http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/index.aspx#resources

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Exploring the Evidence for Prevention. In 2015, the NIH initiated a project involving the Agency for Healthcare Research and Quality (AHRQ), and the National Academies of Sciences, Engineering, and Medicine's (NAS's) Health and Medicine Division (HMD), to conduct a systematic review of the evidence on prevention of clinical Alzheimer's-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 (HMD). 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. This project will provide valuable information regarding scientific support for existing interventions. A report is expected in 2017.

DoD Work on Alzheimer's Disease. Since 2011, the U.S. Department of Defense (DoD) Peer Reviewed Alzheimer's Research Program (PRARP) has been devoted to understanding the association between Traumatic Brain Injury (TBI) and AD/ADRD. Equally important, the program also focuses on reducing the burden on caregivers and individuals living with the common symptoms of TBI and AD/ADRD, especially in the military community. Funding for FY 2013 funding of $12 million was executed by September 30, 2014. For FY 2013, 37 pre-proposals were received for the Convergence Science Research Awards and Military Risk Factor Awards. A total of eight awards were made, bringing the number of funded projects to 29. Using the Common Alzheimer's Disease Research Ontology criteria, FY 2013 funding was distributed among the following categories:

- **Category A**. Molecular Pathogenesis and Pathophysiology of Alzheimer's Disease (4 Projects).
- **Category B**. Diagnosis, Assessment and Disease Monitoring (3 Projects).
- **Category D**. Epidemiology (1 Projects).

In the period from October 1, 2014 to March 12, 2015, three Program Announcements were released to fund research in basic and translational sciences. FY 2015 funding was $12 million. The announcements asked scientists to address one of five overarching research challenges (Paucity of Research Resources; Paucity of Clinical Studies; Need for Diagnostic Technologies, Tests, Interventions, or Devices; Quality of Life; or Caregiver Burden). Awards were made by September 30, 2015.

During the April 31, 2014-March 1, 2015 annual reporting period, one patent was applied for and 14 publications were produced. The PRARP continues partnerships across the DoD, VA, and other governmental agencies by having their staff provide guidance to the PRARP as participants at the program's regular meetings.

Goal 2: Enhance Care Quality and Efficiency

Providing all people with AD/ADRD with the highest-quality care in the most efficient manner requires a multi-tiered approach. High-quality care 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 depends on: (1) smooth transitions between care settings; (2) coordination among health care and LTSS providers; and (3) dementia-capable health care and LTSS.

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 2016 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:
- http://bhw.hrsa.gov/grants/geriatricsalliedhealth/adrd.html

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Provider Education About Federal Programs to Address Alzheimer's Disease. Completed in July 2015, these monthly conference calls to HRSA geriatrics grantees included agency specific presentations on AD/ADRD. Each conference call had between 70 and 90 participants. Participants were informed of

federal AD/ADRD activities by dementia expert staff from the Office of the Assistant Secretary for Planning and Evaluation (ASPE), ACL, AHRQ, CDC, Indian Health Service (IHS), HRSA, and NIA.

Geriatric-Competent Care: Caring for Individuals with Alzheimer's Disease Webinar Series. CMS's Medicare-Medicaid Coordination Office (MMCO), in collaboration with the American Geriatrics Society, Community Catalyst, and the Lewin Group, hosted a series of webinars in 2015 and 2016 to help health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults with AD/ADRD and in working with their caregivers. The webinars are also intended for frontline community partners and delivery staff such as care managers, member service representatives, and home care providers. Continuing education credits offered at no cost to participants. The webinar series is one area of technical assistance supported through the MMCO's Resources for Integrated Care contract focused on increasing the field of providers that understand and are skilled in addressing the complex needs of individuals enrolled in both Medicare and Medicaid.

For more information, see:
- https://resourcesforintegratedcare.com

Healthy Brain Initiative. The CDC Healthy Brain Initiative (HBI) began in 2005 through a Congressional appropriation that established the Alzheimer's-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 and the Balm in Gilead. 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

Implemented Road Map Actions in States. CDC supported a successful collaboration with the Alzheimer's Association in September 2010-September 2015. In FY 2014, CDC provided supplemental funds to support caregiver surveillance through the Behavioral Risk Factor Surveillance System (BRFSS) in states. 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.

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.

Minnesota Healthy Brain Initiative. In 2015, the Alzheimer's Association Minnesota/North Dakota Chapter and the Minnesota Department of Health (MDH) added a focus on efforts that may help delay the onset or progression of dementia for those over age 60 to Minnesota's Statewide Health Improvement Program. The Alzheimer's Association received a MDH contract for Dementia Education and Outreach to Diverse Populations. This MDH-chapter partnership to educate underserved communities is another example of the HBI at work. The BRFSS Cognitive data will be used to educate health care professionals and the public health community across Minnesota.

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 intellectual and developmental disabilities (IDD). The training is part of Oregon's efforts to increase dementia-capability of its ADRC system and statewide LTSS.

Educate Health Care Providers. In September 2013, HRSA, in collaboration with ASPE, supported the development of a Medscape continuing education course entitled "Case Challenges in Early Alzheimer's Disease," aimed at educating primary care physicians, nurse practitioners, and social workers on how to utilize evidence-based strategies to diagnose, monitor, and treat patients with AD/ADRD and improve early detection in primary care and outpatient settings. After 2 years on the Medscape website, over 65,000 health professionals have participated in this training. HRSA, in collaboration with the HHS Office on Women's Health (OWH), is supporting the development of a second Medscape continuing education course on assessing, managing, and treating AD/ADRD in the context of multiple chronic conditions. This educational offering will be available in September 2016.

In 2014 (latest data available), over 51,000 health care professionals received training on AD/ADRD through 636 interprofessional continuing education offerings on geriatrics by HRSA-funded Geriatric Education Centers (GECs). Additionally, in Academic Year 2014-2015, HRSA's Comprehensive Geriatric Education Program (CGEP) awarded traineeships to 73 students, the majority of whom (69%) were studying to become nurse practitioners in Adult Gerontology. All 54 fellows participating in the Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Providers (GTPD) program received dementia training.

IHS Workforce Partnerships. IHS initiated a series of partnerships to increase workforce skills and competency in caring for individuals with dementia and their families. IHS met with the newly awarded HRSA Geriatrics Workforce Enhancement Program (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 in small, rural IHS and Tribal facilitates, and this work will continue in the coming year. 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 Alzheimer's and Related Dementia as part of the IHS Clinical Rounds series.

Educate All Providers to Deliver Quality Health Care to Older Adults, Including Dementia Education and Training. In 2015, HRSA announced a new GWEP that combined elements of the previous four programs (GECs; GTPD programs; Geriatric Academic Career Awards; and the CGEPs) into one program to provide greater flexibility to awardees by allowing them to develop programs that are responsive to specific interprofessional geriatrics education and training needs of their communities. The

purpose of this cooperative agreement program is to develop a health care workforce that maximizes individual and family engagement and improves health outcomes for older adults by integrating geriatrics with primary care. Special emphasis is on providing the primary care workforce with the knowledge and skills to care for older adults, and on collaborating with community partners to address gaps in health care for older adults through individual, system, community, and population-level changes. Focus areas include: (1) transforming clinical training environments to integrated geriatrics and primary care delivery systems to help ensure trainees are well prepared to practice in and lead these kinds of systems; (2) developing providers who can assess and address the needs of older adults and their families/caregivers at the individual, community, and population levels; (3) creating and delivering community-based programs that will provide individuals, families and caregivers with the knowledge and skills to improve health outcomes and the quality of care for the older adult(s); and (4) applicants may also choose to address providing AD/ADRD education to families, caregivers, direct care workers, and health professions students, faculty, and providers.

HRSA awarded 44 GWEP awards in FY 2015, totaling approximately $35.7 million. Awardees identified significant needs for dementia training. As a result, a total of $5.24 million was awarded to all grantees to meet this need, surpassing the $4 million which was set aside specifically for dementia training.

VA Geri-Scholars Toolkit. VA's Geri-Scholars staff training program has created a Geri-Scholars Toolkit covering 12 clinical topics in geriatrics, including dementia. Each topic contains two sections: clinical assessment, management, and treatment; and educational materials for patients and their caregivers. More than 2,800 toolkits have been disseminated to VA rural clinics, community living centers, 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.

Health Equity in Medicare. The first Centers for Medicare & Medicaid Services (CMS) Equity Plan for Improving Quality in Medicare focuses on six priority areas and aims to reduce health disparities in 4 years. The Plan is focused on Medicare populations that experience disproportionately high burdens of disease, lower quality of care, and barriers accessing care. These include racial and ethnic minorities, sexual and gender minorities, people with disabilities, and those living in rural areas.

Civil Monetary Penalty Funds. CMS permits qualified entities to use Civil Monetary Penalty (CMP) funds to improve the quality and care and life of residents of nursing facilities. Funding has been provided for included dementia care, antipsychotic utilization, person-centered care improvements, and reducing avoidable hospitalizations.

Medicaid Home Health Final Rule. CMS issued a Final Rule on Home Health that amends the Medicaid definition of medical supplies, equipment, and appliances and clarifies that the items may be used anywhere *normal life activities* take place (no homebound requirement). The rule adds requirements that clinicians timely document the occurrence of a face-to-face beneficiary encounter (including through the use of telehealth). CMS is working to determine what the new definition might encompass. State officials must determine whether the new definition means that items previously furnished as HCBS should be available to a larger group through the Medicaid State Plan as part of the mandatory home health service.

Strengthen State Aging, Public Health, and Intellectual and Developmental Disability Workforces. HHS will coordinate with states to develop workforces in aging, public health, and IDD that are AD/ADRD-capable and 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 professionals and caregivers from the Area Agencies on Aging (AAAs) participated in the trainings. In addition, HRSA GWEP awardees are

collaborating with 26 AAAs and 13 Quality Improvement Organizations (QIOs) to strengthen state aging, public health, and IDD workforces.

Develop and Disseminate a Unified Primary Care Alzheimer's Disease Curriculum. HRSA is working with federal partners at ACL, CDC, CMS, and VA on a contract to develop a Uniform Curriculum to:

- Educate providers through HRSA's GECs about how to work with people with AD/ADRD and their families; link people to support services in their community; identify signs of caregiver burden and depression; and detect cognitive impairment and assess and diagnose AD/ADRD.
- Educate physicians and other health care providers about accessing LTSS.

The purpose of the curriculum is 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. Specifically, 16 core modules along with nine caregiving modules will be developed and pilot-tested. The development of the caregiver modules was supported by OWH. These modules build 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/ADRD.

The developed materials will be appropriate for guided teaching by faculty in academia and continuing education programs and for interprofessional clinical audiences. The developed materials are intended to be used by GWEP awardees as well as other geriatric educators. They will be designed to serve as a tool to increase the understanding among a broad spectrum of clinicians of the detection and treatment of AD/ADRD.

An Advisory Panel consisting of dementia experts and several federal partners has identified module topics that will be developed. The final format of the materials, which will be web-based, is currently under discussion.

For more information, see:
- http://www.actonalz.org/dementia-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 2016 include "Parkinson's Disease: The Importance of an Interdisciplinary Approach for Identification, Treatment and Patient Support" and "Cognitive Impairment Screening in Primary Care: Clinical and Ethical Indications."

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 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; and other resources. In 2015, the NIA developed a mini-portal of resources for professionals, including the clinician quick guides *Assessing Cognitive Impairment in Older Adults* and *Managing Older Patients with Cognitive Impairment*.

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

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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.

Gerontological Society of America Report. A new 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 (GSA) 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 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 or how to access them. To address this barrier, HRSA is partnering with federal agencies, public and private entities, and providers of health and LTSS to educate these providers, direct services workers, and patients, families, and caregivers about available services and supports for people with AD/ADRD, as well as their caregivers. These activities will continue as part of the training in Action 2.A.1.

Medicaid Health Homes. CMS issued a State Medicaid Directors Letter and general Fact Sheet guidance on the optional Home Health benefit that states can use to target services to people with AD/ADRD.

State-of-the-Science Review of Determinants of Behavioral Symptoms. Dr. Ann Kolanowski has assembled a team to examine the social, environmental, personal and genetic determinants of behavioral symptoms in dementia and produce a state-of-the-science review of this literature for the American Academy of Nursing. An understanding of the evidence, and the socio-political climate in which it is being developed, is foundational to the development and implementation of safe and effective responses to behavioral and psychological symptoms of dementia (BPSD). In this paper, senior interdisciplinary scientists will present a comprehensive synthesis of the current evidence for the determinants of BPSD using a guiding framework developed by team members. Kolanowski's team will discuss the policy implications of this work, consistent with the recommendations of the 2015 White House Conference on Aging and the 2015 National Plan Update.

Massive Online Open Course (MOOC) on Coursera -- Living with Dementia: Impact on Individuals, Families. 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. Developed by Dr. Laura Gitlin of Johns Hopkins University, the course is for anyone (researchers, health professionals, students, families) who want to understand dementia and its impact on everyday life and evidence-based approaches to support families. Offered twice so far, over 50,000 individuals from over 169 countries participated. Videos were viewed over 300,000 times. The course will move to an open access format such that it will be continuously offered. It will be available on Coursera in the fall of 2016.

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. This represents the single largest state investment in these services in history and will make 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.

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 has now begun for a National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers. A steering committee has been appointed, and a draft goal for the summit has been proposed, as follows: "To accelerate the development, evaluation, translation, implementation, and scaling up of strategies to improve quality of care and outcomes across settings, including quality of life and the lived experience of persons with dementia, family members, and caregivers." Cross-cutting themes for the summit include: (1) diversity in care settings, culture, race and ethnicity, socioeconomic status, and health literacy; (2) health disparities across care settings; and (3) etiologies and stages of disease.

The steering committee is focusing first on prioritizing key research questions to be addressed at the Summit and effective ways to involve persons with dementia, family caregivers, care providers, researchers, advocates, and others who have a stake in the development of better care and outcomes for persons with dementia and the role research can play in achieving that goal. No date or location has been set for the Summit, but it is likely to be convened in 2017 in Washington, DC.

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 Action 2.A.1.

For more information, see:
- https://aspe.hhs.gov/national-plan-address-alzheimers-disease-2014-update#action2.A.1

CMS Quality Strategy. CMS updated its Quality Strategy, which guides all agency components toward the common goal of health system transformation. There is a new emphasis on person-centered care and partnership with providers across all health care settings.

For more information, see:
- https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf

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National Quality Forum -- Home and Community-Based Services. CMS continues its work with the National Quality Forum (NQF) and its HHS partners to finalize a conceptual framework for HCBS quality measurement, and a standard definition for HCBS to cross public and private payers. NQF performed an environmental scan of existing HCBS measures and concepts, and is identifying gaps and promising HCBS quality measures.

For more information, see:
- http://www.qualityforum.org/Measuring_HCBS_Quality.aspx

Nursing Home Compare Quality Measures. CMS added the following six new measures to Nursing Home Compare:

1. Percentage of short-stay residents who were successfully discharged to the community (claims-based).
2. Percentage of short-stay residents who have had an outpatient emergency department visit (claims-based).
3. Percentage of short-stay residents who were re-hospitalized after a nursing home admission.
4. Percentage of short-stay residents who made improvements in function (Minimum Data Set [MDS]-based).
5. Percentage of long-stay residents whose ability to move independently worsened (MDS-based).
6. Percentage of long-stay residents who received an anti-anxiety or hypnotic medication (MDS-based).

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

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. The DCN is part of the Hartford Change AGEnts Initiative, which is headquartered at GSA and is 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/

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

Alzheimer's Disease Supportive Services Program. ACL continues to support its 18 current grantees and their partners who are implementing dementia-capable LTSS systems, and any former grantees or partners who wish to participate in learning activities. 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. A limited number of ADSSP grantees are in the final stages of implementing and evaluating the translation of evidence-based interventions in support of individuals with AD/ADRD and their unpaid caregivers. In 2015, ADSSP expanded to include three new states -- Florida, Massachusetts and West Virginia. The new programs include services for IDD and dementia populations in Florida, dementia-friendly communities in West Virginia and bringing dementia-capability to care transitions programs in Massachusetts. ACL anticipates continuation of the ADSSP with new grants in 2016. This program's focus on dementia-capability and dementia-friendly communities is in direct response to the recommendations of the Advisory Council.

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 collaboratives that result in resources that are beneficial to program activities and also made available to the general public. In 2016, ACL launched a new website for the NADRC. 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/

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 Alzheimer's Disease Initiative-Specialized Supportive Services (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 of 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 can improve current guardianship arrangements for older adults and people with disabilities who need support. SDM is a less restrictive alternative to guardianship that uses trusted friends, family members and advocates to help 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

Examining Models of Dementia Care. ASPE has begun 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 so-called "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. The project is expected to be completed in September 2016.

Analysis of New Payment and Service Options for Medicare-Medicaid Dual Eligible Beneficiaries. ASPE has begun 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 a rich mix of coordinated acute care and HCBS in the community. 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. In 2015, the President signed into law the PACE Innovation Act. The PACE Innovation Act gives the Secretary the authority to test -- via pilots -- significant 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 research briefs produced by this project will 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.

VA Models of Non-institutional Long-Term Care. VA shared a summary report of completed non-institutional long-term care pilot programs with dementia components. The report was sent to federal partners, who then shared it with the Advisory Council.

In a follow-up to the VA summary report of these models of care, an ACL webinar was held in May 2016, in which VA staff shared with community partners more detailed information about one new model, the Mobile Adult Day Health Care Program. This model involves community partnerships to provide meeting space for a mobile team providing adult day health care to individuals with dementia, thereby increasing access to this service in an expanded range of convenient locations. More than 300 participants attended the webinar.

Transforming Clinical Practice Initiative. CMS awarded nearly $685 million dollars to 40 national and regional collaborative health care transformation networks and supporting organizations to provide technical assistance to equip clinicians with tools and support needed to improve quality of care and increase beneficiaries' access to information. The Transforming Clinical Practice Initiative (TCPI) supports medical group practices, regional health care systems, regional extension centers, and national medical professional association networks. TCPI efforts help clinicians expand their quality improvement capacity, engage in greater peer-to-peer learning, and utilize health data to determine gaps and target intervention needs. The initiative has two major components: (1) 29 "Practice Transformation Networks," that provide technical assistance and peer supports; and (2) ten "Support and Alignment Networks," to provide a system for workforce development.

For more information, see:

- https://innovation.cms.gov/initiatives/Transforming-Clinical-Practices/

Comprehensive Primary Care Plus Model. CMS recently announced Comprehensive Primary Care Plus (CPC+), a 5-year multi-payer model that begins in January 2017 and can accommodate up to 5,000 practices, which would encompass more than 20,000 doctors and clinicians. Primary care practices can participate in one of two tracks. The two tracks have different care delivery requirements and payment methodologies, but both tracks will encourage physicians to improve the quality and efficiency of care, which will result in healthier beneficiaries and reduce unnecessary health care utilization. In the CPC+

model, beneficiaries with complex needs (e.g., cognitive impairment, chronic conditions, frailty) will be engaged in goal-setting and shared decision-making, receive preventive care and care coordination, and will have 24/7 telephone and electronic access to care.

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

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Health Care Innovation Awards. CMS's Center for Medicare and Medicaid Innovation is awarding up to $1 billion, in more than 100 cooperative agreements, to organizations whose projects offer novel ways to improve beneficiary care. The first evaluation reports were released in April 2015; CMS has now released the second round. Some of the HCIA awards address persons with AD/ADRD and caregiving.

For more information, see:
- https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/

Research Continues to Seek New and Effective Ways to Improve Care. In 2015, NIH-funded researchers reported on the rate of referral to hospice during 2000 and 2007 among over 600,000 older people with advanced dementia. During the last year of life, 35% of this group received inpatient psychiatry treatment just prior to death. Of the 1,027 people who were discharged from a psychiatric hospital and then died within 90 days, fewer than one in ten were referred to hospice. The findings point to the need for improved end-of-life care for people with dementia.

The use of antipsychotic and other psychotropic medications to address behavior and mood among older residents living in long-term care settings has become a concern, especially among residents with dementia. NIH funded a study to address the use of antipsychotic and psychotropic medications in assisted living residences to determine how prescribing may vary according to the characteristics of the facility, and to examine the feasibility of using non-drug alternatives to care.

For more information, see:
- http://www.ncbi.nlm.nih.gov/pubmed/?term=Hospice+Referral+after+Inpatient+Psychiatric+Treatment+of+Individuals+with+Advanced+Dementia+from+a+Nursing+Home
- https://projectreporter.nih.gov/project_info_description.cfm?aid=8942171&icde=28789005&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC

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 Center for Medicare and Medicaid Innovation's (Innovation Center) Health Care Innovation Awards.
- COPE being integrated into a program for Managed Care to be delivered by Volunteers of America.

Strategy 2.F: Ensure that People with Alzheimer's Disease 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

Nursing Home Strategic Plan. An in-person and virtual stakeholder meeting was held in January 2016 to help shape the goals of the CMS Nursing Home Strategic Plan. Stakeholders from academic institutions, advocacy groups (including AD/ADRD), trade associations, caregivers, government, professional societies, providers, and others participated. There will be future opportunities for stakeholders to participate as the Strategy evolves.

Improved Discharge Planning. CMS has proposed to revise the discharge planning requirements that hospitals must meet in order to participate in Medicare and Medicaid. The changes would modernize the discharge planning requirements by bringing them into closer alignment with current practice; helping to improve quality of care and outcomes; and reducing avoidable complications, adverse events, and readmissions. They would also implement discharge planning requirements of the Improving Medicare Post-Acute Care Transformation Act (IMPACT Act) of 2014, to improve consumer transparency and the discharge planning process experience. Through the IMPACT Act, certain facilities are required to develop a discharge plan based on the goals, preferences, and needs of each beneficiary. Under the proposed rule, hospitals and critical access hospitals would be required to develop a discharge plan within 24 hours of admission and complete a discharge plan before the beneficiary's return to home or transfer.

For more information, see:
- https://www.federalregister.gov/articles/2015/11/03/2015-27840/medicare-and-medicaid-programs-revisions-to-requirements-for-discharge-planning-for-hospitals

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Initiative to Reduce Avoidable Hospitalizations Among Nursing Facility Residents. This initiative has been underway since 2013 and has already shown reductions in avoidable hospitalizations. In 2016, CMS selected sites for a new phase of the Initiative to Reduce Avoidable Hospitalizations among Nursing Facility Residents to provide practitioners with additional payments for multi-disciplinary care planning. Medicare currently pays physicians less for a comprehensive assessment at a nursing facility than for the same assessment at a hospital; this model equalizes payments between sites. Nursing facilities will offer additional treatment for common medical conditions that often lead to avoidable hospitalizations; there will be more practitioner engagement when a resident needs higher-intensity interventions due to a change in condition. Participating nursing facilities will also enhance staff training and purchase new equipment to improve certain capacities.

For more information, see:
- https://innovation.cms.gov/initiatives/rahnfr-phase-two/index.html

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Nursing Home Compare. With funding from the IMPACT Act in 2016, CMS will implement a quarterly electronic staffing reporting system for nursing homes that is auditable back to payroll to verify facility-reported staffing information. This new system will increase accuracy and timeliness of data, and allow for the calculation of quality measures for staff turnover, retention, types of staffing, and levels of different types of staffing.

Rhode Island's Financial Alignment Initiative Demonstration for Dual-Eligible Beneficiaries. CMS is partnering with the State of Rhode Island to test a new model for providing Medicare-Medicaid enrollees, including low-income seniors and people with disabilities, with a more coordinated, person-centered care experience. Under this model, CMS and Rhode Island have contracted with a Medicare-Medicaid plan to coordinate the delivery of and be accountable for covered Medicare and Medicaid services for participating Medicare-Medicaid enrollees. The model requires that the plan develop policies and procedures to train care coordination staff in dementia care management, including but not limited to understanding dementia, symptoms and progression, understanding and managing behaviors and communication problems caused by dementia, caregiver stress and its management, and community resources for enrollees and caregivers

For more information, see:
- https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/RhodeIsland.html

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Hospice Referral after Inpatient Psychiatric Treatment of Individuals with Advanced Dementia from a Nursing Home. A publication by Drs. Epstein-Lubow, Tuya Fulton, Marino and Teno entitled *Hospice Referral after Inpatient Psychiatric Treatment of Individuals with Advanced Dementia from a Nursing Home* was published in June 2015. The report addresses the discharge disposition following inpatient psychiatric treatment for advanced dementia. The total population included 685,305 Medicare fee-for-service (FFS) decedents with advanced cognitive and functional impairment, with a mean age of 85.9 years who had resided in a nursing home. In the last 90 days of life, 1,027 (0.15%) persons received inpatient psychiatry treatment just prior to the place of care where the individual died. Discharge dispositions included 132 (12.9%) persons to a medical hospital, 728 (70.9%) to nursing home without hospice services, 73 (7.1%) to hospice services in a nursing home, 32 (3.1%) to home without hospice services, and 16 (1.6%) to hospice services at home. Overall, the rate of referral to hospice services for advanced dementia was relatively low.

For more information, see:
- http://www.ncbi.nlm.nih.gov/pubmed/24803585

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

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.

Assess Health Information Technology to Support the Needs of Individuals with Alzheimer's Disease and Related Dementias. ASPE continued work with HHS's Office of the National Coordinator for Health Information Technology (ONC) and partners in exploring the feasibility and timing of activities to assess, identify, and fill gaps in available health information technology (HIT) and use of standards for the coordination of care plans that meet health concerns, goals, interventions, and other information identified by individuals, caregivers and family members in caring for individuals receiving LTSS, including those with AD/ADRD.

Accountable Health Communities Model. CMS announced a new model to address a critical gap between clinical care and community services in the current delivery system. The model aims to identify Medicare and Medicaid beneficiary health-related social needs and provide referrals to community-based services. The model will build alignment between clinical and community-based services at the local level, and improve beneficiary and caregiver awareness of community services.

For more information, see:
- https://innovation.cms.gov/initiatives/AHCM

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 area.

Integrated Health and Long-Term Services and Supports. The State of Minnesota's Live Well at Home grant program targets grant funding to health care organizations to build models of integrated health and LTSS for individuals with dementia and their caregivers in coordination with aging service providers.

Medicaid and Children's Health Insurance Program Managed Care Final Rule. CMS published the Medicaid and Children's Health Insurance Program (CHIP) Managed Care Final Rule, which aligns key rules with those of other health insurance coverage programs, modernizes how states furnish Medicaid managed care to beneficiaries, and strengthens the consumer experience and key consumer protections. Summary fact sheets are available. This final rule is the first major update to Medicaid and CHIP managed care regulations in more than a decade.

For more information, see:
- https://federalregister.gov/a/2016-09581
- https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/managed-care/managed-care-final-rule.html

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New York State Centers of Excellence for Alzheimer's Disease. NYSDOH invested $4,700,000 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 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 the Veterans Health Administration 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.

Meaningful Access in Medicaid. CMS released a final rule that improves measurement of meaningful access to covered services, and provides greater safeguards for beneficiaries who may otherwise experience difficulty in receiving needed health care services. The rule supports better informed, data-driven decisions for effective service delivery systems, service rate structures, and provider payment methodologies.

For more information, see:

- https://www.medicaid.gov/medicaid-chip-program-information/by-topics/access-to-care/access.html

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Telehealth. In 2015, Medicare began paying separately for non-face-to-face chronic care management services, and included new procedure codes for telehealth including psychotherapy, AWV, prolonged office services, etc. Medicare historically covers telehealth if the beneficiary is seen under certain circumstances. Medicaid permits state flexibility in setting requirements or standards for telehealth including those relating to the originating site, types of telecommunications, and geographic areas where telemedicine can be utilized.

Comparing Outcomes for Dually Eligible Beneficiaries in Integrated Care Models. ASPE has begun a project 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, Medicare Advantage Fully Integrated Dual Eligible Special Needs Plans, 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 suffer from 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, Related Disorders, 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.

New York State Alzheimer's Disease Caregiver Support Initiative for Underserved 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 underserved communities. Fifteen contractors, funded at $100,000 each, provide culturally-competent support initiatives and stress reduction strategies for caregivers of diverse underserved 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

People with AD/ADRD and their families need supports that go beyond the care provided in settings such as doctors' offices, hospitals, and nursing homes. Families and other unpaid caregivers play a central role. Supporting people with AD/ADRD and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and ensuring that safety and dignity are maintained. 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 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 U.S. 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 third year of a 5-year funding period which will end July 31, 2018. In the last year, the grantee handled over 319,000 calls, a 7.4% increase over the prior year.

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 GECs in strategies to improve recognition and diagnosis of dementia.

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 sponsor LTSS Technical Assistance website and shared Tribal models of LTSS in the monthly webinar series.

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.

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/

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 next 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 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 informal caregiving replaces formal caregiving, informal caregivers may provide a net benefit to the country, reducing 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 in a facility that is more costly to the government than earlier support services may have been.

This research aims to provide a framework for policy makers to begin to estimate costs and benefits of policies and programs aimed to help caregivers, including, for example, respite care, paid family leave, workplace flexibility policies and social security credits for caregivers. 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. 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:

1. Expand and enhance respite services in the states.
2. Improve coordination and dissemination of respite services.
3. Streamline access to programs.
4. Fill gaps in service where necessary.
5. 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 finds 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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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.

Improvements in Hospice Care. Hospices serving Medicare beneficiaries now provide for two routine home care rates to provide separate, budget-neutral payments for the first 60 days of hospice care, and care beyond 60 days. In addition to the two routine rates, CMS provides for a service intensity "add-on" payment that will promote and compensate for the provision of skilled visits at the very end of a person's life.

For more information, see:

- https://www.federalregister.gov/articles/2015/08/06/2015-19033/medicare-program-fy-2016-hospice-wage-index-and-payment-rate-update-and-hospice-quality-reporting

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Understanding Caregiver Stress. NIH-funded research is deepening our understanding of the mental and physical health consequences of caring for people with AD/ADRD. For example, in 2015, an NIH-funded study explored whether use of ADS, an intervention which lowers caregivers' daily exposure to stressors, might lead to improved regulation of cortisol, a stress hormone. Using saliva tests to measure cortisol levels over 8 days among 158 caregivers of people with dementia, the researchers found that cortisol levels improved on ADS days compared to days when the participants provided care. This suggests use of ADS may enhance the long-term health of caregivers, and points to the importance of respite care.

NIH also launched a number of research efforts aimed at defining the unique needs of caregivers, to include:

- The Improved Measures of Caregiving Intensity to Predict Health Outcomes study will develop and validate a tool for measuring the emotional and physical intensity of caregiving for people caring for relatives with Alzheimer's, Parkinson's, or other chronic conditions. This study will not only shed light on the health effects of caregiving intensity for families living with dementia, but also inform assessments of caregivers for other chronic diseases.
- The Long-Distance Caregiving: Unique Challenges and Service Needs study will begin to close a major knowledge gap in caregiving research by providing an in-depth examination of long-distance caregiving. Researchers will follow 300 caregivers, including those from minority populations, over 2 years to explore the unique stressors they experience; the factors that

promote or hinder distance caregiving and influence caregiver well-being; and the communication and coordination challenges between formal care providers and long-distance caregivers. The findings will inform the development of tailored interventions and policies supporting long-distance caregivers and the recipients of their care.

For more information, see:

- http://gerontologist.oxfordjournals.org/content/56/2/303.long
- https://projectreporter.nih.gov/project_info_description.cfm?aid=8913402&icde=28779154&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9035643&icde=28787670&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC

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 U.S. 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

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WeCareAdvisor™. WeCareAdvisor™ is a web-based program based on an evidence-informed algorithmic approach, to help families prevent, assess, and manage neuropsychiatric symptoms (NPS), such as agitation, aggression, depression, irritability, and apathy in persons with dementia. Developed by Drs. Kales, Gitlin and Lyketsos, WeCareAdvisor™ is currently being tested in the home environment and has potential to be used across multiple environments and by both paid and unpaid caregivers. WeCareAdvisor™ has three components: the Caregiver Survival Guide which provides comprehensive education about dementia in easy-to-read language; daily/weekly caregiving tips sent to a user's email; and a published, evidence-informed algorithm (Describe, Investigate, Create and Evaluate -- or DICE) that moves users through a series of questions about behavioral occurrences from which a prescription for managing such behaviors is generated. The prescription provides tips that are tailored to the information provided by a caregiver about the behavior and which address four areas: (1) actions the caregiver can take, such as simplifying communication; (2) considerations related to the person with dementia, such as unmet needs (dehydration, fear, lack of sleep); (3) modifications to the physical environment or where the person with dementia lives or the context in which the behavior occurs; and (4) health and safety issues that may be of immediate concern (medications, underlying infection) and need attention from a health care professional. WeCareAdvisor™ is currently in beta testing. [More information is available by contacting: lgitlin@jhu.edu; kales@med.umich.edu; or kostas@jhmi.edu.]

Translation and Evaluation of the Adult Day Service Plus Program. Adult Day Service Plus (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 number of days using ADS, decreased nursing home placement, improved caregiver well-being including decreasing depressive symptoms, upset with behaviors, and also 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 (Principal Investigators: Dr. Laura Gitlin and Dr. Joseph Gaugler).

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.

NAS Study on Family Caregiving for Older Adults. A study is being conducted by NAS's HMD. The study will analyze the prevalence of family caregiving and the demographic, societal, and technological trends that influence it. It will also examine 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 will be assessed and differences associated with race and ethnicity, culture, rural residence, and geography will be examined. The study will also review 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 might include, 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. Public hearings occurred in January 2015 and April 2015, and the study's report is expected in 2016.

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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Geriatric Psychiatrist as Family Caregiver. The 2015 American Association for Geriatric Psychiatry Annual Meeting included a session entitled, "The Geriatric Psychiatrist as Family Caregiver." At this session, geriatric psychiatrists described the challenges of dealing with late-life issues in family members. Topics included balancing autonomy and independence with safety and care needs can present dilemmas, issues around when someone should stop driving, where they should live, how to provide or arrange for additional care. Drs. Benjamin Liptzin, Christopher C. Colenda and Gary Epstein-Lubow presented.

For more information, see:
- http://www.ajgponline.org/article/S1064-7481(14)00397-2/abstract

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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 the processes that families and older adults go through to 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. The findings will be available on the ASPE website in fall 2016.

Review of Long-Term Care Financing and Service Delivery Models. ASPE is currently engaged in a project to develop a series of long-term care financing proposals, the purpose of which is to analyze ASPE's actuarial and micro-simulation modeling capabilities. A number of different options are being developed and then specified for modeling through other ASPE contracts. The work of this project builds upon previous ASPE efforts in this field, specifically work on the Community Living Assistance Services and Supports Act of the Affordable Care Act. The various proposals include both mandatory and voluntary options, and both front-end and catastrophic types of coverage. The options will be made public at an ASPE-sponsored meeting in August.

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

Long-Term Care Ombudsman Regulations. Since 2012, ACL's Office of Long-Term Care Ombudsman Programs has provided, 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: *Involuntary Transfer/Discharge from Nursing Homes: Prevention, Advocacy, and Appeals*. More than 700 people participated in and learned about inappropriate eviction and how to support individuals with dementia. Specialized training for LTCO also occurred during 2015 on advanced illness and health care decision making, bullying, person-centered complaint processes, and the new LTCO regulations related to the needs of people with dementia. In November 2015, ACL staff finalized *Emergency Preparedness and Response -- Model Policies and Procedures for State Long-Term Care Ombudsman Programs* and introduced these model policies and procedures to states.

In 2016, the Office of Long-Term Care Ombudsman Program plans training on emergency preparedness and response, with an emphasis on building coalitions to address emergency preparedness and lessons learned from pilot states (Colorado, Alaska, and Hawaii). In addition, the program will continue to work with states regarding the implementation of the LTCO rule, which becomes effective on July 1, 2016. ACL/AoA's Regional Support Centers are incorporating LTCO rule implementation by states into their 2016 annual reviews. Further training will occur on person-centered complaint processes, including for individuals living with dementia. 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.

Additionally, In 2015, NIA hosted a workshop titled, "Multiple Approaches to Understanding and Preventing Elder Abuse."

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 of the notable achievements in 2015 was 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, 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. In September 2014, the National Partnership, a public-private coalition, established a new 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. The partnership continues to report progress quarterly, both nationally and regionally. The Partnership's larger mission is to enhance the use of non-pharmacologic approaches and person-centered dementia care practices. CMS is monitoring the reduction of antipsychotics, as well as the possible consequences, reviewing residents whose antipsychotics are withdrawn to make sure they do not suffer an unnecessary decline, monitoring antipsychotic measures for the calculations that CMS makes for each nursing home's rating on Nursing Home Compare; the agency's public reporting website.

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_20160505.pdf
- https://www.medicare.gov/NursingHomeCompare/search.html

HIPAA Privacy Rule and Alzheimer's and Related Dementias: A Resource List. With input from the non-federal members of the Advisory Council, as well as other experts, ASPE worked with colleagues in the HHS Office of Civil Rights (OCR) to develop a resource list for providers regarding consent, capacity, and decision making when treating individuals with dementia. Although the resource list does not specifically address dementia, due to constraints on OCR's ability to create guidance on specific diseases, it does provide links to material that would be relevant to providers when helping individuals and their families. There will be further refinement of this document, and it will be posted in its final form on the NAPA website.

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

Picture of Housing and Health: Medicare and Medicaid Use Among Older Adults in HUD-Assisted Housing. ASPE and the U.S. Department of Housing and Urban Development (HUD) will be releasing 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*, analyzes 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 SNF 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 vulnerable 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-medicare-and-medicaid-use-among-older-adults-hud-assisted-housing

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Support and Services at Home Program. ASPE just posted a second report on 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. Relative to the growth of Medicare expenditures in the comparison group, growth in annual Medicare expenditures was lower by an estimated $1,536 per beneficiary among beneficiaries enrolled in SASH panels established before April 2012 (i.e., well-established panels). However, a little more than half of the participants in the sample are not yet experiencing a lower rate of growth in Medicare expenditures. Impact estimates in this report are based on the first 3 years of the implementation of the SASH program, from July 2011 through June 2014.

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

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Medicaid Innovation Accelerator Program. CMS is addressing Medicaid innovation in five areas: substance use, community integration, LTSS, physical/mental health integration, and complex care. A portion of this work will address Medicaid beneficiaries who, because of their health and/or social conditions, are vulnerable to experience high levels of costly and often preventable service utilization, and whose care patterns and costs are potentially impactable. Another focus is to increase tenancy-sustaining services, expand housing development partnership opportunities, and assist states with strategies that expand HCBS.

For more information, see:
- https://www.medicaid.gov/State-Resource-Center/Innovation-Accelerator-Program/Innovation-Accelerator-Program.html

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Unlicensed Care Homes. ASPE just 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

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Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of AD/ADRD; more than 85 percent 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. 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

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 launched in fall 2015 and continues in 2016. The Campaign's website is http://www.brainhealth.gov and its launch focused on St. Louis and Las Vegas in 2015. Focus areas in 2016 are San Francisco and Chicago. Both years' efforts have national elements. Development of a *What is Brain Health?* Campaign for an Hispanic audience is underway this year with the goal of running the Campaign in 2017.

Alzheimer's Disease Information. 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 provides evidence-based information online, in print and via a call center. Information about Alzheimer's and other dementias, 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 and advocacy organizations, via weekly e-alerts to more than 50,000 subscribers, and social media outreach to more than 10,000 followers.

For more information, see:

- http://www.nia.nih.gov/alzheimers/volunteer

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:
- http://www.acl.gov/Get_Help/BrainHealth/Index.aspx
- https://mindyourrisks.nih.gov/
- http://columbianomas.org/study.html

Alzheimers.gov. HHS launched the website http://alzheimers.gov in 2012 and it needs to be refreshed. Two sets of analyses are underway to guide this process. The first analyzes website use to understand how many people are using the site and what information they find most useful. The second assessment involves a scan of other websites providing information on AD/ADRD. The result of these analyses will help determine how the website can best provide valuable information while not duplicating information already available from other sources.

Public Health Research Network. CDC created the new Healthy Brain Research Network (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 the 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 year 1 of a 2-year project to develop and disseminate science-based, culturally-relevant messages and strategies that promote awareness about cognition and cognitive impairment, including AD/ADRD, which will lead to increased detection of this type of impairment. 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 will inform the development, pilot testing, and dissemination of timely public health messages for this population and examine the potential scaling of these findings to other populations.

Lewy Who? Campaign. The Lewy Body Dementia Association (LBDA) launched its *Lewy Who?* Campaign in 2014 to raise the visibility of LBD to the general public and especially adults over the age of 50. The Campaign, now in its second year, features paid advertising, public relations and social media engagement. The ads appearing on AARP.com has resulted in one of the highest click-through rates of its website, underscoring the public's interest in learning more about this common but unfamiliar disorder. An education pamphlet on LBDA's *Lewy Who?* is available.

For more information, see:
- https://www.lbda.org/content/lewy-who

Parity Task Force. As part of wider Administration efforts to expand access to treatment for people with mental health and substance use disorders, the President signed a Presidential Memorandum in March 2016 creating a Mental Health and Substance Use Disorder Parity Task Force. The Task Force will focus key federal agencies on the work of ensuring that Americans receive the coverage and treatment that they need. Task Force membership includes: the White House Domestic Policy Council; the Department of the Treasury; DoD; the U.S. Department of Justice (DoJ); the U.S. Department of Labor (DoL); HHS;

VA; the Office of Personnel Management (OPM); and the Office of National Drug Control Policy (ONDCP).

The objectives of the Task Force are to:

- Increase awareness of the protections that mental health and substance use disorder parity provide.
- Improve understanding of the requirements of mental health and substance use disorder parity among key audiences including health plans, insurers and state regulators.
- Increase transparency around compliance with parity and the support, resources, and tools available to ensure coverage is in compliance with mental health and substance use disorder parity.

The Task Force will present its findings and recommendations in a report to the President by October 31, 2016.

For more information, see:

- https://www.whitehouse.gov/the-press-office/2016/03/29/presidential-memorandum-mental-health-and-substance-use-disorder-parity

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

REACH 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 intervention in at least 50 Tribal communities over the next 3 years. 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. 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.

New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias. This Council is charged with facilitating and reviewing interagency planning and policy on specific agency initiatives for services related to the care of persons with dementia. The group is a continuing forum for discussion related to the formation of a comprehensive state policy related to the disease. The initial report of the Council was released late in 2010. The *2013 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias* was released in early 2014. The third report of the Council is expected to be released in the spring of 2016.

Dementia Friendly America Community Toolkit. DFA offers a four phase community toolkit that convenes community 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. NIA convened a research-specific meeting of 50 dementia leaders February 11, 2015, at NIH in Bethesda. National health experts, including NIH Director Dr. Francis Collins, from the G7 countries -- the United States, Canada, United Kingdom, France, Germany, Italy, and Japan -- shared their recent progress in dementia research and care, and discussed research spending, clinical research strategies, and critical areas for future collaborations.

Global Action Against Dementia. In December 2013, with its Presidency of the G8, the United Kingdom hosted the G8 Dementia Summit, bringing together leaders from around the world. With support from Prime Minister David Cameron, G8 countries established the Global Action Against Dementia (GAAD), which elaborated a shared vision for addressing dementia on a global scale. GAAD was driven largely by stakeholders within the United Kingdom government, senior members of the U.S. Congress, and key advocates within the United States who are also members of the Secretary's Advisory Council on Alzheimer's Research, Care, and Services. In March, 2015, the United States supported shifting leadership of GAAD from the G8 to the World Health Organization, in order to ensure the involvement of low and middle-income countries through expansion of the GAAD beyond the G8.

World Dementia Council. Another of the main outcomes from the G8 Dementia Summit in 2013 was the creation of the World Dementia Council (WDC). WDC is a group of NGO and private sector representatives working in tandem with government representatives of the G8, and now, WHO, to carry out recommendations coming out of the Global Action Against Dementia Summit. While the government of the United Kingdom initially oversaw activities of the WDC, in 2016, the WDC became an independent body. In 2016, the WDC expanded to include membership from low and middle income countries, and four Global Teams were developed. The teams will address: (1) Integrated Development; (2) Research, Open Science and Data; and (3) Care and Risk Reduction. Many of these initiatives are in line with the goals of the National Plan, and since a number of members of the NAPA Advisory Council are on the WDC, we will maintain a liaison and continued coordination between the National Plan and the work of the WDC and other international activities.

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 Research Implementation Milestone Database, a user-friendly web-based tool to track NIH funding initiatives and activities, as well as those by 30 other funding agencies, targeting milestones aimed at achieving the Plan's ultimate research goal. This new data 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 other AD/ADRD research organizations. 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 National Institute of Neurological Disorders and Stroke (NINDS)-led summit in 2016 will be included once available.

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

CDC Data Reports and Publications. CDC released two publications using surveillance data from the 2011-2012 BRFSS about increased confusion or memory loss. These findings highlight that individuals or others within their household may notice changes in memory and confusion over time. This is important because a diagnosis for AD/ADRD is often missed or delayed. Talking with a health care provider about such changes is important to begin determining the reason why the person is experiencing increased confusion or memory loss. These findings also expand what we know about the general public's perceptions about increased confusion or memory loss and its relationship to other physical and mental health issues.

For more information, see:
- http://www.cdc.gov/pcd/issues/2015/14_0429.htm
- http://www.cdc.gov/pcd/issues/2015/14_0430.htm

2015 and 2016 Behavioral Risk Factor Surveillance System Data. CDC worked with partners and revised the BRFSS Cognitive Decline and Caregiving Optimal Modules, which were approved as official optional modules beginning in 2015. In 2015, 35 states collected data using the Cognitive Decline Module and 24 states collected data using the Caregiving Module. There are 15 additional states collecting data using the Cognitive Decline Module, and 16 states collected data using the Caregiving Module. Findings from the 2015 cognitive and caregiving data will be released in late 2016.

Diagnostic Coding for Dementia. HHS is working 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.

Mapping Medicare Disparities Tool. The CMS Office of Minority Health released a new interactive tool to increase understanding of geographic disparities in chronic disease -- including AD/ADRD -- among Medicare beneficiaries. The tool stratifies fee-for-service Medicare data (chronic disease prevalence, cost, readmissions, etc.) by gender, race and ethnicity, age, and dual status, for users to visualize disparities on an interactive map. This helps prioritize research, quality improvement efforts, and can inform county, state, and national policy decisions that might impact health disparities.

Strategy 5.B: Monitor Progress on the National Plan

Alzheimer's Association Care and Support Milestones Journal Article. In 2015, the Alzheimer's Association convened a workgroup of 14 experts from the fields of clinical care, LTSS, and care and support intervention research to recommend milestones for Goal 2 (care) and Goal 3 (support) of the National Plan. The purpose was to stimulate thinking about necessary federal and state policy actions to improve care and support over the next 10 years. It was also intended to encourage discussion by the Advisory Council and the Federal Government about the development of official care and support milestones under the National Plan, consistent with the biomedical research milestones established for Goal 1. In January 2016, the workgroup released 73 recommended milestones for Goal 2 and 56 recommended milestones for Goal 3. These recommendations were subsequently published in the March issue of Alzheimer's and Dementia.

For more information, see:

- http://www.alzheimersanddementia.com/article/S1552-5260%2816%2900035-2/pdf

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Healthy People 2020. CDC, in collaboration with NIH, released the baseline data for the Healthy People 2020 topic areas, *Dementias Including Alzheimer's Disease*. Additionally, CDC, NIH, ACL, and CMS participated in the Healthy People 2020 Progress Review on Older Adults and Dementias, Including Alzheimer's Disease.

For more information, see:

- http://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease/objectives
- http://www.cdc.gov.nchs/healhty_people/hp2020/hp2020_OA_DIA_progress_review.htm

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Non-Federal Items in the 2016 National Plan. The 2016 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 2016 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

Blanchette Rockefeller Neurosciences Institute

Centers for Disease Control and Prevention
Centers for Medicare & Medicaid Services
Consumer Finance Protection Bureau
Corporation for National and Community Services

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

Health Resources and Services Administration

Indian Health Service
Institute of Medicine

Lewy Body Dementia Association

Minnesota Board on Aging

National Association of Chronic Disease Directors
National Center on Elder Abuse
National Human Genome Research Institute
National Indian Council on Aging
National Institute on Minority Health and Health Disparities
National Institute of Neurological Disorders and Stroke
National Institute on Aging
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 on Disability
Oregon Department of Human Services

Social Security Administration
Substance Abuse and Mental Health Services Administration

Veterans Health Administration

Appendix 2: 2016 Recommendations and Federal Response

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

The 2016 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 2016 National Plan should continue to provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing, effectively treating and providing effective care and services for AD/ADRD by 2025.

a. A roadmap for accomplishing the primary goal of the Plan should include input from experts in the field through research summits on AD/ADRD dementias 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.
    - Make significant improvements in research recruitment rates and outreach among diverse populations.
    - 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).
    - Increased attention should be paid to person-centered and family-centered outcomes with respect to research planning and the delivery of care and services.

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 finding 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.

NIH leadership and staff will also 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 recently launched a searchable database at https://www.nia.nih.gov/alzheimers/milestones/. The Advisory Council's recommendations regarding specific research milestones will greatly contribute to these NIH planning processes.

For more information, see:

- https://aspe.hhs.gov/national-plan-address-alzheimers-disease-2015-update
- https://www.nia.nih.gov/alzheimers/bypass-budget-fy2017

RECOMMENDATION 2

A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.

a. Initial estimates of that level are $2 billion per year but may be more. This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research.
b. The annual research funding target should be dynamically modified to approximately 1% of the cost of caring for persons with AD/ADRD.
c. The annual professional judgment budget recommended by the Alzheimer's Accountability Act and prepared by NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 goal of the plan.

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*.

For more information, see:

- https://www.nia.nih.gov/alzheimers/bypass-budget-fy2017

RECOMMENDATION 3

The 2016 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, disease etiologies and disease trajectories to address key clinical features including NPS and functional decline.
f. 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.

Combined Federal Response

Research on provision of care and services for individuals with AD/ADRD and their families is an important research priority at NIH. Two FOAs (PAR-15-348 and PAR-15-351) released in September 2015 focus on identifying, characterizing and addressing the needs of formal and informal caregivers and care recipients. Nearly all of the Advisory Council's recommendations were addressed in the 2015 FOAs, and NIH will be happy to consider all of the Advisory Council's specific recommendations for inclusion in future research agendas.

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

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RECOMMENDATION 4

Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.

a. An integrated conference should be convened 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 reach a consensus 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 this working group is established, 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.

For more information, see:

- https://meetings.ninds.nih.gov/Home/Index/11958

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 WDC.
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 ten countries, including the United States, Australia, Brazil, Canada, Czech Republic, France, Italy, the Netherlands, Poland and the United Kingdom.

In addition, NIA co-hosts the 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 encourage both national and cross-national population-based research, and in the Health Disparities and Alzheimer's Disease FOA (PAR-15-349).

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

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RECOMMENDATION 6

The 2016 National Plan should increase early detection and diagnosis of AD/ADRD by encouraging and promoting cognitive assessment; and confirm measurement strategies to track progress within 2 years.

a. Encourage clinicians to implement GSA's Workgroup on Cognitive Impairment Detection and Earlier Diagnosis' four-step process. The steps include: (1) "Kickstart the cognition conversation;" (2) "Assess if symptomatic;" (3) "Evaluate with full diagnostic workup if cognitive impairment detected;" and (4) "Refer to community resources and clinical trials, depending on the diagnosis."
b. Promote early detection and diagnosis: support continuing education efforts that improve health care providers' ability to recognize early signs of dementia, including AD/ADRD, and to offer counseling to individuals and their care partners. Sessions should enhance health care provider awareness and understanding of the Medicare AWV and knowledge of validated cognitive assessment tools, through local and state conferences.
c. Determine if and how the Medicare AWV can be used to measure the rate of screening for cognitive impairment. Also, determine if and how other measures, such as items within the Physician Quality Reporting System (PQRS), could be used to track progress regarding the rate of screening for cognitive impairment.
d. Measure and publicly report data on AD/ADRD diagnostic levels nationally and by state, released within 6 months of year end.
e. Expand Diagnosis Disclosure, Improve Assessment and Care Planning, and Enhance Care Coordination. Develop and implement educational campaigns directed towards: (a) persons at risk for dementia and their family and caregivers; and (b) clinicians capable of conducting cognitive screening assessments. For the education of clinicians, include information about best practices for how to conduct the cognition conversation such that the diagnosis is understood, how to conduct conversations about care planning, and how to enhance care coordination through referrals to community resources. For the education of persons at risk for dementia and their family and caregivers, include information about what to expect after cognitive screening.

CMS Response

In Response to Recommendation 6.a. CMS appreciates the GSA workgroup's findings and conclusions to increase cognitive impairment detection and earlier diagnosis by primary care providers. The agency is not planning, at the present time, to issue regulations or other policy guidance requiring providers to use a particular tool or tools for detection of cognitive impairment. Physicians have discretion to choose an appropriate tool that meets their needs, and those of their patients, including during Medicare's AWV.

In Response to Recommendation 6.b. CMS regularly updates beneficiaries and other stakeholders regarding Medicare coverage of the AWV, including through the *Medicare & You Handbook*. In addition to the AWV, Medicare covers a range of mental health services including counseling or therapy furnished by a psychiatrist, psychologist, social worker, or certain other practitioners in an outpatient setting. Family counseling may also be covered if the main purpose is to help with the beneficiary's treatment. Medicaid, depending on the state, may furnish an array of rehabilitative and habilitative services.

In Response to Recommendation 6.c. CMS is currently developing electronic clinical quality measures (eCQMs) that address screening for cognitive impairment. These eCQMs complement Medicare's AWV not only for screening but also for family/caregiver engagement. These eCQMs are:

1. 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 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.
2. Documentation of a Health Care Partner for Patients with Dementia or Mild Cognitive Impairment: Percentage of patients age 18 years or older with a diagnosis of dementia or MCI, with documentation of contact information for a designated health care partner during the measurement period.

These eCQMs will be considered for future use in CMS quality reporting programs and, therefore, may allow CMS to track the progress of screening for cognitive impairment.

Regarding "Assess the beneficiary's cognitive function by direct observation, with due consideration of information obtained via beneficiary reports and concerns raised by family members, friends, caretakers, or others," CMS's cognitive impairment measures complement this activity, and both the Assessment measure and the Documentation of a Health Care Partner measure apply to beneficiaries within and outside of an AWV.

In Response to Recommendation 6.d. CMS has published a "Mapping Medicare Disparities" tool that allows stakeholders to access geographic information about chronic conditions, including AD/ADRD. The tool permits comparisons by gender, race and ethnicity, age, and dual status, in outcomes, utilization, and spending. CMS also provides researchers access to Medicare and Medicaid beneficiary, claims, and assessment data through the Chronic Conditions Warehouse. Two of the available conditions are AD, and ADRD or Senile Dementia.

In Response to Recommendation 6.e. CMS supports a person-centered approach to health care delivery, where the beneficiary is at the center of directing their care, achieving the health care goals for the aspects of their lives he or she deems important. Beneficiaries may make decisions based on their personal preferences in partnership with their clinician regarding a diagnosis, as well as other health care matters. The agency is striving to improve clinical care through, for example, the *Comprehensive Primary Care Initiative*, where primary care physicians are asked to engage in five functions: access and continuity, planned care for chronic conditions and preventive care, risk-stratified care management, patient and caregiver engagement, and care coordination across the medical neighborhood. CMS's TCPI is providing peer-to-peer support to primary and other clinicians through improved communication, dedicated coaches, notification alerts, promotion of treatment of behavioral health conditions, support of improved medication management, better data reporting, and promotion of person and family engagement. Other organizations/associations are aligning practice guidelines across specialties and sharing best practices. CMS does not have a mechanism to identify or educate beneficiaries "at risk of" dementia, or their families and caregivers.

HRSA Response

In Response to Recommendation 6.b. HRSA, through its GWEP, will continue to support 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. All 44 GWEP awardees are providing dementia training. GWEP grantees are continuing to educate the health care workforce on the early detection and diagnosis of AD/ADRD including the use of GSA's four-step process and the Medicare AWV. HRSA is in the process of identifying best practices in dementia training.

NIH Response

In Response to Recommendation 6.b. 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.

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-problems

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RECOMMENDATION 7

The 2016 National Plan should enhance care planning and care coordination by increasing the use of person-centered and caregiver goals, and improving measurement within 3 years.

a. Identify standards of care that reflects delivery of a comprehensive assessment to establish the diagnosis of dementia, identification of contributing factors, identification of support needs, and formulation of a care plan.
b. Develop and implement a plan to improve measurement capability so that the perspectives and goals of persons with AD/ADRD, their families and caregivers are known.
c. Incorporate best practices from the CMS Financial Alignment Initiative, including guidance provided in "three-way contracts" between CMS, states and health plans to improve care coordination for dementia. One example is the Dementia Cal MediConnect program which implemented care manager training and technical assistance in response to California's three-way contract specifying that each health plan must have a dementia care specialist.

CMS Response

In Response to Recommendation 7.a. In the CMS Quality Strategy, the agency actively encourages person and family engagement throughout the care continuum, including incentivizing health plans and providers to deploy effective person resources such as person-centered care plans. Person-centered care planning is a focus across CMS's programs, including in Medicaid's TEFT grants and personal health record (PHR), case management, in PACE, HCBS requirements, the Financial Alignment demonstrations; and in Medicare, in the payment for Transitional Care Management and Chronic Care Management services. Often such a plan would include the paid and unpaid supports the beneficiary needs to achieve his/her personal goals. CMS has also worked with the NQF on 12 endorsed quality measures for care coordination, and on the endorsed and submitted measures for person-centered and family-centered care, including a new tool for HCBS experience of care.

In Response to Recommendation 7.b. In 2015, CMS issued guidance on Requirements for Person-Centered Plans (PCPs) for HCBS. The PCP is synonymous with a "plan of care," "care plan," "individual services plan," and other terms used to describe a written individual plan based on the individual's unique needs, goals and preferences. Medicaid's Electronic Long-Term Services and Supports (eLTSS) Initiative is identifying and harmonizing electronic resources to enable the creation, exchange and reuse of interoperable person-centered records for use by clinical and HCBS providers, payers and the individuals they serve. The information within these records can help to improve the coordination of health, social services, and other services that support a beneficiary's mental and physical health.

In Response to Recommendation 7.c. The recommendation references the Cal MediConnect Dementia Project, which was funded via a grant from ACL to the California Department of Aging. Cal MediConnect itself is a demonstration under the Medicare-Medicaid Financial Alignment Initiative, jointly managed by CMS and the California Department of Health Care Services. In Cal MediConnect, CMS and DHCS execute three-way contracts with health plans to deliver a wide array of Medicare and Medicaid services. The three-way contracts for Cal MediConnect include requirements that health plans have

dementia care specialists amongst care coordination staff. The state worked with the Los Angeles Alzheimer's Association chapter to utilize the grant to provide training and technical assistance to the plans to meet this requirement. CMS plans to host a national webinar to share the promising practices facilitated by this project; other states have looked at the dementia language in the contract. Most recently, contracts for a comparable demonstration in Rhode Island include similar requirements.

CMS has bolstered the site-specific activities with national dissemination and capacity-building. CMS, in collaboration with American Geriatrics Society, Community Catalyst, and the Lewin Group, hosted a series of webinars in 2015 and 2016 to help health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults with Alzheimer's disease and in working with their caregivers.

For more information, see:
- https://resourcesforintegratedcare.com

NIH Response

Clinical care research is a critical research priority at NIH, with investments made to improve early diagnosis of AD/ADRD, support translational and clinical research that moves us closer to preventative strategies and treatments, and identify interventions that can reduce caregiver stress and burden. Two FOAs addressing clinical research (PAR-16-364 and PAR-16-365) were issued in October 2015 to stimulate both early and late-phase clinical trials, and many promising new therapies are moving into clinical testing, including LM11A-31, a compound able to enter the brain and prevent the loss of nerve cells and the connections between them; BPN14770, a drug that restores function of damaged synapses in the brain; and allopregnanolone, a neuroactive steroid that promotes growth of new neurons and may protect against Alzheimer's pathology.

In addition, the caregiver FOAs issued by NIA and National Institute of Nursing Research in September 2015 (PAR-15-348 and PAR-15-351) solicit basic and translational research that will increase understanding of the needs of individuals with AD/ADRD, and their caregivers, and develop interventions to reduce caregiver burden and improve patient outcomes across various settings. Specifically, these FOAs encourage research that will lead to better definition and characterization of informal and formal caregiving; the domains of needs of caregivers and care recipients across the care continuum; the key social structural variables which contribute to variance in caregiving burden; and factors that characterize care delivery and care coordination models that reduce burden on caregivers and care recipients. These FOAs also encourage research that will lead to the development of efficacious financial planning interventions aimed at anticipating costs of LTSS.

For more information, see:
- http://grants.nih.gov/grants/guide/pa-files/PAR-16-364.html
- http://grants.nih.gov/grants/guide/pa-files/PAR-16-365.html
- http://grants.nih.gov/grants/guide/pa-files/PAR-15-348.html
- http://grants.nih.gov/grants/guide/pa-files/PAR-15-351.html

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RECOMMENDATION 8

The 2016 National Plan should increase the number of communities working to become dementia-friendly by 50% within 1 year.

a. Encourage efforts to foster Dementia-Friendly Communities. As an example, tools and resources used in Minnesota have been replicated through a privately-funded collaboration called *Dementia Friendly America*; under this initiative all United States communities have access through a website (http://www.dfamerica.org) to free tools, resources, best practices and technical assistance to support them in working to become dementia-friendly. Incorporate examples such as this into an update of the November 2011 Dementia-Capability Toolkit and the September

2014 report, *Dementia-Capable States and Communities: The Basics*; and/or promote expanded use of the Toolkit and report.

b. Promote the Dementia-Friendly Community approach as an organizing vehicle to implement state AD/ADRD plans. A public-private collaborative approach should provide funding that is designed to specifically support communities and/or states with seed money to foster the coordination of community efforts and support technical assistance through a centralized hub and/or state lead entity. In 2016, this collaborative should fund at least 20 communities (via an Request for Proposal process) and a technical assistance hub. The communities chosen should reflect differences in cultural groups and size of community, as well as rural and urban locales.

ACL Response

ACL, through its ADI-SSS and ADSSP cooperative agreements, continues to use available federal funding to provide states and localities with opportunities to implement projects that include dementia-friendly community components. References to the resource mentioned in this sub-recommendation appear in the 2014 report. Any future updates to these materials will also recommend that readers explore dementia-friendly resources as they consider improvements to their service systems.

HRSA Response

In Response to Recommendation 8.b. HRSA is also working with federal partners at ACL, CDC, CMS, and VA on a contract to develop a Uniform Curriculum to educate providers about how to detect cognitive impairment and assess and diagnose AD/ADRD work with persons living with AD/ADRD and their families, link persons living with AD/ADRD and their families to support services in their community, identify signs of caregiver burden and depression; educate physicians and other health care providers about accessing LTSS, and provide caregiver dementia training. The purpose of the curriculum is to build a workforce with the skills to provide high-quality care, ensure timely and accurate diagnosis, and identify high-quality dementia care guidelines and measures across care settings. Specifically, 16 core modules along with nine caregiving modules will be developed and pilot tested. These modules build 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/ADRD.

For more information, see:

- http://www.actonalz.org/dementia-curriculum

RECOMMENDATION 9

The 2016 National Plan should convene a national dementia care and services research summit.

a. Build on existing work to identify research priorities related to improving early detection and diagnosis of AD/ADRD, providing care and services to persons with dementia and family caregivers, and providing recommendations as to standards of care, best practices and priorities.

Combined Federal Response

The federal agencies are working together and with the appointed Steering Committee to support the development and implementation of a National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers.

RECOMMENDATION 10

States, HHS, and Tribes must assure robust dementia-capable LTSS systems to meet the growing impact of AD/ADRD.

a. Increase the number of states with an identified state lead entity for AD/ADRD to coordinate activity across state agencies and programs, and to work with state, local and private sector partners to implement strategies in concert with the National Plan.
b. National partners should work with HHS and states to assure engagement of state governors and legislatures in state efforts to address dementia-capable LTSS, expand use of evidence-based and best practices, and advocate for adequate funding for LTSS.
c. Double current funding for the ADSSP and ADI-SSS program to increase state and communities' use of evidence-based and evidence-informed strategies, programs, and dementia-capable systems.
d. Provide adequate funding to support state lead entities to plan and coordinate public and private activities to assure states are able to address the growing impact of AD/ADRD and assure dementia-capable health and LTSS systems.
e. Increase state and local public health role in supporting brain health, prevention, surveillance, and community policies to support cognitive health, implementation of CDC's Healthy Brain Initiative: Public Health Road Map, and incorporation of brain health and AD/ADRD into other existing public health efforts.
f. Amend Older Americans Act and expand funding to support making Title III services available to people under age 60 with younger-onset dementia.
g. Adopt common metrics that states, Tribes, and communities can use to measure and track progress in developing dementia-capable LTSS.

ACL Response

ACL continues to make federal funding available to promote new dementia-capable service systems across the country, expand existing systems, and foster evidence-based approaches to serving special populations at risk of acquiring dementia. Under ACL's grant programs, dementia-capable systems are required to have lead entities and these systems have access to a national resource center, which has developed a tools states and communities can use to measure their progress toward reaching and expanding dementia-capability. ACL would welcome opportunities to work with state and local organizations to disseminate the learnings from these grants to states and localities. Other recommendations in this section would require changes to federal law or appropriations.

CMS Response

CMS supports person-centered and family-centered care (see CMS Quality Strategy). In Medicaid, CMS permits states to electively offer self-directed services to beneficiaries who are eligible for their HCBS programs. To implement Medicaid HCBS programs, states are required to provide CMS with performance measures tailored within the HCBS quality framework. CMS, with other HHS operating divisions, is working with NQF to begin the process of understanding more about quality measurement gaps in HCBS. CMS has also issued a Notice of Proposed Rulemaking, CMS 3260-P that, among other improvements, outlines proposed requirements for cultural competence in long-term care facilities.

In Response to Recommendation 10.a. CMS does most of its work at the state level on LTSS including services to older adults and people with disabilities, through the Medicaid program, as Medicaid covers certain institutional and HCBS to eligible beneficiaries. CMS agrees that the involvement of state Medicaid agencies is important in coordinating programs and policies that impact individuals with AD/ADRD, and its state partners design some programs by "targeting" beneficiaries with certain conditions. CMS approves aspects of the Medicaid state plan including waivers that are submitted by states.

In Response to Recommendation 10.b. CMS works regularly with the listed national partners and others on many issues related to LTSS in Medicare and Medicaid including HCBS, nursing facility care, quality improvement, caregiving, and other topics that impact people with AD/ADRD.

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.

RECOMMENDATION 11

HHS, states, Tribes, and health care and aging services must assure that family or unpaid caregiver health and well-being is addressed.

a. Assure that health and related systems funded with federal resources provide chronic disease management and related services for people with AD/ADRD, as well as family caregivers.
b. Educate and clarify for health care providers and health systems how Medicare care planning and other covered benefits can be provided to a beneficiary with AD/ADRD in compliance with HIPAA, when a family caregiver is present and the individual with the disease is not.
c. Provide full funding for the National Family Caregiver Support Program, including funding to ensure regular evaluation of the impact of the program on family caregivers for people with AD/ADRD.
d. The process of diagnosis should include engaging individuals and families in care planning and referrals to appropriate community resources to support this planning. Care planning should address health, LTSS, caregiving resources, legal, estate planning, and finances.
e. Provide care planning with an unpaid/family caregiver as a covered benefit under Medicare and Medicaid.
f. Identify family/unpaid caregivers in EHRs of individuals with AD/ADRD, as well as in the caregiver's own medical records.
g. Expand pilot payment programs in Medicare and Medicaid models that include caregiver support for patients with AD/ADRD, many of whom have complex care needs.
h. Identify and advocate for employment practices and policies that allow employers to balance paid employment with unpaid care.
i. Support the expansion to scale of evidence-based and evidence-informed caregiver support programs and their cultural adaptations.

ACL Response

In Response to Recommendation 11.a. People in the early stages of dementia and family caregivers of those with the condition are able to participate in chronic disease self-management education programs under ACL grants to state agencies, non-profit organizations, universities, and others. ACL encourages program outreach to these populations.

CMS Response

CMS strives to address beneficiaries' strengths, capacities, goals, preferences, needs, and desired outcomes through a person-centered approach to care. There are occasionally special opportunities for CMS to facilitate "caregiver support" through, for example, Special Improvement Projects (Medicare QIOs), CMP funds, and other mechanisms, such as Medicaid (e.g., Health Homes, HCBS programs). There is no entitlement to caregiver support programs in Medicare, or Medicaid. In Medicaid, states may optionally choose to include services or delivery models (e.g., respite care, self-direction) that may assist caregivers.

In Response to Recommendation 11.a. Medicare may pay for a health care professional's assistance in preparing and monitoring a comprehensive care plan tailored to a beneficiary's needs if the person has two or more chronic conditions through payment for the Chronic Care Management code. The beneficiary's care plan will typically include a list of goals and problems, 24/7 access for urgent care needs, support in transitioning from one health care setting to another, review of medicines and medication management, and other chronic care needs. The service is billed monthly and the Part B deductible and coinsurance apply for Original Medicare beneficiaries. In Medicaid, states may optionally establish under the state plan Health Homes for Medicaid beneficiaries with two or more chronic conditions, or those at risk for a second chronic condition. Health home providers integrate and coordinate all primary, acute, behavioral health and LTSS in a holistic manner. In addition, some services under Medicare and Medicaid, like respite care, may be furnished to the beneficiary, yet indirectly benefit an unpaid caregiver,as well. Medicaid's PACE benefit also supports some of the care and services mentioned.

In Response to Recommendation 11.b. Beneficiaries may have a representative of their choosing who has 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. Advance Care Planning is covered as an optional element of the Medicare AWV, and Medicare may also cover this service if it is reasonable and necessary as part of a beneficiary's medical treatment.

Within these national coverage parameters, local Medicare contractors may make decisions about when they will pay for this voluntary service through local coverage determinations or on a case-by-case basis. Across its programs, CMS supports person-centered care, directed by the beneficiary, to identify strengths, capacities, preferences, needs, and desired outcomes. Person-centered planning includes independent facilitation, and contributors to the care plan are chosen by the beneficiary. These participants assist in identifying goals and facilitating access to the unique mix of paid and non-paid services and supports needed to assist the beneficiary in achieving individually-defined health care outcomes. CMS also encourages supported decision making (SDM), through which older adults with cognitive impairment retain choice and control over decision making in their lives and are able, with individualized assistance, to express their wants and needs in areas such as health care, financial decisions and voting rights.

In Response to Recommendation 11.d. As noted above, beneficiaries may have a representative of their choosing (including an emergency contact) who has 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. Medicare's Chronic Care Management and Transitional Care Management codes, the AWV, and the Advance Care Planning code include elements of the "care planning" referenced above. In Medicaid, states may elect to provide case management as part of certain benefits (e.g., PACE, HCBS programs, Health Homes, state plan service, etc.). The Financial Alignment Initiative for dually eligible beneficiaries also include elements of care planning.

In Response to Recommendation 11.e. In both Medicare and Medicaid, eligibility for a service is determined in regard to the enrolled beneficiary, not a caregiver. However, as noted above, beneficiaries may choose, through a legal representative, or through alternative means such as SDM that preserve self-determination and individual rights, to include an unpaid caregiver in care planning discussions with providers of clinical and other services.

In Response to Recommendation 11.f. As noted above, beneficiaries may have a representative of their choosing who has 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. This person may be identified in the

beneficiary's health record, at their option, or in association with a legal directive. Medicare beneficiaries also have the option of participating in Advance Care Planning (such as through the AWV), which may include the design of an advance directive. The Patient Self-Determination Act of 1990 addresses the rights of health care consumers to stipulate how they want to be treated by providers when they are incapacitated, through an advance directive, or by appointment of a health care agent. The law also requires that facilities that participate in Medicare and Medicaid must follow certain rules (e.g., maintain advance directive policies, document the existence of an advance directive in the beneficiary's medical record, and comply with relevant state law; facilities also may not condition care based on whether the beneficiary has an advance directive). CMS, through the Center for Medicaid and CHIP Services (CMCS), is presently working with nine states to create and test a structured, longitudinal, person-centered eLTSS plan for beneficiaries receiving HCBS. The eLTSS plan is to be exchanged electronically across multiple HCBS and institutional settings, and with beneficiaries and payers. The person-centered eLTSS plan will be led by the beneficiary and includes individuals chosen by the beneficiary to participate in his or her care. The standards identified for the eLTSS plan support consistent data collection and interoperable exchange with various information systems to include clinical information systems, state Medicaid and health information exchange systems, PHR systems, and other information systems (e.g., case management, legal, justice, education, protective services, etc.). CMCS is also working on development of a PHR that will provide HCBS recipients with a range of LTSS information to facilitate decision making, and encourage a more active role for beneficiaries and caregivers in managing care that will result in better outcomes.

In Response to Recommendation 11.g. CMS periodically offers opportunities for states and other entities to apply for demonstrations and models and other special initiatives through the Innovation Center, and other centers (e.g., CMCS, Center for Clinical Standards and Quality, etc.). States and accountable entities, when applying for/implementing such opportunities, also have some discretion in choosing what topics to address (e.g., AD/ADRD) within these opportunities. 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 tested under the authority of section 1115A of the Social Security Act meet statutory criteria established in the Affordable Care Act. 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 government, 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.

HRSA Response

In Response to Recommendation 11.b and 11.d. HRSA is partnering with federal partners, public and private entities, the health care provider community, and community organizations that provide LTSS to effectively educate physicians and other health care providers, direct services workers, and patients, families, and caregivers about support resources and services available to assist people with AD/ADRD and their caregivers.

NIH Response

NIH considers research on caregivers to be a high priority and two FOAs (PAR-15-348 and PAR-15-351) were issued in September 2015 to promote research on this topic. Both of these FOAs address many of the research recommendations noted above, by focusing on developing interventions that apply across the full care continuum; defining caregiving and assessing the impact of formal and informal care over the trajectory of AD/ADRD; addressing palliative care needs and supporting caregivers in their role as surrogate decision makers; and developing financial planning interventions aimed at anticipating costs of LTSS and palliative care.

One of the these FOAs (PAR-15-348) specifically addresses the need identified in the recommendations above to expand evidence-based and evidence-informed programs, by encouraging randomized trials for comparative effectiveness research on AD/ADRD caregiver interventions, as well as partnerships with

community organizations, particularly those that have potential to deliver programs at regional or national scale.

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

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RECOMMENDATION 12

Federal agencies in partnership with national organizations and states, support research to identify standards and best practices to improve quality of life and LTSS for individuals and families affected by AD/ADRD.

a. Provide training for paid/paraprofessional caregivers in every care setting to address cultural and dementia competence. HHS should identify model state standards of care and policies that promote fair and reasonable compensation and appropriate dementia care training.
b. Assess and share findings on the impact of CMS's 2014 HCBS settings rule on individuals with AD/ADRD and their caregivers.
c. Assess and share findings on the impact of states' managed LTSS systems on individuals with AD/ADRD and their caregivers.

CMS Response

In Response to Recommendation 12.a. CMS requires that providers be qualified to render covered, medically necessary services in both Medicare and Medicaid. Under Medicaid, while training costs for an individual or entity to become a qualified provider are not reimbursable costs associated with continuing education and training for Medicaid providers may in some circumstances be allowable expenses. Should a state wish to promote, for example, advanced provider skills training to increase the availability of providers qualified to serve beneficiaries with dementia, costs associated with that advanced training could be included in the development of rates paid for services requiring more complex levels of care. The state could set provider qualification requirements at a separate and distinct level for those advanced level providers, and pay higher rates. States have some flexibility within Medicaid to approach CMS to develop such programs and rates. In long-term care facilities, the Affordable Care Act requires dementia management training as part of the 12 hours per year in-service training for nurse aides.

In Response to Recommendation 12.b. CMS is monitoring implementation of the HCBS Final Rule on states and their HCBS systems (e.g., compliance with integrated settings requirements). However, CMS has no mechanism to assess and share findings on the impact of the final rule on beneficiaries with dementia, specifically -- or their caregivers. States may target certain groups of beneficiaries for HCBS programs. Only one state (Virginia) has chosen to identify AD/ADRD as a HCBS target group. CMS encourages states to apply for programs that serve beneficiaries with particular conditions, and provides technical assistance during the development process. There is currently no mechanism, however, to identify at the federal level which beneficiaries are diagnosed with a particular condition, and are also participating in a HCBS program. States may have better data on beneficiary participation and eligibility for programs designed, for example, for older adults.

In Response to Recommendation 12.c. CMS issued a comprehensive Final Rule in May 2016 for Medicaid that unifies flexible requirements across managed care authorities and recognizes that managed care is key to the provision of LTSS. As noted above, unless a state has identified beneficiaries with dementia as a target group, or otherwise flagged these individuals as an included population, CMS has no mechanism to track the impact of managed care delivery systems on individuals with dementia and/or their caregivers. (It is unclear if the referenced "caregivers" are paid caregivers, or unpaid caregivers.) If the former, CMS has some discretion in working with states to identify Medicaid providers that have the appropriate skills and/or credentials to provide covered services in development or provider qualifications.

HRSA Response

In Response to Recommendation 12.a. As part of HRSA's GWEP, awardees educate and train caregivers. Since the start of the program in July 2015, approximately 13,384 caregivers have received training on a variety of topics. The top five training topics include: (1) the basics of AD/ADRD; (2) evidence-based programs for family caregivers; (3) promoting self-care by the caregivers; (4) community resources to support caregivers; and (5) managing dementia. The total number of caregivers predicted to be trained over the 3 years of the grant is 52,352.

NIH Response

In September 2015, NIA and NINR issued another funding opportunity (PAR-15-350) that encourages LTSS research that focuses on the challenges faced by informal/family caregivers from diverse racial, ethnic and socioeconomic backgrounds and disparities in access to and utilization of formal long-term supports and services for those with dementia.

In addition to releasing these program solicitations, NIH staff has been engaged along with HHS leadership and representatives of multiple NGOs in discussions about the best approach to take with respect to developing a research summit focused on care and services. NIH will take the Advisory Council's recommendations regarding topics to consider for future research under advisement as it helps to plan this research summit, when it next revises its research milestones, and as it develops future ***Bypass Budgets for Alzheimer's Disease and Related Dementias***.

For more information, see:

- http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html
- https://www.nia.nih.gov/alzheimers/bypass-budget-fy2017

Appendix 3: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2015 and 2016
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. Next Summit expected in 2017-2018	NIH/NIA	National & international experts, public & private stakeholders, Research Subgroup, academia, industry, professional & advocacy groups	Second Summit February 2015 Next Summit Projected 2017-2018	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 IADFRC--July 2015 (in-person meeting at AAIC); Fall 2015 conference call	2015 AD Summit Recommendations http://www.nia.nih.gov/research/recommendations-nih-ad-research-summit-2015 Updated AD Research Implementation Milestones https://www.nia.nih.gov/budget-files/fy-2017-alzheimers-disease-bypass-budget-milestones.pdf
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	
1.A.5	Create a timeline with milestones for achieving Goal 1.	Create & update milestone document.	NIH/NIA		Ongoing	Updated AD Research Implementation Milestones https://www.nia.nih.gov/budget-files/fy-2017-alzheimers-disease-bypass-budget-milestones.pdf Developed searchable AD/ADRD Research Implementation Milestones Database https://www.nia.nih.gov/alzheimers/milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2015 and 2016
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 3rd 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 are expected to be approved by NINDS Advisory Council in September of 2016 & by the NAPA Council in early 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 10th Meeting of the Down Syndrome Consortium: A Public-Private Partnership	Input solicited on special research priorities related to Down Syndrome Research 10th Meeting of the Down Syndrome Consortium: A Public-Private Partnership https://downsyndrome.nih.gov/meetings/Pages/010815.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
Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease						
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	Release of NIH Funding Opportunity Announcements: PAR-15-358: Capturing Complexity in the Molecular & Cellular Mechanisms Involved in the Etiology of Alzheimer's Disease (R01) http://grants.nih.gov/grants/guide/pa-files/PAR-15-358.html PAR-15-357: Understanding Alzheimer's Disease 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 Alzheimer's Disease http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html PAR-15-349: Health Disparities and Alzheimer's Disease http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html AMP-AD Activities are also relevant: AMP-AD 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 2015 and 2016
1.B.2	Expand genetic epidemiologic research to identify risk & protective factors for AD/ADRD.	Conduct whole genome sequencing 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	Continue to support efforts through the Alzheimer's Disease Sequencing Project (ADSP), Alzheimer's Disease Genetics Consortium (ADGC) and NIA Genetics of Alzheimer's Disease Data Storage Site Data are available for 15,630 subjects (cases, controls & family members) including phenotype & individual-level information. ADSP https://www.niagads.org/adsp/ ADGC https://www.niagads.org/content/alzheimers-disease-genetics-consortium-adgc-collection NIAGADS https://www.niagads.org/
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	Alzheimer's Disease Cooperative Study http://www.adcs.org/ In 2015, the ROAR team continued to promote a toolkit of customizable materials for aging services and public health professionals to use in community settings and social media, and expanded the potential reach by translating materials into Spanish and Chinese. https://www.nia.nih.gov/health/publication/roar-toolkit NIA's ADEAR Center developed a web mini-portal in 2015 for encouraging participation in Alzheimer's research. http://www.nia.nih.gov/alzheimers/volunteer ADEAR sends out monthly e-alerts to nearly 35,000 subscribers announcing new recruiting trials and featuring registries and matching services such as the Alzheimer's Prevention Registry and Brain Health Registry. In 2016, NIA is joining collaborative efforts with FDA and the PCORI-funded Alzheimer's and Dementia Patient/Caregiver-Powered Research Network to encourage research participation.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2015 and 2016
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	PAR-15-350: Emerging Directions for Addressing Health Disparities in Alzheimer's Disease http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html PAR-15-349: Health Disparities & Alzheimer's Disease http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html In 2015, 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
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 Alzheimer's Disease & 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 Alzheimer's Disease & Age-related Cognitive Decline http://grants.nih.gov/grants/guide/pa-files/PAR-16-365.html See also AMP: AMP-AD https://www.nia.nih.gov/alzheimers/amp-ad An updated list of NIA-supported clinical trials can be found in the 2014-2015 Alzheimer's Disease Progress Report https://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/category-c-translational#trials 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 2015 and 2016
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. New FOAs include: PAR-16-364: Phase III Clinical Trials for the Spectrum of Alzheimer's Disease & 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 Alzheimer's Disease & Age-related Cognitive Decline http://grants.nih.gov/grants/guide/pa-files/PAR-16-365.html The annual list of ongoing AD/ADRD trials is available in the 2014-2015 Alzheimer's Disease Progress Report https://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/category-c-translational#trials Development of the IADRP will facilitate tracking research efforts, including treatment studies. http://iadrp.nia.nih.gov/cadro-web/
Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease						
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/ PAR-15-359: Novel Approaches to Diagnosing Alzheimer's Disease & Predicting Progression http://grants.nih.gov/grants/guide/pa-files/PAR-15-359.html PAR-15-350: Emerging Directions for Addressing Health Disparities in Alzheimer's Disease http://grants.nih.gov/grants/guide/pa-files/PAR-15-350.html PAR-15-349: Health Disparities & Alzheimer's Disease http://grants.nih.gov/grants/guide/pa-files/PAR-15-349.html

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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, CMS	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
Strategy 1.D: Coordinate Research with International Public and Private Entities						
1.D.1	Inventory AD/ADRD research investments.	International Alzheimer's Disease Research Database launched July 2012 & continually updated.	NIH/NIA		Ongoing	IADRP now includes data from 35 public & private funding organizations across 10 countries. http://iadrp.nia.nih.gov/cadro-web/
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	Alzheimer's Disease Funders' meeting held during the 2015 AAIC; quarterly funders calls led by NIA & Alzheimer's Association. Also, IADRP which includes data from 35 public & private funding organizations across 10 countries is publicly-available for use.
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; & other resources. 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
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. ADEAR Center https://www.nia.nih.gov/alzheimers 2014-2015 AD Progress Report https://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/introduction
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

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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 will begin on the 3rd Road Map that will identify action items for public health professionals related to cognitive health.
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 Geriatrics Centers 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	Progress report for the 1st 6 months of funding: This is an interim report. Between July 1, 2012, & December 31, 2012, the 45 GECs provided 178 interprofessional continuing education offerings & trained 10,976 participants. Each event trained participants 2-25 different health professions. 248 community partners participated with GEC grantees in providing this training including 28 QIOs, 15 Alzheimer's Association Chapters, 8 Area Health Education Centers, & 8 Veterans Administration Medical Centers. 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

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2.A.2	Encourage providers to pursue careers in geriatric specialties.	Educate providers about opportunities through: (1) the CGEP, (2) the Geriatric Academic Career Awards Program; & (3) training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists.	HRSA		Ongoing	18 CGEP grants awards were made with a start date of July 1, 2012. Of the 18 awards, 12 include support for 66 advanced practice nursing traineeships with a specialty in care of the older adult. All trainees are receiving a significant amount of education on assessing & caring for the individual with dementia, including consideration of their families & caregivers. 33 faculty members are also receiving training to improve their skills related to the assessment and care of persons with dementia. In addition, 2,462 practicing health care providers, caregivers, and community members received participated in continuing education offerings on AD/ADRD. GTPD programs: 12 grants are currently being funded through the GTPD program. Starting July 1, 2012, 54 fellows received didactic & clinical experiences on the diagnosis & management of dementia. In addition, grantees trained an additional 330 learners by involving fellows in outreach & education. For example, 1 grantee involves the fellows in providing community education on dementias, & another is supporting a second year fellow in developing a curriculum for caregivers of persons with dementia. There is a significant level of collaboration among GTPD grantees & GECs & the Alzheimer's Association on continuing education activities. In some instances, fellows attend continuing education programs on dementia, & in others, they are the instructors & presenters for such programs. Several grantees are involving their GTPD fellows in educating pre-licensure medical & dental students, using their experiences in managing dementia to provide didactic lectures to students.
2.A.3	Strengthen state aging, public health, & IDD workforces.	Educate the workforces through various means including online training, webinars, fact sheets & other tools.	HRSA	ACL/AoA	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 26 AAAs & 13 QIOs to strengthen state aging, public health, & IDD workforces. AoA has a person-centered counseling program, which includes education about cognitive issues & dementia-capability. Training programs will be pilot-tested in 2016
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	September 2016	

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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	Ongoing	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#resources The interagency ROAR (NIH, ACL, CDC) group hosted a 4th annual webinar series in 2015 for these professionals on AD/ADRD & caregiving resources, current research studies, & caregiver support programs that drew record attendance (500+ participants for each of 3 webinars) & offered continuing education credit. 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 Healthy Brain Initiative: 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.
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 track in planning 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.
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	
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.
2.A.10	Decision Support for Clinicians.	Develop & pilot-test decision support tools for clinicians using the IHS EHR.	IHS		Ongoing	Pilot-test in 6 sites.
2.A.11	Interdisciplinary Team Training in recognition, assessment, & management of dementia in small rural Indian Health facilities.	Provide the VA Rural Interdisciplinary Team Training to 10 IHS & Tribal sites with a focus on dementia care.	IHS	VA	Ongoing	20 sites by September 2017.

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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 Alzheimer's Disease & Their Caregivers.
2.A.13	Fill service gaps in dementia-capable systems by expanding the availability of specialized services & supports to target previously underserved 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	The CMS Medicaid IAP is supporting state Medicaid agencies in community integration through LTSS. One targeted area of support is helping a select number of Medicaid agencies plan & implement quality & outcome incentives in their community-based LTSS 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 Community Living Centers.	Share with federal partners a summary report on implementation & evaluation of VA's dissemination of CMS Hand-in-Hand dementia training materials in VA Community Living Centers.	VA	ASPE, CMS, ACL, HRSA	Ongoing	

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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.	CMS, NIH/NIA	CDC	Ongoing	The CMS Medicaid IAP is supporting state Medicaid agencies in community integration through LTSS. One targeted area of support is helping a select number of Medicaid agencies plan & implement quality & outcome incentives in their community-based LTSS programs. https://www.medicaid.gov/state-resource-center/innovation-accelerator-program/community-integration-ltss/ci-ltss.html 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	2 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	
Strategy 2.C: Educate and Support People with Alzheimer's Disease 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.

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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.
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.
Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease						
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 were released in May 2016 (see Plan updates).
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	
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		Report expected September 2016	
2.E.6	Analyze reimbursements for high-quality, community-based, ambulatory mental health & substance use disorder services.	2 year demonstration program of Certified Community Behavioral Health Clinics.	ASPE	SAMHSA	Ongoing	http://www.samhsa.gov/section-223

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Strategy 2.F: Ensure that People with Alzheimer's Disease 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	
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						
2.G.1	Implement & evaluate care coordination models.	Implement & evaluate care coordination models.	CMS/CMMI		Ongoing	HCIAs Rounds 1 & 2 in process; Medicare & Medicaid Coordination Office demonstration projects started. http://www.integratedcareresourcecenter.com/
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 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	

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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	
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 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 awarded (#1P50 HS 019917) & 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 awarded (#5R18HS027836) 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.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2015 and 2016
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	Release of 2 highly relevant PARs: PAR-15-348: Research on Informal & Formal Caregiving for Alzheimer's Disease (R01) PAR-15-351: Research on Informal & Formal Caregiving for Alzheimer's Disease (R21) released. • 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.
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
3.B.6	Examine technological solutions to support family caregivers.	Grant awarded--awaiting results.	AHRQ		December 2019	Grant awarded (#5R18HS027836) 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). Implementation in 50 Tribal communities by February 2018.

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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						
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. In 2011-Q4, 23.9% of long-stay nursing home residents were receiving an antipsychotic medication; since then there has been a decrease of 28.8% to a national prevalence of 17% in 2015-Q4. Success has varied by state & CMS region, with some states & regions having seen a reduction of greater than 20%. Information for Ombudsman Program http://www.theconsumervoice.org/advocate/antipsychotic-drugs http://www.theconsumervoice.org/advocate/antipsychotic-drugs#education Other information https://www.nhqualitycampaign.org/star_index.aspx?controls=welcome
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	
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	Conducted NIH Workshop on Multiple Approaches to Understanding & Preventing Elder Abuse https://www.nia.nih.gov/about/events/2015/nih-workshop-multiple-approaches-understanding-and-preventing-elder-abus
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

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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						
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	Part 1: 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 Part 2: Publication expected later in 2016.
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 2015 and 2016
Goal 4: Enhance Public Awareness and Engagement						
Strategy 4.A: Educate the Public about Alzheimer's Disease						
4.A.1	Design & conduct a national education & outreach initiative.	Plan, fund, & implement AD/ADRD awareness activities, in racially and 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, and 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	http://www.eldercare.gov NIA operates 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.
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
Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease 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	
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.
4.B.3	Get Tribal input on AD/ADRD.	Convene Tribal leaders.	IHS	ASPE, ACL/AoA	Ongoing	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2015 and 2016
4.B.4	Support improved coordination between IHS, Tribal, & Urban Indian Health programs & the Tribal Aging Network around 4 person-centered goals.	Improve coordination between IHS, Tribal, & Urban Indian Health programs & the Tribal Aging Network around 4 person-centered goals.	IHS	ASPE, ACL/AoA	Ongoing	
		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	VA	Ongoing	
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	
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	
5.A.3	Summarize data on cognitive impairment across states.	Report on 2012 BRFSS data on perceptions about increased confusion & memory loss.	CDC		Ongoing	The 2013 data was recently analyzed & state-specific reports were developed & released. 2015 data was collected in 35 states & releases will begin in fall 2016.
5.A.4	Develop & disseminate measures of awareness of AD.	Release report on validated survey questions.	CDC		Ongoing	
5.A.5	Summarize existing data on people with AD/ADRD & their caregivers.	Develop & release chartbook.	ASPE	CDC/NCHS, NIH/NIA, ACL/AoA	Ongoing	CDC is developing a brief report/fact sheet summarizing results from 2011-2013 BRFSS caregiver module with respect to those caring for person with AD/ADRD. The documents will be released in late 2016. Results from the 24 states who administered the BRFSS caregiving module in 2015 will begin to be released in late 2016.
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	
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	

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2015 and 2016
5.B.2	Update the National Plan annually.	Release updated National Plan.	ASPE		Ongoing	

References

1. Hebert LE, Weuve J, Scherr PA, Evans DA. "Alzheimer's Disease in the United States (2010-2050) Estimated Using the 2010 Census." *Neurol*, 2013; 80:1778-1783.

2. Burns A, Iliffe S. "Alzheimer's Disease." *BMJ*, 2009; 338:b158.

3. Alzheimer's Disease Education and Referral (ADEAR) Center. Alzheimer's Disease Fact Sheet. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 11-6423. July 2011.

4. National Institute on Aging. 2009 Progress Report on Alzheimer's Disease: Translating New Knowledge. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 10-7500. November 2010.

5. Alzheimer's Disease Education and Referral (ADEAR) Center. Alzheimer's Disease Fact Sheet. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 11-6423. July 2011.

6. National Institute on Aging. 2009 Progress Report on Alzheimer's Disease: Translating New Knowledge. U.S. Department of Health and Human Services, National Institutes of Health. NIH Publication No. 10-7500. November 2010.

7. Mahoney R, Regan C, Katona C, Livingston G. "Anxiety and Depression in Family Caregivers of People with Alzheimer's Disease: The LASER-AD Study." *J Am Geriatr Soc*, 2005; 13(9):795-801.

8. Hurd M, Martorell P, Delavande A, Mullen K, Langa K. "Monetary Costs of Dementia in the United States." *N Engl J Med*, 2013; 368:1326-1334. http://www.nejm.org/toc/nejm/368/14/.

9. Maslow K. "How Many Hospital Patients Have Dementia?" In Silverstein N and Maslow K, eds. Improving Hospital Care for People with Dementia. New York, NY: Springer; 2006.

10. Magaziner J, et al. "The Prevalence of Dementia in a Statewide Sample of New Nursing Home Admissions Aged 65 and Older." *Gerontol*, 2000; 43(4):514-520.

11. Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, et al. "Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia." *JAMA*, 2002; 287:2090-2094.

12. Taylor DH, Ezell M, Kuchibhatia M, Ostbye T, Clipp EC. "Identifying the Trajectories of Depressive Symptoms for Women Caring for Their Husbands with Dementia." *J Am Geriatr Soc*, 2008; 56(2):322-327.

List of Acronyms Used

A4	Anti-Amyloid Treatment in Asymptomatic Alzheimer's
AAA	Area Agency on Aging
AAIC	Alzheimer's Association International Conference
ACL	Administration for Community Living
AD	Alzheimer's Disease
ADC	Alzheimer's Disease Center
ADCS	Alzheimer's Disease Cooperative Study
ADEAR	Alzheimer's Disease Education and Referral
ADGC	Alzheimer's Disease Genetics Consortium
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
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
ASPE	Office of the Assistant Secretary for Planning and Evaluation
AWV	Annual Wellness Visit
BMI	Body Mass Index
BPSD	Behavioral and Psychological Symptoms of Dementia
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CEAD	Center of Excellence for Alzheimer's Disease
CFPB	Consumer Finance Protection Bureau
CGEP	Comprehensive Geriatric Education Program
CHIP	Children's Health Insurance Program
CMCS	Center for Medicaid and CHIP Services
CMMI	Center for Medicare and Medicaid Innovation
CMP	Civil Monetary Penalty
CMS	Centers for Medicare & Medicaid Services
CMT	Contract Management Team
CNCS	Corporation for National and Community Service
COPE	Care of Persons with Dementia in their Environments
DCN	Dementia Caregiving Network
DFA	Dementia Friendly America
DICE	Describe, Investigate, Create and Evaluate algorithm
DNA	Deoxyribonucleic Acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DoL	U.S. Department of Labor
DSRTF	Down Syndrome Research and Treatment Foundation

eCQM	electronic Clinical Quality Measures
EHR	Electronic Health Record
eLTSS	electronic Long-Term Services and Supports
FDA	Food and Drug Administration
FFS	Fee-For-Service
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Dementia Degeneration
FY	Fiscal Year
GEC	Geriatric Education Center
GSA	Gerontological Society of America
GTPD	Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers
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
HMD	NAS Health and Medicine Division
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
ICD-9	International Classification of Diseases, 9th revision
ICD-10	International Classification of Diseases, 10th revision
ICRC	Integrated Care Resource Center
IDD	Intellectual and Developmental Disability
IHS	Indian Health Service
IMPACT Act	Improving Medicare Post-Acute Care Transformation Act
LBD	Lewy Body Dementia
LBDA	Lewy Body Dementia Association
LGBT	Lesbian, Gay, Bisexual, and Transgender
LTCO	Long-Term Care Ombudsman
LTSS	Long-Term Services and Supports
MCI	Mild Cognitive Impairment
MDH	Minnesota Department of Health
MDS	Minimum Data Set
MMP	Medicare-Medicaid Plan
MOOC	Massive Online Open Course
NADRC	National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer's Project Act
NAS	National Academies of Science, Engineering and Medicine
NCEA	National Center on Elder Abuse
NCHS	National Center for Health Statistics
NGO	Non-Governmental Organization

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
NQF	National Quality Forum
NSF	National Science Foundation
NYSDOH	New York State Department of Health
OASH	Office of the Assistant Secretary for Health
OCR	HHS Office of Civil Rights
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
PACE	Program of All-Inclusive Care for the Elderly
PCP	Person-Centered Plan
PET	Positron Emission Tomography
PHR	Personal Health Record
PQRS	Physician Quality Reporting System
PRARP	Peer Reviewed Alzheimer's Research Program
PRC	Prevention Research Center
QIO	Quality Improvement Organization
RDS	Research Down Syndrome
REACH	Resources for Enhancing Alzheimer’s Caregivers’ Health
RFA	Request for Application
RFI	Request for Information
ROAR	Recruiting Older Adults into Research
SAMHSA	Substance Abuse and Mental Health Services Administration
SASH	Support and Services at Home
SDM	Supported Decision Making
SSA	U.S. Social Security Administration
TAP	Tailoring Activities for Persons with Dementia and Caregivers
TBI	Traumatic Brain Injury
TCPI	Transforming Clinical Practice Initiative
VA	U.S. Department of Veterans Affairs
VCID	Vascular contributions to Cognitive Impairment and Dementia
VD-HCBS	Veteran-Directed Home and Community-Based Services
WDC	World Dementia Council
WHO	World Health Organization
WV CARES	West Virginia Coordinated Action, Response, Education and Support

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