National Plan to Address Alzheimer's Disease: 2020 Update

U.S. Department of Health and Human Services

National Plan to Address Alzheimer's Disease: 2020 Update

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Introduction

National Alzheimer's Project Act

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

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

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

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

Alzheimer's Disease and Related Dementias

Alzheimer's disease (AD) is an irreversible, progressive brain disease that affects as many as 5.5 million Americans.[1] It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living (ADLs) and self-care).[2] In 1906, Dr. Alois Alzheimer first documented the disease when he identified changes in the brain tissue of a woman who had memory loss, language problems, and unpredictable behavior. Her brain tissue included abnormal clumps (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles). Brain plaques and tangles, in addition to the loss of connections between neurons, are the main pathological features of AD.[3] However, other pathologic features occur commonly in the brain of older Americans diagnosed with AD and these are thought to also contribute to the burden of dementia in the United States.[3,4]

In addition to AD, this National Plan addresses Alzheimer's disease and related dementias (ADRD) consistent with the approach Congress used in NAPA. ADRD include frontotemporal dementia (FTD), Lewy body dementia (LBD), vascular contributions to cognitive impairment and dementia (VCID), and mixed dementias -- especially AD mixed with cerebrovascular disease or Lewy bodies. It is often difficult to distinguish between AD and ADRD in terms of clinical presentation and diagnosis. Some of the basic neurodegenerative processes have common pathways. Many people have the pathology of more than one type of dementia in their brains.[5] People with all 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/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.[4,6]

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.[4] 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-onset 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 2 decades. The Bureau of the Census estimates that the number of people age 65 and older in the United States will almost double, to 88 million by 2050. The prevalence of people with AD/ADRD doubles for every 5-year interval beyond age 65. Without a preventive treatment or cure, the significant growth in the population over age 85 that is estimated to occur between 2015 and 2050 (from 6.3 million to 19 million) suggests a substantial increase in the number of people with AD/ADRD.

Significant emotional, physical, and financial stress is placed on individuals with AD/ADRD and their family members. Unpaid caregivers, such as family members and friends, provide the majority of care for people with AD/ADRD in the community. Unpaid caregivers often do not identify themselves as such; they may be a wife, daughter, husband, parent, son, or friend helping a person whom they care about. However, the intensive support required for a person with AD/ADRD can negatively impact the caregiver's emotional and physical health and well-being, and their ability to work. Unpaid caregivers often report symptoms of depression and anxiety, and they have poorer health outcomes than their peers who do not provide such care.[6]

Dementia care costs are significant and often a burden to families and others providing unpaid care. Recent estimates from one nationally representative study found that paid and unpaid care costs for people older than age 70 with dementia in the United States in 2010 were between $159 billion and $215 billion. These figures include direct medical expenditures, costs for long-term services and supports (LTSS) including institutional and home and community-based services (HCBS), and two different estimates of the value of unpaid care provided by family members and friends. These costs could rise dramatically with the increase in the numbers of older adults in coming decades. Care costs per person with dementia in 2010 ranged from $75,000 to $83,000 depending on how unpaid care costs were estimated.[7] These national dementia care costs are comparable to, if not greater than, those for heart disease and cancer.[8]

Caring for people with the disease also strains health and long-term care systems. Individuals with AD/ADRD use a disproportionate amount of health care resources; for instance, they are hospitalized 2-3 times as often as people of the same age who do not have the disease.[9] Similarly, estimates from national data show that nearly seven out of ten residents in assisted living residences have some form of cognitive impairment.[10] As the number of people with AD/ADRD grows over the next 3 decades, these diseases will place a major strain on these care systems as well as on Medicare and Medicaid, the major funders of institutional, clinical care, and HCBS. Although Medicaid, a program for eligible low income Americans, covers long-term care such as nursing home care and HCBS, Medicare does not. Most Americans underestimate the risk of disability and the need for long-term care. More than half of older adults turning 65 today will develop a disability such as AD/ADRD serious enough to require LTSS, although most will need assistance for less than 2 years. About one in seven will have a disability for

more than 5 years. On average, an American turning 65 today will incur $138,000 in future LTSS costs. Families will pay about half of the costs themselves out-of-pocket, with the rest covered by current public programs and private insurance.[11]

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 known to definitively prevent, treat, or cure the diseases.

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

3. Family members and other unpaid caregivers, who take on the responsibility of caring for a loved one with AD/ADRD, also need services and supports. The majority of people with AD/ADRD live in the community, where their families provide most of their care. The toll of caregiving can have major implications for caregivers and families as well as population health, with about one-third of caregivers reporting symptoms of depression.[10,12]

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 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 legislation and authority. The

federal working group process continues to improve coordination and awareness throughout the Federal Government and set in motion commitments for further collaboration. Further, this process has allowed for identification of non-AD-specific programs and resources that may be leveraged to advance AD/ADRD care and prevention.

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

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

Goals as Building Blocks for Transformation

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

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

2020 Update

This is the 2020 Update to the National Plan. The activities outlined in this National Plan Update vary in scope and impact, and include:

- Immediate actions that the Federal Government has taken and that it should take.

- Actions toward the goals that can be initiated by the Federal Government or its public and private partners in the near term.

- Longer-range activities that would require numerous actions by federal and non-federal partners to achieve.

This is a National Plan, and active engagement of public and private sector stakeholders is needed to achieve the goals. In the case of many of the activities, the path forward will be contingent on resources, scientific progress, and focused collaborations across many partners. Over time, HHS will work with the Advisory Council and stakeholders to incorporate additional transformative actions.

This is the eighth Update to the National Plan. To see how Actions have progressed, changed, and expanded since 2012, see the side-by-side index at https://aspe.hhs.gov/report/national-plan-action-side-side.

New for 2020: COVID-19 Efforts

In 2020, the world is facing a global pandemic due to the outbreak of the Novel Coronavirus, COVID-19, a highly infectious disease. COVID-19 significantly complicates the health and safety of older adults, particularly those experiencing cognitive impairment, and their caregivers. Age, multiple chronic conditions, and disability are risk factors of greater morbidity and mortality due to COVID-19 making people with dementia one of the most at-risk groups. In particular, COVID-19 impacts people in congregate care facilities such as nursing homes where residents live in confined spaces and receive personal care from staff who support many residents. As of September 24, an estimated 80,193 people in long-term care facilities had died in 2020 due to COVID-19 accounting for at least 41% of all United States deaths.[13]

Even people who have not been infected with the COVID-19 virus face significant impacts. Widespread stay-at-home orders and closing of non-essential businesses have touched almost every community. People with dementia, their caregivers, health and LTSS providers, and the research community have all changed due to COVID-19. Increased depression, social isolation, self-neglect, falls, and excess mortality are among the non-COVID positive impacts of this pandemic on people with dementia. People with dementia and their caregivers have foregone health care out of fear of contracting COVID-19, and face challenges filling and managing prescriptions. The pandemic has also resulted in shortages and disruptions in nutrition and meal delivery services, which can result in food insecurity.[14]

Federal agencies, particularly those that are part of HHS and the Veterans Health Administration (VHA), have pivoted programs, policies, and activities to address the COVID-19 pandemic. Many of these changes are aimed at protecting people at risk of acquiring the virus, including people in nursing homes; ensuring access to health care and LTSS; addressing the impacts of stay-at-home orders such as social isolation and food insecurity; ensuring that research progress is not stalled; and, in the case of the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), discovering a vaccine through clinical trials to protect people from COVID-19. This section highlights some of the activities undertaken as of September 30, 2020, to address the COVID-19 pandemic and its impact on people with dementia and their caregivers.

Administration for Community Living

In response to the COVID-19 pandemic, the Administration for Community Living (ACL) received over $1.2 billion in funding from the Families First Act and Coronavirus Aid, Relief, and Economic Security (CARES) Act to support older adults across the nation. People living with dementia and their caregivers are benefiting from the additional resources made available through the COVID-19 pandemic funding. Both Families First and CARES Act funding provided resources for HCBS in support of caregivers, ombudsmen, nutrition programs, tribes and Centers for Independent Living. People living with dementia and their caregivers are interspersed within all of those populations targeted for additional resources during the public health emergency (PHE). The emergency Families First funding provided $250 million for nutrition services, the CARES Act funding resulted in $955 million in support of older adults and people with disabilities for HCBS including but not limited to $20 million to State Long-Term Care Ombudsman (LTCO) programs to purchase technology and hardware to expand their virtual presence in providing consumer advocacy services to residents of long-term care facilities.

At the onset of the COVID-19 pandemic, ACL had many active state and community-based projects dedicated to supporting persons living with dementia and their caregivers, as well as training professionals and communities in the delivery of dementia-capable supports and services. ACL was able to provide its grantee community with the flexibility to pivot within their approved program plans to adapt supports and services to continue supporting the members of their communities. ACL grantees are providing a broad range of services through their funded programs including, but not limited to, delivery of evidence-based and evidence-informed dementia-specific interventions for persons living with dementia and caregivers, geriatric

assessments, care transitions programs, adult day programs, caregiver support groups and memory cafés, The majority of the ACL-funded activities were designed and implemented with in-person protocols. As a result of the pandemic it became necessary for grantees to reconsider the manner in which their programs are delivered and the ways in which they could modify to remain engaged with the members of their community. In response to stay-at-home orders and with dedication to continuing to support their people, states and communities adapted their supports and services to allow them to remain engaged with the existing consumers of their programs, as well as continuing to take referrals. Telehealth protocols were put in place, virtual support groups and adult day activities sprung up across the nation. Programs protocols were adapted to increase responses to the needs of community members at risk of developing dementia, including those experiencing challenges related to isolation and loneliness. ACL provided venues for funded programs to collaborate on addressing challenges in service delivery, resulting in an increase in efficiency and innovations. As the COVID-19 challenges continue, grantees have a forum through which they can review the return to service provision. Those states and communities that are ahead of others, in terms of bringing people back to in-person programs, are able to share their experiences, so the others can prepare themselves for the road ahead. A key learning of the experience of the national shut down is that there are some services for persons living with dementia and their caregivers that can be provided virtually, without cost to the quality of services. The expectation is that when all in-person programs are able to resume, the new normal is likely to include hybrid programs that include both in-person and virtual opportunities.

For more information, see:
- https://acl.gov/COVID-19

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Office of the Assistant Secretary for Planning and Evaluation

The HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) is continuing its role of advising the Secretary of HHS on policy development throughout the COVID-19 pandemic. ASPE is analyzing data on COVID-19 and its impact, as well as conducting policy analyses to inform decision making on issues including health, disability, behavioral health, long-term care, and human services. ASPE is also tracking how the pandemic is affecting the health, long-term care, and human services systems, and policy changes implemented to address issues in these areas. For example, ASPE conducted a study of the impact of COVID-19 on the nursing home workforce, and the state and facility-level policy changes that have been implemented to mitigate the effects of the pandemic on this workforce.

ASPE has also supported response efforts in collaboration with other HHS agencies. ASPE staff have been deployed to the COVID-19 response team led by HHS leadership and the Federal Emergency Management Agency (FEMA), and have served on the Healthcare Resiliency Working Group and the Community Risk Mitigation Working Group. ASPE used state and federal data to calculate anticipated need for nutrition services and personal protective equipment (PPE), enabling FEMA to respond to those needs with greater accuracy and plan for future need. ASPE assisted the HHS Assistant Secretary for Preparedness and Response in developing the resources *FEMA/HHS Community Mitigation Task Force Sustaining Nutritional Needs for At-Risk Individuals and Information on Federal Programs to Sustain Nutrition for At-risk Individuals.*

For more information, see:
- https://www.phe.gov/emergency/events/COVID19/atrisk/Documents/sustaining-nutritional-needs-atrisk-individuals-v2.pdf
- https://www.phe.gov/emergency/events/COVID19/atrisk/Documents/Federal-Homelessness-Programs-v2.pdf

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Centers for Disease Control and Prevention

CDC is taking steps to proactively address issues arising from COVID-19 affecting persons with dementia and their caregivers. CDC's Alzheimer's Disease and Healthy Aging Program (AD+HAP) developed a dedicated COVID-19 webpage highlighting CDC's COVID-19 guidance for older adults. Since its launch in March 2020, there have been more than 250,000 page views through August 14. Content includes videos, fact sheets, infographics and health equity considerations for racial and ethnic minority groups. Resources are available in multiple languages. Videos are also available in American Sign Language. AD+HAP disseminates a weekly newsletter to more than 67,000 subscribers. It is a primary channel for disseminating information about COVID-19 web updates and webinars. AD+HAP continues to provide older adult Subject Matter Experts (SMEs) to the COVID-19 pandemic response in CDC's Emergency Operations Center.

For more information, see:
- https://www.cdc.gov/aging/index.html
- https://www.cdc.gov/aging/covid19-guidance.html
- https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/

CDC is also reaching and engaging the public and stakeholders through webinars, town halls, public messaging campaigns, and other outreach with partners. For example, CDC has worked closely with the Alzheimer's Association, AARP, state and local health departments, state offices of aging, and national clinician groups to share information on how older adults, persons with dementia, and caregivers can protect their communities. CDC is also collaborating on several projects to reduce social isolation and maintain mental health among older adults.

In addition, CDC older adult SMEs are addressing racial, ethnic, and age disparities in COVID-19 related health outcomes by developing and participating in webinars, collaborating with partners on culturally-relevant messaging and guidance, and reporting the most recent COVID-19 data to the public and health professionals. CDC older adult SMEs have participated in several highly attended webinars on topics such as best practices for contact tracing involving persons with cognitive impairment and their caregivers and how to plan for emergencies and other care needs among persons with dementia. Along with those living with dementia, SMEs developed guidance for Tribal Elders on social isolation, ways to reduce the spread of the virus, and ways to care for someone who contracted COVID-19.

CDC has also developed guidance and numerous documents for the public to keep persons with dementia and their caregivers safe from COVID-19. This guidance addresses how both formal and informal caregivers can maintain their own health and the health of the person with dementia for whom they are caring. Specific guidance was also developed to address COVID-19 circumstances in nursing homes, assisted living, and memory care units.

For more information, see:
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html
- https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-home-long-term-care.html
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/assisted-living.html
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/memory-care.html

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Centers for Medicare & Medicaid Services

Upon the declaration of COVID-19 as a national emergency in March 2020, the Centers for Medicare & Medicaid Services (CMS) took action to better serve Medicare, Medicaid, and Children's Health Insurance Program (CHIP) beneficiaries in its response to COVID-19. A crucial step was to increase flexibilities by issuing Section 1135 waivers, which waive various

administrative requirements to increase access to medical services during a disaster or emergency, and a declared PHE. CMS provided flexibilities to allow more telehealth and phone health delivery options and verbal orders, rather than written orders, for certain types of care. CMS also waived certain provider reporting requirements, Pre-Admission Screening and Annual Resident Review time requirements, discharge planning, advance directives, transfers, and other issues across a range of facility and provider types. The Medicaid program also provided flexibilities through Section 1115 demonstration waivers, Section 1915(c) Home and Community-Based Services Waivers (Appendix K), Disaster State Plan Amendments, and managed care options.

In May, CMS announced a COVID-19 transparency effort to keep nursing home residents safer during the PHE. Nursing homes are now required to inform residents, their families, and representatives of COVID-19 cases in their facilities. CMS also requires nursing homes to publically report cases of COVID-19 to the CDC. CMS publishes this information to the COVID-19 Nursing Home Data website so the public can view information on the cases and deaths among nursing home residents and staff in the 15,000 nursing homes reporting this data. On September 17, CMS published information about flexible visitation policies in nursing homes to help combat the impact of the pandemic on social isolation and mental health of residents and their families.

For more information, see:
- https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/
- https://www.cms.gov/files/document/qso-20-39-nh.pdf

CMS convened the Coronavirus Commission on Safety and Quality in Nursing Homes to comprehensively assess the nursing home response to the PHE. The Commission included representatives from states' Departments on Aging, various health care systems, and multiple provider associations and released a report in September 2020 that identified 26 recommendations to improve care. Some of these recommendations include updating cohorting guidance to better address mental health needs of both staff and residents, providing workforce hazard pay to staff, and improving upon health information technology (HIT) to better integrate nursing home data with that of other health care systems.

For more information, see:
- https://www.cms.gov/files/document/covid-final-nh-commission-report.pdf

CMS has also developed useful guidance for health care providers, health care facilities, labs, and LTSS providers on topics including telehealth, survey and certification, Medicare coverage, and Medicaid and CHIP coverage, among others. For example, the *Long-Term Care Nursing Homes Telehealth and Telemedicine Toolkit*, a memorandum on *COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes*, and a compilation of *COVID-19 Guidance and Updates for Nursing Homes during COVID-19*.

For more information, see:
- https://www.cms.gov/files/document/covid-19-nursing-home-telehealth-toolkit.pdf
- https://www.cms.gov/files/document/qso-20-31-all.pdf
- https://www.cms.gov/files/document/covid-guidance-and-updates-nursing-homes-during-covid-19.pdf
- https://www.cms.gov/about-cms/emergency-preparedness-response-operations/current-emergencies/coronavirus-waivers
- https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf
- https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/coronavirus-disease-2019-covid-19/index.html
- https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg

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Indian Health Service

Indian Health Service's (IHS) Tribal, and Urban Indian Health programs rapidly shifted care from in-person to telephone and video-based visits to limit risk of exposure of elders with dementia and other at-risk individuals to COVID-19. For example, the Chinle Service Unit deployed care coordinators with tablets to the homes of high-risk individuals in remote rural homes on the Navajo Nation to facilitate video-visits. The Uniting Tribal Nursing Homes in Excellence collaborative of Tribal LTSS programs has been meeting regularly to share tactics and approaches to maintain the health of their residents and staff, and limit risk of exposure to COVID-19, and presented on the CMS/ACL/IHS LTSS Webinar series hosted by the CMS Tribal LTSS Technical Assistance website. IHS and Tribal contact tracers, public health nurses, and community health representatives have worked with families to protect elders with dementia living in multi-generational homes from exposure.

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National Institutes of Health

As a national and global leader in biomedical research, NIH has played a critical role in COVID-19 response efforts, including those which assist persons living with and at risk for dementia. The NIH-Wide Strategic Plan for COVID-19 Research outlines strategic priorities for addressing the COVID-19 PHE, including key response efforts such as the Rapid Acceleration of Diagnostics (RADx^{SM}) initiative and the Accelerating COVID-19 Therapeutic Interventions and Vaccines public-private partnership. These initiatives seek to expedite the development of COVID-19 diagnostic tests and vaccines and therapeutics, respectively, speeding them to our nation's most susceptible populations, including older adults and individuals living with dementia. In addition to these efforts, NIH has also generated special funding opportunities called Notices of Special Interest (NOSIs) in response to the urgent research needs of the COVID-19 PHE. A complete list of these funding opportunities is available online.

For more information, see:
- https://www.nih.gov/sites/default/files/research-training/initiatives/covid-19-strategic-plan/coronavirus-strategic-plan-20200713.pdf
- https://www.nih.gov/research-training/medical-research-initiatives/radx
- https://www.nih.gov/research-training/medical-research-initiatives/activ
- https://grants.nih.gov/grants/guide/COVID-Related.cfm

At the institute level, the National Institute on Aging (NIA) issued its own NOSI in order to stimulate much-needed research on aging and COVID-19. The NIA NOSI is intended to support administrative and revision supplements on COVID-19 related topics in the realm of neuroscience and AD/ADRD research, aging biology, behavioral and social research, and geriatrics and gerontology. In addition, NIA has issued a funding opportunity for a COVID-19 clinical trial implementation grant on aging-related topics in at-risk older adult populations, including those with cognitive impairment and AD/ADRD. NIA is also co-sponsoring a variety of other COVID-targeted funding opportunities, such as those specific to the RADx Underserved Populations initiative, which seeks to enable and enhance COVID-19 testing in under-served and vulnerable populations (e.g., residents of nursing homes and assisted living facilities, individuals with cognitive impairment or dementia). More generally, NIA has provided support to its stakeholders and grantees throughout the COVID-19 PHE, including those who work in the field of AD/ADRD. This support has encompassed ongoing communications on COVID-19 related issues (e.g., March 27, April 8, and July 8 web updates, among others), outreach on federal COVID-19 resources for older adults, and flexibilities for grant applicants whose research has been affected by the pandemic.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-022.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-20-234.html
- https://www.nia.nih.gov/research/grants-funding/nia-covid-19-response
- https://www.nih.gov/research-training/medical-research-initiatives/radx/funding#radx-up
- https://www.nia.nih.gov/research/blog/2020/03/covid-19-adjusting-new-normal
- https://www.nia.nih.gov/research/blog/2020/04/new-funding-opportunities-join-fight-against-covid-19
- https://www.nia.nih.gov/research/blog/2020/07/data-harmonization-and-sharing-are-essential-covid-19-research
- https://www.nia.nih.gov/health/government-covid-19-resources-older-adults
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-033.html

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U.S. Department of Veterans Affairs

The U.S. Department of Veterans Affairs (VA) VHA National Geriatrics and Extended Care Program Office, as well as its individual programs, have provided guidance and trainings to support field staff and caregivers in a variety of settings to ensure the safety of both veterans and caregivers during this unprecedented time of COVID-19 pandemic. These efforts support all VA patients, including those living with dementia. For example, guidance limiting face-to-face visits between VA providers and veterans in Home-Based Primary Care (HBPC), Geriatric Patient Aligned Care Teams, and Medical Foster Homes (MFH) was provided early on and has been updated to reflect the varying stages of re-opening on a regional level. Guidance for increased virtual visits was provided that allowed multiple commercial applications to be used for communication with veterans and their caregivers, including FaceTime, Skype, and Zoom. Community Adult Day Health Care (CADHC) Service Plans were amended to enable, with state approval, supportive services for veterans in their homes in lieu of attendance at CADHC Centers. PPE use recommendations for in-home care was created for veteran caregivers based on general guidance from the CDC. MFH facilitated monthly calls to provide education on creating COVID-Specific Emergency Plans, admission planning, and COVID-19 testing in Community Residential Care settings. Additionally, all programs have held regular virtual meetings with local and VA Veterans Integrated Service Network program coordinators to provide an avenue for discussion of successes and challenges as well as sharing best practices. SharePoint sites were quickly created to allow sharing of documents, online links and other guidance to VA staff at all levels to ensure the continued safe care of our veterans.

In order to ensure the residents in the 134 VA Community Living Centers (CLCs, formerly known as VA Nursing Home Care Units) were protected, admissions were curtailed and staff were limited to only those essential to the care of the veterans. VA CLCs continued the practice of consistent staff assignment to help with minimizing the potential spread of COVID-19 and to promote this best practice that supports individuals with dementia as well as other residents. To protect the residents by reducing the probability of COVID-19 entering the CLCs, outpatient visits were cancelled unless medically necessary and appointments were facilitated using iPads. The VA Office of Connected Care provided additional iPads to connect CLC residents with family and friends. VA CLCs' quality improvement organization (QIO), called Community Living Centers' Ongoing National Center for Enhancing Resources and Training, helps CLCs share innovative practices for increasing meaningful engagement and reducing the impact of social isolation, which are particularly difficult for residents with dementia and others during this pandemic. VA CLCs are also participating in a 1-year COVID-19 research study begun in 2020 and funded by NIA. The overall study objective is to describe the differential impact of COVID-19 on nursing home residents with AD/ADRD versus those without AD/ADRD, on clinical presentation and COVID-19 testing, outcomes and spread.

VHA's 20 geriatric Centers of Excellence, called Geriatric Research, Education, and Clinical Centers (GRECC), reported that their FY 2020 work included 321 dementia activities in the areas

of research, education, and clinical demonstration projects. Of these GRECC dementia activities, 13% were directly related to COVID-19. Of the FY 2020 GRECC COVID-19 dementia activities, approximately 18% were research activities; 42% were education activities; and 40% were clinical demonstration project activities.

VHA has developed a wide range of other resources that are particularly relevant during the COVID-19 pandemic to support veterans with or without dementia, caregivers, and clinical and community leaders. VA Voluntary Service is leading an inter-office group to develop a Compassionate Contact Corps of volunteers to reach out to veterans via phone or video to reduce social isolation. VHA Office of Rural Health Dementia Caregivers Video Series provides helpful tips for handling many common caregiving challenges for those who are prevented from in-person support due to the pandemic. VA Caregiver Support Program developed an information sheet for caregivers during COVID-19. VA National Center for Post-traumatic Stress Disorder (PTSD) developed resources for managing stress during the pandemic, many of which are relevant for persons with dementia and/or their caregivers.

For more information, see:
- https://www.ruralhealth.va.gov/vets/resources.asp#dem
- https://www.caregiver.va.gov/
- https://www.caregiver.va.gov/pdfs/CSP-Caregiving-During-COVID-19_TipSheet-23April-2020.pdf#
- https://www.ptsd.va.gov/covid/index.asp
- https://www.publichealth.va.gov/n-coronavirus/

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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, they are 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.

Strategy 1.A: Identify Research Priorities and Milestones

Research agencies undertake research planning processes on an ongoing basis, but a special effort is needed to identify the priorities and milestones to achieve Goal 1. The actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders are involved in the planning process aimed at minimizing AD/ADRD as a health burden by 2025. During the course of this work, NIH and partner agencies will develop research priorities and a plan for implementing each phase of research in a coordinated manner.

(ONGOING) Action 1.A.1: Regularly convene an Alzheimer's disease research summit to update priorities

In the spring of 2018, the NIH *Alzheimer's Disease Research Summit 2018: Path to Treatment and Prevention* expanded on the research agenda set in place at the first two of such summits held in 2012 and 2015. The 2018 gathering brought hundreds of experts in AD and other chronic diseases together to identify critical knowledge gaps and set priorities across the AD/ADRD research community for the kinds of new resources, infrastructure, and multi-stakeholder partnerships needed to fully realize emerging research opportunities. NIH is committed to regularly updating its research priorities and planning is underway for an AD research summit in the spring of 2021.

For more information, see:
- https://www.nia.nih.gov/research/milestones
- https://www.nia.nih.gov/research/nih-ad-summit-2018-program-agenda

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(UPDATED) Action 1.A.2: Solicit diverse community input on Alzheimer's disease research priorities

National research summits (including the *Alzheimer's Disease Research Summit*, *Alzheimer's Disease-Related Dementias Summit*, and *National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers*, on a rotating basis) are held yearly to gather scientific input. These larger meetings take place in addition to smaller workshops, scientific gatherings, and requests for information which help gather community input. These contributions all factor into NIH's research plan for the 2025 goal, which is outlined as a series of research implementation milestones. These milestones and the accompanying milestone database are updated annually based on this diverse input. This planning process and its systematic updates have informed the research community about NIH's interests and priorities in funding projects in AD/ADRD. As of July 2020, the milestone database now includes better tracking of progress including success criteria and specific implementation activities.

For more information, see:
- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones
- https://www.nia.nih.gov/2020-dementia-care-summit
- https://www.nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018
- https://www.nia.nih.gov/research/milestones

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(**ONGOING**) Action 1.A.3: Regularly update the National Plan and refine Goal 1 strategies and action items based on feedback and input

HHS and its federal partners will use the diverse input received through the Research Summits on AD, ADRD, and now Care and Services to inform implementation of the National Plan. An updated Goal 1 will reflect the priorities, milestones, and timeline elements identified through these processes to accelerate research in this area. These will be incorporated into the next iteration of the National Plan and will be updated on an annual basis with the assistance of consensus advice from the Advisory Council.

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(**ONGOING**) Action 1.A.4: Update research priorities and milestones

To ensure that the research priorities and milestones reflect the broad input of the scientific community and the public, one Advisory Council meeting per year will be focused on this area. A relevant subcommittee focused on research or Goal 1 will collect input and recommend priorities and milestones for consideration by the Advisory Council as official recommendations. As appropriate, researchers in the field will also be invited to present at these meetings.

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(**ONGOING**) Action 1.A.5: Create a timeline with milestones for achieving Goal 1

Since the advent of the National Plan, NIH's planning process for research on AD/ADRD has expanded in inclusion and scope among NIH Institutes and Centers and stakeholders across the scientific and care communities. Hearing a diversity of expertise and opinions is critical to updating research recommendations based on an open review of scientific progress. It also ensures prioritization based on important scientific questions that must be answered to advance our understanding of these complex disorders and helps identify how federal and other public and private organizations can most effectively collaborate to address research priorities. Ultimately, information obtained through the various research summits results in the formation and/or update of implementation research milestones that set forth activities through FY 2025 to address the ultimate goals of the National Plan. The latest of these updates took place after the *Alzheimer's Disease Research Summit* in April 2018 and *Alzheimer's Disease-Related Dementias Summit* in March 2019.

For more information, see:
- https://www.nia.nih.gov/research/milestones
- https://www.nia.nih.gov/sites/default/files/2018-07/fy2020-milestones-chart.pdf

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(**UPDATED**) Action 1.A.6: Regularly convene an Alzheimer's disease and related dementias summit to review progress on research recommendations, and refine and add new recommendations as appropriate, based on recent scientific discoveries

The National Institute of Neurological Disorders and Stroke (NINDS) convened the third ADRD Summit on March 14-15, 2019. As in the past, researchers, clinicians, patients, caregivers, families, and advocates gathered to assess scientific progress and update research recommendations for the broad AD/ADRD scientific community. The Summit resulted in 47 new or refined recommendations to help guide future research in mixed dementias, VCID, FTD, and LBD as well as the broader cross-cutting areas of dementia nomenclature and AD/ADRD health

disparities. At this meeting, there was also a new session focused on emerging scientific topics: TAR DNA-binding protein 43 (TDP-43) pathology in common dementias and traumatic brain injury (TBI) as a risk factor for AD/ADRD. Many central themes characterized the Summit, including the pressing need for biomarkers (especially given the preponderance of mixed pathologies in dementia) and continued efforts to ramp up basic, clinical, and translational research. Participants also discussed ideas for enhancing health disparities research, strengthening research infrastructure and training, and developing a common nomenclature across the dementia research and practice communities. Final research recommendations from ADRD Summit 2019 were adopted by the NINDS Advisory Council in September 2019 and the NAPA Advisory Council in January 2020. Responding to the recommendations, NINDS released eight targeted funding opportunities in FY 2020 with several more planned in FY 2021.

For more information, see:
- https://www.ninds.nih.gov/sites/default/files/2019_adrd_summit_recommendations_508c.pdf
- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2019-prioritized-research-milestones
- https://www.ninds.nih.gov/News-Events/Events-Proceedings/Events/Alzheimers-Disease-Related-Dementias-Summit-2019

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(UPDATED) Action 1.A.7: Regularly convene a Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers

Following the success of the first Summit in 2017, the second National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers, hosted and sponsored by the NIA with support from contributors through the Foundation for the NIH, was planned for March 24-25, 2020, on the NIH main campus. The novel coronavirus pandemic and related physical distancing guidelines led NIA to cancel the in-person Summit and instead host a Virtual Summit Series on July 10, July 21, and August 13, 2020, with a virtual Twitter poster session on August 7, 2020. Recordings of the sessions are available on the Summit website. The research gaps and opportunities will be finalized in the fall of 2020 and made publicly-available in early 2021.

For more information, see:
- https://www.nia.nih.gov/2020-dementia-care-summit
- https://www.nia.nih.gov/2020-dementia-care-summit#Materials
- https://www.nia.nih.gov/research/summit-gaps-opportunities
- https://twitter.com/search?q=%23DementiaCareSummit&src=typeahead_click&f=live

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(ONGOING) Action 1.A.8: Create and implement a strategic plan for the Congressionally Directed Medical Research Programs Peer Reviewed Alzheimer's Research Program

The Congressionally Directed Medical Research Program (CDMRP) is a partnership between the U.S. Congress, the military, and the public to fund innovative and impactful research in targeted program areas. One of the CDMRP programs is the Peer Reviewed Alzheimer's Research Program (PRARP), which is specifically focused on understanding the relationship between TBI and dementia. In 2019, the PRARP will release an updated Strategic Plan that identified the high-impact research goals in the areas of TBIs and AD/ADRD. The Strategic Plan summarizes research funding and findings though the PRARP program since 2011, and identified short, medium, and long-term goals for the program.

For more information, see:
- https://cdmrp.army.mil/prarp/default

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(ONGOING) Action 1.A.9: Develop and administer a scientific landscape survey for the Congressionally Directed Medical Research Programs Peer Reviewed Alzheimer's Research Program

The CDMRP PRARP is administering a survey to the general public regarding future research directions for dementia subsequent to TBI. The survey requests input regarding future research directions for: (1) Basic and Translational science; (2) Quality of Life and Caregiving Research; and (3) Efforts regarding future pre-clinical and clinical research. Individuals or groups interested in participating in future surveys must register at eBRAP.org for updates from the PRARP. The survey response closes at the end of October 2019.

For more information, see:
- https://cdmrp.army.mil/prarp/pdfs/PRARP%20Survey%20For%20Distro_FY20.pdf
- https://ebrap.org/eBRAP/public/index.htm

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

HHS and its federal partners will expand clinical trials on pharmacologic and non-pharmacologic ways to prevent AD/ADRD and manage and treat its symptoms. The Federal Government will address the challenge of enrolling enough people in clinical trials who are representative of the country's population, including racial and ethnic populations that are at higher risk for AD/ADRD, through new partnerships and outreach. These actions will build on ongoing research focused on the identification of genetic, molecular and cellular targets for interventions and build on recent advances in the field.

(UPDATED) Action 1.B.1: Expand research to identify the molecular and cellular mechanisms underlying Alzheimer's disease and related dementias, and translate this information into potential targets for interventions

In the past year, NIA and NINDS have issued several funding opportunity announcements (FOAs) focused on research to help develop a better understanding of the growing list of genetic risk factors and molecular pathways that are involved in AD/ADRD. In response to these FOAs and investigator-initiated studies, researchers are developing a new generation of research tools to identify, explore, and validate a variety of targets with therapeutic potential. These sophisticated tools allow researchers to collect and integrate layers of biological data in novel ways -- opening the door to new insights into the origins and progression of AD/ADRD.

These new tools are also helping researchers gain a clearer picture of the complex underlying mechanisms of these devastating neurological disorders. They are leading to an understanding of the interplay among relevant molecules and systems, the relationship between amyloid and tau proteins, the role of immunity and inflammation, and the involvement of metabolic and cardiovascular pathways. This broader view of the basic biology of AD/ADRD could lead to potential breakthroughs. One type of tool that is critical for understanding what may be happening in the brains of patients is animal models. To fill the critical need for next-generation animal models for ADRDs, NINDS recently awarded several large grants under the "Development and Validation of Advanced Mammalian Models for ADRD" FOA in order to develop models for FTD, VCID, LBD, and mixed dementias/neurodegeneration.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-029.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-031.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-033.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-039.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-047.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-497.html

- https://grants.nih.gov/grants/guide/pa-files/PAR-18-516.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-544.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-760.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-070.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-071.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-167.html
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-013.html
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-19-010.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-016.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-025.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-040.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-041.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-19-510.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-19-511.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-013.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-015.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-026.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-027.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-030.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-039.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-004.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-005.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-003.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-006.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-007.html

A key part of NIH's strategy for developing new treatments for AD/ADRD is to bolster the translation of basic research discoveries into discovery and development of new drugs and devices for disease treatment and prevention. The length of time required for researchers to discover a biological mechanism of disease, such as a gene variant that does not function normally, and then develop an effective treatment without toxic side effects has been 12-15 years. Additionally, very few drug candidates or devices succeed through the pipeline to reach Food and Drug Administration (FDA) approval, because they are not found to be both safe and effective. To accelerate the discovery of effective treatments that will become broadly available to the public, NIH has developed programs to make data, knowledge, and research tools widely available to all researchers. Instead of competing with each other, stakeholders in industry, academia, and government are collaborating to reach a common goal: developing effective treatments for AD/ADRD.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-029.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-546.html
- https://grants.nih.gov/grants/guide/pa-files/par-18-820.html
- https://grants.nih.gov/grants/guide/pa-files/par-19-146.html
- https://grants.nih.gov/grants/guide/pa-files/par-19-147.html
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-014.html

Thanks to the substantial investment in AD/ADRD research over the past several years, NIH has increased its drug discovery efforts significantly. Of the many therapeutic programs supported by NIH for AD/ADRD, 10 have now matured through the pre-clinical development process and are currently being tested in humans in Phase I and Phase II clinical trials. These 10 new drug candidates target multiple aspects of the disease process including neuroinflammation, proteostasis (e.g., abnormal protein folding), neurogenesis, synaptic dysfunction, etc.

Established in 2019, TaRget Enablement to Accelerate Therapy development for Alzheimer's Disease (TREAT-AD) consortium is another recent addition to NIH-supported translational infrastructure established through the Alzheimer's Centers for Discovery of New Medicines. This $73 million enterprise has two translational centers with a common mission: to diversify and accelerate therapy development for AD/ADRD through the development of open source tools, reagents, and methods for robust validation of candidate targets delivered by Accelerating Medicine Partnership-Alzheimer's Disease (AMP-AD) and other target discovery programs and by integrating a set of novel targets into drug discovery campaigns. Each TREAT-AD center brings together world-class expertise in data science, computational biology, disease biology, structural biology, assay development, medicinal chemistry, pharmacology, and clinical research.

For more information, see:
- https://www.nia.nih.gov/news/nih-funded-translational-research-centers-speed-diversify-alzheimers-drug-discovery

NIH's Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs are an integral source of capital for early-stage United States small businesses that are creating innovative technologies to improve health. These programs help small businesses break into the federal research and development arena, create life-saving technologies, and stimulate economic growth. This funding also helps the private sector bring promising technologies to the consumer market. Through these programs, NIH is leveraging the economic engine of small businesses to enhance scientific innovation. Before the increased funding for AD/ADRD (2010-2013), NIA awarded 73 AD/ADRD SBIR/STTR grants to 59 small companies. After the increased appropriations (2016-2019), NIA approximately tripled that achievement by awarding 235 AD/ADRD SBIR/STTR grants to 168 companies for discovery and development of new treatments as well as biomarker research and technologies for improving care and caregiving.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-512.html
- https://grants.nih.gov/grants/guide/pa-files/pas-19-316.html
- https://grants.nih.gov/grants/guide/pa-files/pas-19-317.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-025.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-026.html

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(UPDATED) Action 1.B.2: Expand genetic epidemiologic research to identify risk and protective factors for Alzheimer's disease and related dementias

Another key component in the growing toolkit of precision medicine for AD/ADRD is the Alzheimer's Disease Sequencing Project (ADSP), an international resource of genetics data from multiple centers and studies. Launched in 2012, the ADSP is designed to promote innovative collaboration among scientists to provide genetic samples for sequencing with the goal of identifying from multi-ethnic populations new genetic variants that influence risk and protection from AD/ADRD. The NIA Genetics of Alzheimer's Disease Data Storage Site (NIAGADS) serves as the ADSP Data Coordinating Center. In 2017, NIA launched the ADSP Follow-Up Study, which aims to pursue rare variants in a range of different populations (e.g., African American, Hispanic, American Indian and Alaska Native [AI/AN], Asian). In keeping with the high priority that the AD/ADRD genetics community places on diversity, the ADSP has prioritized the study of ethnically diverse populations.

NIAGADS now hosts 72 human genetics datasets, with 91,633 samples and has a genomics database for cross-referencing and visualizing known genomic variants. All data generated by the ADSP is deposited into NIAGADS. As of August 2020, NIAGDAS has shared 4,789 whole-genomes and 20,504 whole-exomes to the research community and anticipates sharing an

additional 13,000 whole-genomes by the end of the year. Using data from NIAGADS and other repositories, scientists have been able to expand the number of known genetic risk factors for AD/ADRD, and several others are under investigation.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-16-205.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-16-406.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-17-214.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-234.html
- https://grants.nih.gov/grants/guide/pa-files/par-20-099.html
- https://www.niagads.org/
- https://www.niagads.org/adsp/content/home

In addition to ADSP, NIA has several ongoing FOAs that call for research to enhance the ability to uncover the genetic underpinnings of AD/ADRD, furthering our understanding of rare risk and protective variants. Today, thanks in part to the increased investment in AD/ADRD research, scientists have identified variants in more than 50 regions of the genome that may increase risk for the disease. Of these, variants in more than 23 individual genes have been linked to increased risk of late-onset Alzheimer's disease (LOAD). These genetic regions appear in clusters that point toward what may be highly relevant molecular pathways. By understanding key pathways, researchers may be able to develop prevention strategies and treatments for AD/ADRD.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-889.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-269.html

To advance further discovery for genetic factors and molecular pathways involved in FTD, NIH is also supporting the FTD Sequencing Consortium. This genetics consortium is composed of researchers at universities in the United States and at NIH who are utilizing whole-genome sequence technology to generate sequence for 4,000 autopsy-confirmed and clinical characterized FTD cases.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-18-082.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-017.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-003.html
- https://www.allftd.org/

Several new and ongoing clinical studies are seeking to determine risk profiles for ADRDs. For example, in late 2019 NINDS launched Determinants of Incident Stroke Cognitive Outcomes and Vascular Effects on Recovery, a large 6-year prospective clinical research study which aims to determine the specific subsets of stroke events that cause and do not cause cognitive impairment and dementia in post-stroke populations. The study includes a special focus on race and ethnic populations that experience dementia health disparities, as well as elucidating what additional clinical factors and co-morbidities synergize with stroke to result in cognitive impairment and dementia outcomes.

For more information, see:
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-013.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-013.html
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9918026&icde=51396638&ddparam=&ddvalue=&ddsub=&cr=5&csb=default&cs=ASC&pball=

In 2020, VA launched a new research partnership initiative with NIA for AD/ADRD called the "Alzheimer's Disease Veteran-Centric Alliance Network for HealthCare Excellence (AD-VANCE) initiative." The mission of AD-VANCE is to leverage partnerships to improve the health and care of veterans with AD/ADRD and the well-being of their caregivers. AD-VANCE is a formal name going forward for ongoing and planned VA-NIA collaborative activities on AD/ADRD. The inaugural major collaborative effort under the AD-VANCE initiative is the VA-NIA Genetics Initiative for Alzheimer's Disease. This collaboration leverages veterans' data from the VA Million Veteran Program (MVP) to understand genetic risk factors for AD/ADRD.

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(UPDATED) Action 1.B.3: Increase enrollment in clinical trials and other clinical research through community, national, and international outreach

Starting in 2016, with facilitation by the Alzheimer's Association and in close collaboration with experts from government, private, and academic sectors, NIA led an effort to develop comprehensive goals and strategies to enhance recruitment into clinical research, particularly focusing on underrepresented communities. To ensure broader input, NIA gathered feedback on the recruitment strategies through the IdeaScale crowdsourcing platform. These efforts resulted in the *National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research*, which was presented at the NAPA Advisory Council meeting in October 2018.

For more information, see:
- https://www.nia.nih.gov/research/recruitment-strategy

In 2019, NIA launched Alzheimer's and Dementia Outreach, Recruitment, and Engagement Resources (ADORE), a searchable collection of materials designed to support recruitment and retention into clinical trials and studies. ADORE stems from the National Strategy and represents some of the materials and activities that Alzheimer's Disease Research Centers (ADRCs), NIA and the broader NIH, and other organizations have developed to engage people in research. In addition, NIA developed several collateral materials to include in ADORE, including a recruitment planning guide, a series of testimonial videos, and an easy-to-read booklet to promote older adult research participation. NIA is currently developing a web-based communication tool that will enable health care professionals in the community to easily produce a "package" of tailored materials and strategies that can be branded locally to increase participant recruitment for clinical studies. This web-based tool will allow the research community to access, adapt, and personalize the materials described above that NIA has developed for underrepresented communities.

For more information, see:
- https://www.nia.nih.gov/research/adore
- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources

NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through its Alzheimer's Disease and Related Dementias Education and Referral (ADEAR) website portal; clinical trials listing and monthly e-alert to more than 16,000 subscribers; social media messages through Facebook and Twitter; infographics; presentations; promotion of ADORE materials; and collaboration with other federal agencies and advocacy organizations to encourage research participation among older adults, including through the Focus on Aging interagency webinar series. All materials are drafted in plain language formats for ease of communications.

For more information, see:
- https://www.nia.nih.gov/news/focus-aging-federal-partners-webinar-series

Tracking the enrollment and recruitment performance of AD/ADRD clinical studies is a priority. NIA is currently investing in the expansion of its clinical trial data infrastructure to more

seamlessly track enrollment to NIA-funded clinical studies with the goal of proactively supporting recruitment needs across the breadth and scope of NIA's portfolio.

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

Additionally in 2018, NIA released an FOA -- Examining Diversity, Recruitment and Retention in Aging Research (PAR-18-749) -- to encourage building new, collaborative teams to target gaps in recruitment and retention methods and outcomes, as well as establishing the community infrastructure needed to accelerate studies. This FOA will be active until January 26, 2021.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html

In 2020, the VA is one of the recruitment networks for the NIA-funded Pragmatic Evaluation of Events And Benefits of Lipid-lowering in Older Adults (PREVENTABLE) trial, which aims to determine whether statin can prevent dementia and disability in addition to heart disease and other cardiovascular-related deaths. The VA Cooperative Studies Program (CSP) Pharmacy Coordinating Center serves as the central pharmacy for the trial to distribute medications to study participants.

For more information, see:
- https://www.defensemedianetwork.com/stories/va-research-the-va-and-clinical-trials-veterans-affairs/
- https://www.trialsitenews.com/nia-invests-90m-into-preventable-study-determining-the-benefits-of-statins-atorvastatin-in-the-elderly-with-duke-and-wake-forest-leading-the-effort/
- https://dcri.org/preventable/

In 2019, the Health Resources and Services Administration's (HRSA) Geriatrics Workforce Enhancement Program (GWEP) Notice of Funding Opportunity included language calling for applicants to describe how they would educate and train patients, families, caregivers, direct care workers, health care providers, and health professions students, faculty, residents, and fellows on when it is appropriate to recruit older adults into research.

For more information, see:
- https://bhw.hrsa.gov/fundingopportunities/default.aspx?id=4c8ee9ff-617a-495e-ae78-917847db86a9

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(UPDATED) Action 1.B.4: Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer's disease and related dementias studies

See Action 1.B.3 for updates regarding the *National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research* released in fall 2018. This strategy includes approaches to increase enrollment of racial and ethnic minorities in AD/ADRD studies as recommended by the National Strategy Group's Local, Diverse Working Group and outlined in the *Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide*.

For more information, see:
- https://www.nia.nih.gov/research/recruitment-strategy
- https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf

In April 2018, NIA released a new FOA -- Examining Diversity, Recruitment and Retention in Aging Research (PAR-18-749) -- to encourage building new, collaborative teams to target gaps in recruitment and retention methods and outcomes, as well as to establish the community infrastructure needed to accelerate recruitment. This FOA remains active. Another active FOA

encourages applications that examine mediators of disparities in AD/ADRD, using diverse cohorts of subjects with a focus on strategies for recruitment and retention in clinical trials. In addition to disparities-focused initiatives, NINDS has now issued several clinical research FOAs which require investigators to apply their research questions to at least two populations of study.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-012.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-013.html

Additionally, the National Institute on Minority Health and Health Disparities (NIMHD) has begun a new clinical trial on "Addressing the Knowledge and Recruitment Gap in Alzheimer's Disease and Precision Medicine among Native People". An innovative pragmatic Randomized Controlled Trial with 4,000 AI/AN enrollees. This study will evaluate recruitment strategies for AI/AN and proposes several specific aims: create culturally tailored materials on AD/ADRD and Precision Medicine (PM) (phase 1); evaluate the clarity and acceptability of the materials and their effect on completion of the AD-PM Module in a randomized controlled trial and subsequent enrollment into an AD-PM cohort (phase 2); identify patient-level predictors of enrollment; and evaluate potential differences in the effectiveness of recruitment approach by age, sex, education, cultural identity, and rurality (phase 2).

For more information, see:
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9570695&icde=41152371&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball=
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-047.html
- https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=15EEC10D4C8DC5D37598B8961CAA4A01A2FFCEB861BF

The NIA-supported Alzheimer's Clinical Trials Consortium (ACTC) also aims to develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations, and establish a new minority outreach and recruitment team. This clinical trials network with 35 United States sites will develop, harness, and deploy the best practices and latest methods for the conduct of AD/ADRD trials.

For more information, see:
- https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias

NIA also supports 31 ADRCs at major medical institutions across the United States. Researchers at these ADRCs are working to translate research advances into improved strategies for prevention, diagnosis, treatment, and care for people living with AD/ADRD. Although each ARDC has its own area of emphasis, the ADRCs also enhance research on AD/ADRD via a network approach that encourages the exchange of new research ideas and approaches as well as data, biological samples, and genetic information. The ADRCs also enhance and promote diversity of research participants. For example, the ADRCs have set up a Latino interest group that includes a listserv for Latino researchers and those with an interest in research with Latino participants, and issues specific to Spanish language assessment. This group is helping to ensure that materials are available in Spanish, addressing the needs of Spanish speaking participants, and assuring research capacity (with both materials and staff training) for assessment in Spanish. In addition to Spanish, assessments at ADRCs have also been translated into Chinese. To enhance the model further, in 2019, NIA launched a funding opportunity for Exploratory ADRCs. These new exploratory centers will expand the geographic, scientific and population diversity of both researchers and participants in the overall ADRC network.

For more information, see:
- https://www.nia.nih.gov/research/adc
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-20-023.html
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6249084/

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(UPDATED) Action 1.B.5: Conduct clinical trials on the most promising pharmacologic interventions

Most of the NIH-supported drug trials for AD/ADRD are in an early stage, which means Phase 1 or Phase 2 trials, but several Phase 3 trials are also in progress. With each successive phase, a longer period of time and more participants are needed to conduct the study. A number of NIA's large, late-stage clinical trials, which primarily target amyloid, will be complete before 2025. While the lack of success in multiple amyloid trials is disappointing, it is not uninformative; AD/ADRD researchers continue to learn from each unsuccessful study. Moreover, NIA supports a diverse set of intervention targets (neurotransmitter receptors, cell metabolism, vasculature, growth factors, etc.); amyloid is only one of those targets. Of the almost 50 pharmacological trials supported by NIA, most investigate targets other than amyloid.

Launched in 2017, a new clinical trials consortium funded by NIA is expected to accelerate and expand studies for therapies in AD/ADRD. The new NIA-funded ACTC will develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations, and establish a new minority outreach and recruitment team. ACTC is a "next-generation" infrastructure designed to harness best practices and latest methods for AD trials.

The ACTC's design allows rapid start-up of clinical trials and provides infrastructure and support in areas such as imaging, biostatistics, data management, and recruitment. It also requires and supports sharing of data and biosamples. With the current funding announcement, NIH anticipates applications to develop and implement Phase I-Phase III clinical trials that would use ACTC coordination and management for promising pharmacological and non-pharmacological interventions.

For more information, see:
- https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html

In addition to the ACTC infrastructure, NIH currently sponsors approximately 200 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD. NIH also released several FOAs specifically focused on clinical trials for AD/ADRD. These include pharmacologic as well as lifestyle interventions.

For more information, see:
- https://www.nia.nih.gov/research/ongoing-AD-trials
- https://grants.nih.gov/grants/guide/pa-files/par-18-877.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-878.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html

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(UPDATED) Action 1.B.6: Continue clinical trials on the most promising lifestyle interventions

See Action 1.B.5 for updates regarding the ACTC and ongoing clinical trials supported by NIA. Over 100 of the approximately 230 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD investigate non-pharmacological interventions including testing lifestyle factors such as diet and exercise. NIA has also released FOAs specifically focused on clinical trials for AD/ADRD.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html
- https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias
- https://www.nia.nih.gov/research/ongoing-AD-trials

Findings from a related clinical trial called Intensive Versus Standard Ambulatory Blood Pressure Lowering to Prevent Functional Decline in the Elderly (INFINITY) were consistent with the SPRINT MIND results. The INFINITY trial indicated that, after 3 years of treatment, intensive lowering of blood pressure slowed white-matter disease in adults age 75 and older with high blood pressure.

For more information, see:
- https://www.nia.nih.gov/news/intensive-blood-pressure-control-slowed-white-matter-disease-adults-age-75-and-older

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(UPDATED) Action 1.B.7: Expand research focused on needs related to the intersection of Down syndrome and Alzheimer's disease and related dementias

The FY 2018 omnibus appropriations report provided NIH with the opportunity to not only expand its current efforts on Down syndrome and AD/ADRD, but to build an integrated effort across NIH that will be truly transformative in this area and other commonly co-occurring conditions in individuals with Down syndrome. The INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) project was launched in June 2018 in support of a congressional directive. INCLUDE focuses on three overall goals: (1) conducting targeted, high-risk, high-reward basic science studies on chromosome 21; (2) assembling a large study population of individuals with Down syndrome; and (3) including individuals with Down syndrome in existing clinical trials.

In FY 2018, NIH spent almost $23 million to jump-start INCLUDE via administrative supplements, including one focused on creating an AD clinical trial network for adults with Down syndrome. This network, the Alzheimer's Clinical Trial Consortium-Down Syndrome Network (ACTC-DSN) aims to utilize the existing depth and breadth of expertise across its ACTC infrastructure to conduct AD clinical trials in adults with Down syndrome. The overarching goal of the project is to build an efficient clinical trial network to address the critical need for treatment of AD in adults with Down syndrome. In FY 2019, through the INCLUDE project, a project focused on clinical trials to prevent Alzheimer's Disease in Down syndrome was funded.

For more information, see:
- https://www.nih.gov/include-project
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9749625&icde=46135063&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9893363&icde=46762199

NIA and National Institute of Child Health and Human Development (NICHD) have been funding an Alzheimer's Biomarker Consortium -- Down Syndrome since 2015, which aims to identify biomarkers that indicate AD is developing or progressing and track the AD process in people with Down syndrome. NIA is also funding a Phase I clinical trial to investigate the safety and tolerability of an immunotherapy vaccine for treatment of AD in adults with Down syndrome.

For more information, see:
- https://www.nia.nih.gov/research/abc-ds
- https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx

NIA and NICHD have also collaborated to produce and disseminate information for people with Down syndrome and their families regarding the interplay of Down syndrome and dementia, and the importance of participating in research. Efforts include a fact sheet, *Alzheimer's Disease in People with Down Syndrome*, and outreach via email and social media.

For more information, see:
- https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome

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(ONGOING) Action 1.B.8: Issue a joint Department of Veterans Affairs/National Institute on Aging career development award for physician scientists new to the area of dementia research

In FY 2020, the VA received several research proposals in response to the early career physician-scientist mentored research in AD/ADRD funding announcement. Funds have been committed to supporting the meritorious awards. This program has been approved for another year.

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(ONGOING) Action 1.B.9: Expand research for care and support of individuals with cognitive and behavioral symptomatology related to both traumatic brain injury and dementia

The CDMRP PRARP has continued to offer two funding opportunities to support research focused on robust, patient-centered approaches to address cognitive and behavioral symptomatology common to TBI and dementia. The Innovations in Care and Support Award (InCASA) mechanism was offered for the first time for the CDMRP PRARP in 2019. The InCASA supports innovative research that improves the quality of life and care for individuals living with the common symptoms of TBI and/or AD/ADRD and/or their families and care providers. For this funding opportunity, applicants were encouraged to propose work that should challenge existing research paradigms, or exhibit high levels of creativity. The Research Partnership Award (RPA) mechanism was also offered as a multi-partnered funding opportunity. The RPA requires partners from diverse backgrounds to come together and work on a project that neither individual investigator alone could achieve. Applications to this mechanism were required to demonstrate long and short-term benefits of their projects. Applications to the RPA were also required to show how the efforts will ultimately benefit individuals affected by AD/ADRD, their caregivers, and their families.

For more information, see:
- https://cdmrp.army.mil/funding/archive/prarparchive

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

Significant advances in the use of imaging and biomarkers in brain, blood, and spinal fluid have made it possible to detect the onset of AD/ADRD and track its progression, with the hope that it will be possible to monitor the effect of treatment in people with the disease. Without these advances, these neurodegenerative processes could only be evaluated in non-living tissues. Accelerated research will improve and expand the application of biomarkers in research and practice. These advances have shown that the brain changes that lead to AD/ADRD begin up to 10 years before symptoms. Identifying imaging and other biomarkers in presymptomatic people will facilitate earlier diagnoses in clinical settings, as well as aid in the development of more efficient interventions to slow or delay progression.

(UPDATED) Action 1.C.1: Identify imaging and biomarkers to monitor disease progression

The Alzheimer's Disease Neuroimaging Initiative (ADNI) has contributed to much progress in neuroimaging and biomarker refinement. ADNI, a long-running, NIH-supported study, was designed to develop tools for clinical trials by tracking how neuroimaging and fluid biomarkers change with disease onset and progression. Launched by NIH in 2004, this landmark public-private partnership looks at how the evolution of clinical symptoms and neurocognitive testing in healthy controls, people with mild cognitive impairment (MCI), and people with mild AD correlates with changes in multiple biomarkers reflecting disease development. The biomarkers developed and validated in ADNI are being used more and more in clinical trials. ADNI has also pioneered rapid, transparent data-sharing while protecting participants' privacy. Qualified researchers across the world can access ADNI brain scan images and biomarker data through a web-based portal as soon as data are quality-controlled and added to the database. ADNI also shares the blood, cerebrospinal fluid, and DNA it has collected with other investigators who are developing novel biomarkers. Now in its 16th year, the three phases of ADNI (ADNI1/GO, ADNI2, and ADNI3) have developed biomarkers for use in selecting clinical trial participants and for assessing treatment outcomes. When ADNI3 was launched in 2016, ADNI data had already been downloaded for research purposes more than 11 million times, and scientists had used ADNI data to publish more than 1,200 scientific papers.

For more information, see:
- http://adni.loni.usc.edu/

Additionally, the AMP-AD Biomarkers Project, a public-private partnership, is exploring the utility of tau PET imaging and novel fluid biomarkers for tracking response to treatment and/or disease progression. Under the Biomarkers Project, NIA-supported, Phase II/III secondary prevention trials are testing several anti-amyloid therapies. Through the AMP-AD partnership, imaging and fluid biomarker tests already included in these trials will be supplemented with tau PET imaging and novel fluid biomarkers. Screening and baseline data from the trials will be made broadly available through the Global Alzheimer's Association Interactive Network collaborative platform. Trial data and biological samples will also be shared after the trials are completed.

For more information, see:
- https://www.nia.nih.gov/research/amp-ad
- https://amp-pd.org/

In 2019 and early 2020, NIH-supported scientists reported advances in the development of blood-based tests that could enable rapid screening of volunteers who wish to enroll in studies. Using a blood test to screen would reduce the number of research volunteers who undergo brain PET imaging or spinal taps, which are expensive and invasive. For now, these blood tests can be used only by researchers in clinical research studies. It is likely that eventually FDA-approved tests will be made available to physicians, enabling them to screen their patients for AD/ADRD before symptoms appear. In addition to blood tests, other NIH-supported research projects are designed to look beyond current measures to identify people with dementia earlier in the disease process.

These include changes in vision and pupil responses that may signal Alzheimer's, or a combined decline in memory and walking speed as a sign of dementia.

For more information, see:
- https://www.nia.nih.gov/news/nia-small-business-funding-seeks-find-blood-based-diagnostic-alzheimers-disease
- https://www.nia.nih.gov/news/blood-test-shows-promise-predicting-presymptomatic-disease-progression-people-risk-familial
- https://www.nia.nih.gov/news/blood-test-method-may-predict-amyloid-deposits-brain-potentially-indicating-alzheimers-disease
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html

To enable better patient stratification, diagnosis, and tracking of disease progression in LBD, FTD, VCID, and dementias with mixed etiologies, NINDS has released several funding opportunities to support the development of biomarkers, including imaging ligands, for ADRD. For example, NINDS and NIA co-manage an integrated research consortium called ALLFTD, which is conducting detailed natural history studies of FTD, ultimately aimed at developing sensitive clinical assessments and biomarker tools for future use in FTD clinical trials. Specifically, the consortium aims to find the best biomarkers, such as MRI neuroimaging and blood biomarkers, to track disease burden and develop ways to calculate and predict risk of worsening symptoms. NINDS also recently launched the Center Without Walls (CWOW) for PET Ligand Development for ADRDs -- this consortium is applying cryo-electron microscopy to visualize, at atomic-level resolution, the structures of protein aggregates found in several ADRDs. These highly detailed structures will then be used to design and validate sensitive PET imaging probes in order to better "see" differing ADRD disease pathologies in patients. Such PET markers should enhance differential dementia diagnosis and serve as markers of disease progression in future AD/ADRD clinical trials. NIH is also continuing to support five research teams that aim to discover biomarkers that will improve the efficiency and outcome of Phase II clinical trials for LBD. In the past year, the Accelerating Medicine Partnership for Parkinson's Disease (AMP-PD) has added data and samples from patients with LBD. This public-private partnership is conducting deep molecular characterization and longitudinal clinical profiling of Parkinson's disease and LBD patient data and biosamples with the goal of identifying and validating diagnostic, prognostic and/or disease progression biomarkers.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-18-082.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-170.html
- https://grants.nih.gov/grants/guide/pa-files/PAS-19-210.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-022.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-016.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-014.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-012.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-014.html

NIH continues to support a small vessel VCID Biomarkers Consortium (MarkVCID) to develop and validate candidate human biomarkers for small vessel disease in the brain that would enable more accurate identification of those at-risk for long-term cognitive decline and tracking of disease progression in individuals already affected by cognitive impairment and dementia. Several biomarker kits have been developed and preliminarily validated -- these kits will soon move into Phase 2 testing for use in high thru-put clinical trials.

For more information, see:
- https://markvcid.partners.org/

In addition to these large initiatives, NIA and NINDS have released FOAs in the past year that call for research to further the development of imaging and biomarker research.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-017.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-21-001.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-026.html

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(UPDATED) Action 1.C.2: Maximize collaboration among federal agencies and with the private sector

NIH engages in multiple partnership opportunities with the private sector and other federal agencies to facilitate collaborative efforts across the entire AD/ADRD research landscape. ADNI, AMP-AD, and AMP-PD discussed above, are three large examples of these partnerships.

For more information, see:
- http://adni.loni.usc.edu/
- https://amp-pd.org/
- https://www.nia.nih.gov/alzheimers/amp-ad

Another example is the Collaboration for Alzheimer's Prevention (CAP). CAP is a public-private partnership that brings together research groups to harmonize biomarker, clinical, and cognitive measures and align data-sharing and sample-sharing approaches used in certain trials so that findings can inform the entire research community. CAP includes researchers from three trials co-funded by NIH, industry, and foundations: the Alzheimer's Prevention Initiative, the Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease study, and the Dominantly Inherited Alzheimer Network Trials Unit. Collaborative efforts like CAP provide an effective platform for implementation of AD research standards and advancing AD prevention research with rigor, care, and maximal impact.

For more information, see:
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847536/
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5111162/

Tau Center Without Walls (Tau CWOW) is a multi-center, interdisciplinary program that was established in FY 2016 to investigate the molecular mechanisms of tau toxicity in FTD. One of the requirements of this program is to have ongoing collaborative partnerships with non-profit, non-governmental organizations and philanthropic entities, such as Association for Frontotemporal Degeneration (AFTD), CurePSP, and the Rainwater Charitable Foundation.

For more information, see:
- http://tau-center-without-walls.org/
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-023.html

Also, the International Alzheimer's and Related Dementias Research Portfolio (IADRP) facilitates the tracking of research support in the public and private sectors, including the initiatives mentioned above.

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

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

In order to facilitate communication and collaboration, build synergy, and leverage resources, it is imperative that research across nations and across funders be coordinated. The actions below will formalize the coordination process beyond HHS and the Federal Government and make research available to the public for input.

(UPDATED) Action 1.D.1: Inventory Alzheimer's disease and related dementias research investments

IADRP -- a free, searchable database providing a global overview of AD/ADRD research and funding -- is an invaluable tool for assessing and planning AD/ADRD 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 information on over 10,000 unique projects from 2008 through 2020, reflecting more than $8 billion in research funding worldwide. The number of contributors is growing, too. During the past 5 years, more than 40 funding organizations across greater than 10 countries have joined the IADRP effort.

In 2018, the IADRP database was relaunched with several changes to the Common Alzheimer's Disease Research Ontology (CADRO), including greater specificity in the coding of FTD, LBD, and VCID. Additionally, users can now link research to related clinical trials, patents and data repositories, as well as visualize search results with dynamic charts and graphs.

For more information, see:
- https://iadrp.nia.nih.gov
- https://iadrp.nia.nih.gov/about/cadro

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(UPDATED) Action 1.D.2: Expand international outreach to enhance collaboration

In collaboration with the European Union (EU) Joint Programme -- Neurodegenerative Research (JPND), NIH is participating in the upcoming EU mapping exercise that invites 20+ countries to submit their recently funded neurodegenerative research. This exercise will serve as a platform for increased collaboration among international dementia researchers and funding organizations.

For more information, see:
- http://www.neurodegenerationresearch.eu/initiatives/mapping-excercise/data-collected/
- https://www.neurodegenerationresearch.eu/wp-content/uploads/2018/07/JPND-Mapping-Exercise-Report-28Final2912072018.pdf

Additionally, NIA participated in the Alzheimer's Disease Funders' meeting held during the 2020 Alzheimer's Association International Conference (AAIC), as well as quarterly international funders' calls led by the Alzheimer's Association. Also, IADRP, maintained by NIA, includes data from over 40 public and private funding organizations across more than 10 countries and is publicly-available for use.

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

The NIA-supported Health and Retirement Study (HRS): Harmonized Cognitive Assessment Protocol (HCAP) project is an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide. The primary aim of the HRS, funded by NIA and the Social Security Administration (SSA), is to collect and distribute multi-disciplinary data for research on aging. To provide the research community with new and richer data to study the prevalence, predictors, and outcomes of cognitive impairment and dementia, NIH first supported

HCAP during the HRS's 2016 field period, in which investigators administered a supplemental in-home, 1-hour battery of cognitive tests to 3,496 randomly selected HRS respondents age 65 and older, along with a 20-minute informant interview. The data from that 2016 assessment have now been made publicly-available to the scientific community, and analyses are underway. A second wave of HCAP assessment was scheduled for 2020 but was postponed due to the COVID-19 pandemic.

For more information, see:
- https://grants.nih.gov/grants/guide/pa-files/PAS-17-028.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-016.html
- https://hrs.isr.umich.edu/welcome-health-and-retirement-study
- https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9618704&icde=42939202
- https://projectreporter.nih.gov/project_info_description.cfm?aid=10003934&icde=51152035&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball=
- https://projectreporter.nih.gov/project_info_description.cfm?aid=10017122&icde=51152035&ddparam=&ddvalue=&ddsub=&cr=3&csb=default&cs=ASC&pball=
- https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology
- http://hrsonline.isr.umich.edu/index.php?p=shoavail&iyear=ZU&_ga=2.3082800.1242911673.1556821900-1050997585.1555960426

HCAP is also being administered in other developed and developing countries, where HRS-like representative population surveys are conducted, including China, England, India, Mexico, South Africa, and parts of the EU. To date, the data from England and Mexico have been publicly released, and initial data release from China and India is expected by the end of 2020.

For more information, see:
- http://www.mhasweb.org/Data.aspx

In 2019, the NIA funded a research network to support the continued harmonization of the HCAP studies and a related project focused on harmonizing cognitive assessments in Irish, English, and American longitudinal studies to support cross-national research on the epidemiology of dementia.

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(UPDATED) Action 1.D.3: Identify research priorities via surveys tracking health conditions and risk factors

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, ongoing telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. It is conducted by all states under the direction of CDC with state public health authorities. There are two optional modules that states can include in their annual BRFSS survey on the topics of caregiving and cognitive decline. The Caregiver Module from 2015 to 2018 has been administered in 44 states, the District of Columbia, and Puerto Rico; while the Cognitive Decline Module was administered in 50 states, the District of Columbia, and Puerto Rico in 2015-2016. Collecting and analyzing this data allows the study of burden, impact, and trends and is used by decision makers to decide course of action for research as well as interventions. In August 2020, CDC released a Technical Assistance Document for both the Caregiving and Cognitive Decline modules designed to assist data users through the analytic process. The data are available in a searchable data portal, data briefs, and infographics with national estimates, by state, sex, rural status, veteran status, and race/ethnicity.

For more information, see:
- https://www.cdc.gov/aging/publications/BRFSS-caregiver-brief-508.pdf
- https://www.cdc.gov/aging/agingdata/index.html
- https://www.cdc.gov/aging/data/index.htm
- https://www.cdc.gov/aging/healthybrain/brfss-faq.htm
- https://www.cdc.gov/aging/publications/briefs.htm
- https://www.cdc.gov/brfss/index.html

Cognitive Performance and Subjective Cognitive Decline (SCD) are included on the National Health and Nutrition Examination Survey (NHANES). NHANES is designed to assess the health and nutritional status of adults and children in the United States. Conducted since 1960, the survey includes both interview and physical examination components. The survey examines a nationally representative sample of about 5,000 persons each year. The NHANES interview includes demographic, socioeconomic, dietary, and health-related questions. The examination component consists of medical, dental, and physiological measurements, as well as laboratory tests administered by highly trained medical personnel.

For more information, see:
- https://www.cdc.gov/nchs/nhanes/
- https://wwwdev.cdc.gov/nchs/nhanes/

Data on Cognitive Performance and SCD in adults aged 60 years and older were collected from 2011-2014. Assessments conducted included:
- SCD;
- 10-item word list learning with both immediate and delayed recall;
- Animal Fluency; and
- Digit Symbol Substitution.

NHANES Cognitive Performance and SCD data from 2011-2014 are publicly accessible and available at the NHANES website. All data for cognitive performance can be found under Questionnaire Data. SCD data are in the Medical Conditions data file, and data for the cognitive functioning assessments are in the Cognitive Functioning data file. For an example of an analysis conducted using these data and a more detailed description of NHANES and the cognitive variables are available in an online article.

For more information, see:
- https://wwwdev.cdc.gov/nchs/nhanes/
- https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf

Data on Cognitive Performance and SCD in adults aged 60 years and older were collected from 2019-2020. Assessments conducted included:
- SCD; and
- Montreal Cognitive Assessment (MoCA).

NHANES Cognitive Performance and SCS data from 2019–2020 are anticipated to publicly accessible and available at the NHANES website in 2021.

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

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

Currently, promising research and interventions are published in the research literature and presented at scientific meetings. Additional steps are needed to highlight promising findings and to facilitate dissemination and implementation of effective interventions to the general public, medical practitioners, the pharmaceutical industry, and public health systems, quickly and accurately.

(ONGOING) Action 1.E.1: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings

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

Additionally, the AMP-AD is a precompetitive public-private effort of government, industry, and non-profit organizations that focuses on discovering novel therapeutic targets and biomarkers for validating existing and new targets. The AMP-AD Target Discovery Project has generated a wealth of molecular data from over 3,000 human brain and plasma samples collected in several NIA-supported AD cohorts and brain banks. The project makes these datasets available to the greater research community through the AMP-AD Knowledge Portal.

In 2018, these novel target predictions, along with the data and analyses that led to their discovery, were made available via a new AMP-AD data resource, the AGORA platform. This web-based, interactive platform will enable researchers in academia and biotech and pharmaceutical communities to leverage AMP-AD analyses and results to enhance their own work and build on the AMP-AD discoveries.

For more information, see:
- https://ampadportal.org/
- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals
- https://www.nia.nih.gov/research/amp-ad

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(UPDATED) Action 1.E.2: Continue to promote use of the Alzheimer's Disease Education and Referral Center to provide evidence-based information on Alzheimer's disease and related dementias to the public and others

NIA's ADEAR Center routinely disseminates information on AD/ADRD research findings through the NIA website, regular weekly and monthly email alerts to more than 16,000 subscribers, and social media (Twitter and Facebook). Progress in AD/ADRD research is also reported in the annual NIH Bypass Budget proposal.

In FY 2019, one GWEP grant recipient (University of Southern California) is partnering with three Alzheimer's Disease Centers (ADCs). The remaining 47 are encouraged to work with nearby ADCs.

For more information, see:
- https://www.nia.nih.gov/about/bypass-budget-proposal-archive
- https://www.nia.nih.gov/alzheimers

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(ONGOING) Action 1.E.3: Issue guidance about drugs for early-stage Alzheimer's disease and related dementias

In February 2013, the FDA published a _Draft Guidance for Industry: Early Alzheimer's disease: Developing Drugs for Treatment_, which addresses FDA's current thinking regarding the selection

of patients with early AD for enrollment into clinical trials and the selection of endpoints for clinical trials in these populations. The document discusses a contemporary approach to the diagnosis of patients with AD and a categorical framework useful for the design and evaluation of clinical trials in different stages of AD. The 2018 publication replaced an earlier draft guidance that FDA published in 2013.

In 2013, FDA issued a determination that a disease-modeling tool submitted by the Critical Path Institute for trials in mild-to-moderate AD is fit for purposes, meaning it is scientifically supported and suitable for the purpose of aiding in the design of future clinical trials in these populations. Simulations relying on this model can provide support for the choice of trial design features and facilitate protocol review.

In 2016, FDA published a *Final Guidance for Clinical Considerations for Investigational Device Exemptions (IDEs) for Neurological Devices Targeting Disease Progression and Clinical Outcomes* which discusses general study design considerations for clinical trials that investigate neurological devices using biological markers and clinical outcome assessments.

For more information, see:
- https://www.fda.gov/media/110903/download
- https://www.fda.gov/regulatory-information/search-fda-guidance-documents/clinical-considerations-investigational-device-exemptions-ides-neurological-devices-targeting

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(UPDATED) Action 1.E.4: Expand and disseminate research on co-occurring conditions and dementias

The third Healthy Brain Initiative (HBI) *Road Map for State and Local Public Health* was released in late 2018 by CDC and the Alzheimer's Association identifying 25 actions for public health professionals related to cognitive health, including cognitive impairment and caregiving for persons with cognitive impairment through 2023. In 2019, the first *Road Map for Indian Country* was released identifying eight priority actions for Indian Country.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html
- https://www.cdc.gov/aging/healthybrain/roadmap.htm

CDC published a peer-reviewed paper of co-occurring chronic health conditions and a companion data brief and podcast (in English and Spanish) in 2020. Additionally, CDC has partnered with the National Association of Chronic Disease Directors (NACDD) to develop a series of rack cards for distribution at public health and other medical clinics and other appropriate areas, including health fairs or other health promotional events. These rack cards are designed to educate about risk reduction practices related to AD/ADRD, including the importance of physical activity, healthy diet, blood pressure control, blood sugar management, and smoking cessation. These risk reduction messages can then be integrated alongside existing health promotion messaging among states and other partners.

For more information, see:
- https://academic.oup.com/innovateage/article/4/1/igz045/5687172
- https://www.cdc.gov/aging/publications/chronic-diseases-brief.html
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/410065

In addition, NIA and NINDS jointly produce and disseminate content on AD/ADRD, including FTD, LBD, VCID, and mixed etiology dementias.

For more information, see:
- https://www.nia.nih.gov/health/alzheimers/related-dementias
- https://www.ninds.nih.gov/current-research/focus-disorders/alzheimers-related-dementias
- https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Frontotemporal-Dementia-FTD
- https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Lewy-Body-Dementia-LBD-Research
- https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Vascular-Contributions-Cognitive
- https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Mixed-Etiology-Dementias-MED

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(UPDATED) Action 1.E.5: Provide information to the public on brain health

On February 2, 2016, NINDS launched a public health campaign called "Mind Your Risks®" on the link between hypertension and cognitive decline for integration with the HHS "Million Hearts Campaign". This campaign is still active.

For more information, see:
- https://mindyourrisks.nih.gov/

The campaign, "What is Brain Health?" formerly managed by ACL was transferred to NIA in 2017. NIA also maintains a web portal on Cognitive Health and Older Adults.

For more information, see:
- https://brainhealth.nia.nih.gov/
- https://www.nia.nih.gov/health/brain-health-resource
- https://www.nia.nih.gov/health/cognitive-health

ACL's Alzheimer's Disease Programs Initiative (ADPI) grantees embed brain health education in their funded activities. Through partnerships with private non-profit educational entities grantees are bringing a broad range of brain health resources to the communities they serve. ADPI-funded activities include, but are not limited to, brain health educational opportunities as a means to introducing opportunities for AD/ADRD screening/assessments and benefits counseling. ACL continues to maintain their brain health curriculum *Brain Health: You Can Make a Difference!* Brain Health Basics. The resource offers a PowerPoint presentation for professionals to use in educating older adults and adults with disabilities about brain health as we age, and a related handout for consumers.

For more information, see:
- https://acl.gov/brain-health

CDC disseminates a weekly newsletter to more than 67,000 subscribers. It is a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health.

CDC recently launched a series of podcasts titled "Aging and Health Matters" that includes short discussions on issues in older adult health, including AD/ADRD and caregiving. Topics include: "Healthy Body, Healthy Brain", Alzheimer's Disease-Genes do not equal Destiny", and "Memory Problems? Talk to your Doctor" among others.

For more information, see:
- https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101

In 2019, all of the 48 HRSA-funded GWEPs were educating and training the public on brain health, including by sharing resources.

In 2020, the VA posted information about brain health on its Office of Geriatrics and Extended Care website. The information was developed by the VA GRECC program.

For information, see:
- https://www.va.gov/geriatrics/brain/
- https://www.va.gov/GERIATRICS/docs/GRECCBrainHealthBooklet.pdf

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(COMPLETED) Action 1.E.6: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings

CDC, in collaboration with the American College of Preventive Medicine, developed a Brain Health Continuing Education Course and resource page. Its main purpose is to increase physician and health care professionals' awareness of brain health as a serious health condition, and to increase the number of physicians and health care professionals acting to address, diagnose, and refer patients with brain health issues to care and community support programs. The module was included as an elective in the "Lifestyle Medicine Core Competencies Online Program" in December 2018.

For more information, see:
- https://www.acpm.org/page/brainhealth

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(UPDATED) Action 1.E.7: Facilitate translation of findings into public health practice

CDC provided funds to the Alzheimer's Association to co-develop the third in a series of HBI Road Maps to advance cognitive health as an integral component of public health. This HBI *State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map* was co-authored by experts in public health and brain health, including scientists at CDC. The Road Map outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Twenty-five specific actions are proposed in four traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

Additionally, CDC has developed a series of five Issue Maps that highlight specific sets of Road Map actions related to caregiving, risk reduction, early detection of AD/ADRD, and the education of health professionals. The associated planning tool was developed to guide state and local public health professionals through quick steps in selected Road Map items and getting started with implementation in their jurisdictions. Two podcasts were also produced discussing the updated Road Map. In 2019, the first *Road Map for Indian Country* was released identifying eight priority actions for Indian Country.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/roadmap.htm
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html
- https://www.cdc.gov/aging/publications/podcasts.htm

The BOLD Infrastructure for Alzheimer's Act was passed into law on December 31, 2018 (P.L. 115-406), and amends the Public Health Service Act (Section 398A; 42 U.S.C. 280c-3-4) to facilitate the translation of findings into public health practice. The activities outlined in BOLD are designed to create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It is designed to promote implementation of CDC's HBI *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* and the *Road Map for Indian Country*.

For more information, see:
- https://uscode.house.gov/statutes/pl/115/406.pdf
- https://www.cdc.gov/aging/healthybrain/roadmap.htm
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html

Specifically, the BOLD Infrastructure for Alzheimer's Act directs CDC to:
1. Establish Alzheimer's and Related Dementias Public Health Centers of Excellence (PHCOEs);
2. Provide Funds to Support Public Health Departments; and
3. Increase Data Analysis and Timely Reporting.

CDC awarded the first recipients of the BOLD PHCOE and BOLD Public Health Programs awards in late FY 2020. Recipients to establish PHCOE are: "Dementia Caregiving at University of Minnesota"; "Dementia Risk Reduction at the Alzheimer's Association"; and "Early Detection of Dementia" at the NYU School of Medicine. States awarded at the Enhanced Level for BOLD Public Health Programs include Georgia, Minnesota, Rhode Island, Virginia, and Wisconsin. At the Core Level are Colorado, Hawaii, Iowa, Maine, Mississippi, Nevada, North Carolina, Oklahoma, and Vermont, as well as Los Angeles County and the Northwest Portland Area Indian Health Board.

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

CDC is partnering with the Association of State and Territorial Health Officials (ASTHO) to produce a series of products to support public health agencies in identifying priorities, areas of synergy within existing or upcoming jurisdictional plans, and opportunities for integrating cognitive health into public health efforts as guided by the HBI Road Maps. Products designed to facilitate implementation of the HBI Road Maps include a series of HBI Action Institutes across the country in each HHS region, health communication materials for AI/AN communities, and a series of recorded webinars to promote the importance of public health in addressing brain health.

For more information, see:
- https://www.astho.org/Healthy-Aging/

Additionally, CDC has partnered with The Balm in Gilead and the National Brain Health Center for African Americans (NBHCAA) to address the higher prevalence of dementias and disparities in dementia diagnosis and treatment among African Americans through strategic and culturally tailored public health approaches. In partnership with CDC, The Balm in Gilead has garnered more than 25,000 social media impressions during week long "Road to Memory Sunday" campaign over the past year; 1,000+ viewers participated in the Facebook Live Memory Sunday Town Hall, with over 300 shares including 73 Facebook Watch Parties, distributed over 1,700 copies of *The Book of Alzheimer's* and *Memory Sunday Toolkit* to congregations and community partners. Furthermore, they have produced a four-part virtual web series to engage public health officials, health care providers, and other key stakeholders working to address today's challenges of brain health and AD/ADRD among African Americans and communities of color. Each session within the series aims to connect public health issues of aging with a cultural understanding of faith and spirituality. Through insightful and evidence-based discussion, participants will learn

how effectively connect faith and public health approaches to raise awareness about the impacts of AD/ADRD and mobilize communities in a deliberate way to improve brain health equity.

CDC is partnering with the National Indian Health Board (NIHB) to expand knowledge of public health practice within AI/AN communities. NIHB is expanding website content aimed at health practitioners, as well as conducting a virtual Brain Health Action Institute for Tribal Nations. This institute, facilitated by NIHB, will support tribes and Tribal organizations in using the HBI *Road Map for Indian Country* to start conversations, as well as develop and plan strategies for improving brain health in their own communities. The *Road Map for Indian Country* is the first-ever public health guide focused on dementia in AI/AN communities.

CDC contributed to the *Public Health Perspectives on the Family Care Gap* textbook with a book chapter that illustrates a public health approach to supporting caregivers of people with dementia using the HBI *State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map*. It is framed using essential public health services and identifies 25 strategies for public health action to support caregivers. It also addresses the anticipated family care gap and urges the collaboration of public health systems to collect data and equitably implement evidence-based policies and programs that support people providing care in their communities. This book will be published in 2021.

CDC has updated the "Caregiving and Subjective Cognitive Decline" infographic series. The infographics were developed using 2015-2018 BRFSS data from the Caregiving and SCD modules. The infographic populations include: National Combined Data, African American, AI/AN, Asian/Pacific Islander, Hispanic, Women, Men, Rural, LGBT, and Veterans. These infographics can be used to educate the public and aid in making decisions on how to allocate resources and funding.

For more information, see:
- https://www.cdc.gov/aging/publications/briefs.htm
- https://www.cdc.gov/aging/healthybrain/brfss-faq.htm

The National Combined Data, African American, AI/AN, Asian/Pacific Islander, Hispanic, Women, and Men populations have been translated to Spanish.

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

CDC updated technical assistance documents meant to provide guidance for BRFSS coordinators and researchers who would like to conduct analyses of the data collected through the 2018 BRFSS Caregiver Optional Module and the 2018 BRFSS Cognitive Decline Module. These documents provide basic computer code for analyzing the data with a goal to enable consistency in analytic methods and results reported.

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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 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. Care quality should be measured accurately and 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

The workforce that cares for people with AD/ADRD includes health care and LTSS providers such as: primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct care workers, home health aides, and certified nursing assistants, who provide care across the care continuum. These providers need accurate information about furnishing care to a person with AD/ADRD including the benefits of early diagnosis, how to address the physical, cognitive, emotional, and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities. Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by people with AD/ADRD. In addition, work is needed to expand the capacity of the primary care community to serve people with AD/ADRD. Dementia-specific capabilities within the direct care workforce need to be expanded and enhanced. The actions below will facilitate specific training for care professionals in order to strengthen a workforce that provides high-quality care to people living with AD/ADRD.

(UPDATED) Action 2.A.1: Educate health care providers

In FY 2019, HRSA competed the GWEP and made 48 awards. All GWEP awardees are educating and training the workforce on how to care for persons living with dementia. Of the $35.7 million GWEP budget, $8.7 million was for dementia education and training activities. In Academic Year 2018-2019 (latest available data), GWEP grants provided 445 AD/ADRD courses and training of 73,115 health care providers and 24,434 caregivers in ADRD. In FY 2019, HRSA also competed the Geriatrics Academic Career Award (GACA) program and made 26 awards totaling $1.9 million. GACA grant recipients are encouraged to provide dementia education to the workforce.

NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. NIA also produced and disseminates *Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians and Managing Older Patients with Cognitive Impairment*.

For more information, see:
* http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients
* https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals

Additionally, in 2018 NIA released an FOA -- Small Research Grant Program for the Next Generation of Clinical Researchers in AD/ADRD Research -- aimed at producing trained clinical investigators pursuing careers in the field of AD/ADRD research. Additionally, NIA currently supports over 60 clinical trials aimed at testing interventions to improve care for persons with dementia and their caregivers. In 2020, the NIA ACTC (described in Action 1.B.5) launched the Institute on Methods and Protocols for Advancement of Clinical Trials in AD/ADRD (IMPACT-AD) course that aims to educate and promote diversity among research professionals and future researchers in the AD/ADRD field.

For more information, see:
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-002.html
- https://impact-ad.org/about/
- https://www.nia.nih.gov/research/ongoing-AD-trials#section5

ACL, through its ADPI program, continues to expand efforts to educate professionals (at all levels) engaged in providing care and services to persons living with AD/ADRD and their caregivers. ACL-funded programs are developing and translating tools to educate and support clinicians ranging from micro-learning modules for primary care providers and doctors, to training programs tailored to community health workers. Several funded programs partner with GWEP grantees to maximize the impact that both funding streams can have in the communities they support. Since receiving approval to collect information on the training of professionals (doctors, nurses, social workers, home health aides, first responders, etc.) in 2017, ACL grantees have reported training in excess of 70,000 professionals through their funded state and community programs. Many of the training materials developed through ACL-funded AD/ADRD programs can be found on the web page of the National Alzheimer's and Dementia Resource Center (NADRC).

For more information, see:
- https://alzpossible.org/training/
- https://nadrc.acl.gov/

The VA's Geriatric Scholars program offers staff training to integrate geriatrics into primary care practices, including Rural Interdisciplinary Team Training (RITT). VA Geriatric Scholars includes a wide variety of training activities, many of which include or are focused on dementia training. Examples of FY 2020 training activities included webinars on: differential diagnosis of delirium, dementia, and depression; outpatient management of behaviors in dementia; behavioral strategies to optimize self-care for clients living with dementia; understanding daily risk of abusive and neglectful behaviors in dementia family caregiving. VA's Employee Education System (EES) makes the webinars available for external audiences through the TRAIN interagency sharing platform.

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(UPDATED) Action 2.A.3: Strengthen state aging, public health, and intellectual and developmental disability workforces
HHS will coordinate with states to develop workforces in aging, public health, and intellectual and developmental disability (IDD) that are AD-capable and culturally-competent. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network.

ACL, through the NADRC, offers an annual dementia-specific webinar series, training in excess of 10,000 persons per year. The series targets AD/ADRD professionals, attracting family caregivers as well, and includes information on related dementias, innovative interventions and a wide variety of caregiving topics. Continuing education units (CEUs) are available to attendees, and the webinars are archived on the NADRC web page. In 2019, NADRC published a new guide entitled *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for*

Professionals which provides background and strategies for professionals working with individuals living with IDD and dementia.

In 2017, ACL received Office of Management and Budget (OMB) authority to collect data on professionals trained through ADPI grant funding. Since receiving approval to collect training data, ACL grantees have trained in excess of 70,000 professionals in the many facets of working with persons living with dementia and their caregivers.

Each year, in support of paid and unpaid caregivers, NADRC develops tools and issue briefs on dementia-specific topics. New materials developed are disseminated through the ACL grant programs, as well as at professional conferences and the NADRC website. ACL is constantly adding new tools and issue briefs to its growing library. Topics of materials developed by NADRC include, but are not limited to: advance planning, living alone, compendiums of dementia-specific interventions, and outcome measures. The NADRC website is also home to the materials delivered through the ADPI grant program. The Alzheimer's Disease Supportive Services Programs (ADSSP), Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS), and ADPI program deliverables determined to be potential resources for the non-grantee community are posted for review and utilization by the dementia service provider community.

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

Cross-agency collaborations have enhanced workforce dementia training and expertise. In FY 2019, the 48 HRSA GWEP grantees collaborated with 50 Area Agencies on Aging (AAAs) and seven QIOs to strengthen state aging, public health, and IDD workforces. In addition, 19 of the HRSA 48 GWEPs collaborated with the VA to assist with training on dementia.

CDC funded the University of Illinois at Chicago in FY 2021 as part of the National Healthy Brain Initiative. Their focus will be the People with IDD Healthy Brain Initiative (PwIDD-HBI) which addresses stigma, early diagnosis, and culturally-relevant care to engage decades of collaboration with a robust network of people with IDD, their caregivers, health care providers, and community-based organizations (CBOs) that are supporting people with IDD. Guided by the HBI Road Map Series and the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) "My Thinker's Not Working" National Strategy for people with IDD, PwIDD-HBI will develop and implement public health strategies to improve the quality of life of people with IDD by raising awareness of AD/ADRD among people with IDD as a public health issue and support caregivers to care for people with IDD and care for themselves. The purpose of this project is to concentrate current efforts in AD/ADRD and people with IDD fields into one community of practice for people with IDD, caregivers (paid and unpaid), health care providers, public health and policy stakeholders. A Healthy Brain community of practice for people with IDD will be a "one-stop space" that offers products, trainings, and materials to raise awareness of AD/ADRDs among people with IDD decrease disparities for those experiencing AD/ADRD and improve people with IDD and caregiver's quality of life.

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

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(UPDATED) Action 2.A.4: Develop and disseminate a unified primary care Alzheimer's disease and related dementias curriculum for clinical professionals and caregivers

In FY 2015-FY 2017, HRSA partnered with federal staff at ACL, CDC, CMS, HHS Office on Women's Health (OWH), and VA on a contract to develop a "Dementia Curriculum for Health Care Professionals and Caregivers." The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. The curriculum was first made available in 2017. From December 2017 to August 2020, there were 57,663 page

views on the Alzheimer's curriculum page. It continues to be a valuable resource for clinicians, families, and caregivers.

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

CMS's "Resources for Integrated Care (RIC)", which partners with health plans and providers, also offers a Geriatric-Competent Care Webinar Series designed to help health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults and in working with their caregivers, with some focus on dementia. The webinars are intended for front line community partners and delivery staff such as care managers, member service representatives, and home care providers. Recent topics have included: supporting people with dementia and their caregivers during the COVID-19 pandemic; empowering unpaid caregivers of older adults during times of stress and isolation; preparing the workforce to be more disability-competent; and how to use person-centered language.

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

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(UPDATED) Action 2.A.5: Ensure aging and public health network providers have access to research-based up-to-date information on Alzheimer's disease and related dementias

As described in Action 1.E.5, CDC has developed a weekly newsletter that is sent out to over 67,000 subscribers, including public health professionals. The newsletter focuses on a variety of topics that are applicable to the AD/ADRD and Healthy Aging community. Some of the foundational topics include: caregiving, SCD, general health, emergencies, care planning, and COVID-19 guidance (since March 2020). The newsletters are a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health.

For more information, see:
- https://tools.cdc.gov/campaignproxyservice/subscriptions.aspx?email=YOUREMAILHERE@youremail.com&topic_id=USCDC_944&origin=&pop=t

NIH initiated a project involving the Agency for Healthcare Research and Quality (AHRQ), and the National Academies of Science, Engineering, and Medicine (NASEM), to conduct a systematic review of the evidence on prevention of clinical Alzheimer's-type dementia, MCI, and age-related cognitive decline (through AHRQ), and to shape these findings into a set of recommendations for public health practice and research (through NASEM). The NASEM report, detailing recommendations for public health messaging based on findings was released in June 2017.

For more information, see:
- http://nationalacademies.org/hmd/reports/2017/preventing-cognitive-decline-and-dementia-a-way-forward.aspx

In 2018, NIA commissioned a second systematic evidence review by AHRQ of care and caregiving interventions for dementia to determine which of these interventions have an evidence base that is sufficient to support widespread dissemination. Findings from the evidence review released in August 2020, as well as a later set of recommendations, will inform NIA's future research investments and activities. One example is NIA's Imbedded Pragmatic Alzheimer's disease and related dementias Clinical Trials (IMPACT) Collaboratory. The goal is to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems for people living with dementia and their caregivers. Any research gaps identified in the evidence review can be considered by the Collaboratory researchers for additional exploration within its framework.

For more information, see:
- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report
- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol
- https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers
- https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two

NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. In 2020, NIA updated its list of cognitive screening tools and AD/ADRD resources for professionals.

For more information, see:
- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals
- https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients

In 2020, NIA, ACL, CDC and HRSA revived their annual "Focus on Aging: Federal Partners' Webinar Series". The webinar series addresses important topics for public health and health care professionals, aging services organizations, the research community, and other stakeholders in aging. In addition to general topics of interest for older adults and those who work with them, each webinar will include information specific to individuals with AD/ADRD and their caregivers.

For more information, see:
- https://www.nia.nih.gov/news/focus-aging-federal-partners-webinar-series

See Action 1.E.6 for details on the "Brain Health Continuing Education" course developed by CDC and the American College of Preventive Medicine.

For more information, see:
- https://www.acpm.org/page/brainhealth
- https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproductandproductID=2417https://effectivehealthcare.ahrq.gov/products

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(**UPDATED**) **Action 2.A.6: Engage the public health workforce on brain health**

CDC has developed a "Public Health Curriculum" in partnership with the Alzheimer's Association and Emory University. The "Public Health Curriculum" is a comprehensive course designed to educate public health students about the growing issues related to AD/ADRD and is tied to the "Core Competencies for Public Health Professionals". It includes slides, teacher notes, and other elements to create a complete course for educators to use in the classroom. The curriculum is also relevant to other audiences for broader reach. The course was available in late 2019 with additional enhancements in 2020, such as video modules.

CDC, with support from the BOLD Infrastructure for Alzheimer's Act is creating a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It is designed to promote implementation of CDC's HBI *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* and the HBI *Road Map for Indian Country*. In October 2020, CDC will fund three PHCOE in dementia and 16 state, local and tribal cooperative agreements to increase education of public health officials and others on brain health, promote risk reduction, early detection and preventing avoidable hospitalizations,

decreasing health disparities and supporting caregiving and planning for people living with the disease.

For more information, see:
- https://www.cdc.gov/aging/aginginfo/alzheimers.htm
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html
- https://www.cdc.gov/aging/healthybrain/roadmap.htm
- https://www.cdc.gov/aging/bold/index.html

In addition, see Action 1.E.7 for an update on CDC's partnership with ASTHO, Action 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities, and Action 1.E.4 for information on CDC's partnership with NACDD to develop public health-focused rack cards.

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(UPDATED) Action 2.A.7: Strengthen the ability of primary care teams in Indian Country to meet the needs of people with Alzheimer's disease and related dementias and their caregivers

IHS incorporated training for AD/ADRD into the online continuing education curriculum for IHS/Tribal/Urban Indian Health program nursing. A web-based course on AD/ADRD was provided in April-June 2016 at the IHS Clinical Rounds. Results were addressed at the IHS *Nursing Leadership* meeting on May 17, 2016. A clinical training on diagnosis and management of AD/ADRD for an ACL/IHS/CMS LTSS conference was delivered in November 2016.

The preconference day of the 2019 National Diabetes Conference focused on geriatrics, including diagnosis and management of AD/ADRD.

There is an ongoing collaboration with the VA Greater Los Angeles GRECC and the VA Geriatric Scholars Program in team training in diagnosis and management of AD/ADRD through RITT for rural IHS and Tribal facilities and in training for support of caregivers through the IHS Addressing Challenging Behaviors in Dementia (ABCD) program.

See Action 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

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(ONGOING) Action 2.A.8: Develop a baseline understanding of self-reported competence and confidence of Indian Health Service, Tribal and Urban Indian Health nursing staff in care of individuals with Alzheimer's disease and related dementias

IHS created a survey to assess nursing in IHS, Tribal, and Urban Indian Health programs on self-reported competence, confidence, and recent training specific to care for individuals with AD/ADRD. The survey has been pilot-tested at one Tribal site.

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(UPDATED) Action 2.A.9: Improve educational resources for primary care staff in Tribal communities caring for individuals with Alzheimer's disease and related dementias and their families

IHS, in conjunction with HRSA, worked to pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, and Urban Indian Health Programs. Pending completion of the brief, targeted provider-focused curriculum, IHS will be able to report on success rates and take-up of this curriculum and further implementation in other Tribal communities.

In 2020, ACL introduced a new grant program, ADPI: Dementia Capability in Indian Country. The program is designed to bring culturally-competent AD/ADRD training and education to Indian Country. Four tribes received 3 year awards in August 2020.

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(ONGOING) Action 2.A.10: Provide decision support for clinicians in Tribal communities

IHS worked to develop and pilot-test decision support tools for clinicians using the IHS electronic health records (EHRs). As of 2018, IHS has developed templates to support the Annual Wellness Visit (AWV), including cognitive assessments and chronic care management (CCM).

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(UPDATED) Action 2.A.11: Provide interdisciplinary team training in recognition, assessment, and management of Alzheimer's disease and related dementias in small rural Indian Health Service's facilities

IHS worked with the VA to provide the VA RITT to ten IHS and Tribal sites with a focus on dementia care. So far, 15 separate RITTs have been completed for more than 18 Tribal and IHS programs. The trainings include webinars, accredited through EES and TRAIN for VA and community clinicians. The latest training provided was on PTSD and Memory (January 24, 2018). Training continued in 2019 and the first quarter of 2020, and in March 2020 included the newly developed ABCD training to support public health nursing in their role of caregiver support.

For more information, see:
- http://www.gerischolars.org/course/view.php?id=29

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(ONGOING) Action 2.A.12: Strengthen states' ability to provide and sustain dementia-capable home and community-based services

ACL's ADPI program continues to make funds available to states to develop and implement dementia-capable HCBS. Through the ADPI program, states are able to pilot programs in support of persons living with AD/ADRD and their caregivers in an effort to develop evidence for sustainability post-grant funding.

In 2017, ACL rolled out its dementia-capability assessment tool for implementation through the ACL state and community grant program. The tool assesses program partners over the course of a grant to measure the improvement in dementia-capability over time. The tool is available for non-grantees on the NADRC website.

For more information, see:
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/sites/default/files/uploads/docs/NADRC_Dementia_capability_assessment_public_posting-508.docx

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(UPDATED) Action 2.A.13: Fill service gaps in dementia-capable systems by expanding the availability of specialized services and supports to target previously under-served populations

In 2014, ACL began funding community programs designed to fill service gaps in existing dementia-capable systems. Funded programs are required to target program activities providing effective supportive services to persons living alone with AD/ADRD, improving quality and effectiveness of services for individuals aging with IDD and AD/ADRD or those at high risk, and delivery of behavioral symptom management training and expert consultations for family caregivers. In 2019, 29 programs were funded, and in 2020, 19 programs were funded bringing the program total to 108 state and community programs funded in the United States and its territories since 2014.

Medicare Advantage organizations may consider an item or service as a supplemental benefit if it is used to diagnose, compensate for physical impairments, acts to ameliorate the functionality/psychological impact of injuries or health conditions, or reduces avoidable emergency and health care utilization. This permits the plans to optionally offer supplemental benefits such as adult day health, meal delivery or transportation for non-medical needs like grocery shopping, environmental modifications, palliative care, and in-home supports that could support certain beneficiaries with dementia.

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(UPDATED) Action 2.A.14: Improve home and community-based services provided through state Medicaid waivers

CMS continues to hold webinars, national calls, and provide information to key stakeholders on HCBS topics. For example, CMS is supporting state Medicaid agencies in topics like electronic visit verification and conflict of interest. CMS also recently worked with its partners at ACL to address person-centered planning and practice, culminating in a 2020 report that describes facilitator core competencies, a framework for measurement, and strategies for meaningful engagement.

For more information, see:
- http://www.qualityforum.org/Publications/2020/07/Person_Centered_Planning_and_Practice_Final_Report.aspx
- https://www.medicaid.gov/medicaid/hcbs/training/index.html

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(ONGOING) Action 2.A.15: Train future public health professionals on Alzheimer's disease and related dementias

CDC has developed a "Public Health Curriculum" in partnership with the Alzheimer's Association and Emory University. The "Public Health Curriculum" is a comprehensive course designed to educate public health students about the growing issues related to AD/ADRD and is tied to the "Core Competencies for Public Health Professionals". It includes slides, teacher notes, and other elements to create a complete course for educators to use in the classroom. The curriculum is also relevant to other audiences for broader reach. The course was available in late 2019 with additional enhancements in 2020, such as video modules.

For more information, see:
- https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum

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(COMPLETED) Action 2.A.16: Understand the impact of minimum wage increases on nursing homes

Nursing homes employ large proportions of their workforce at the minimum wage. This project sought to understand the potential impacts of federal minimum wage increases on nursing staff hours and labor costs of nursing homes. The analysis found that in 2017, approximately 44% of

nursing homes are in states that use the federal minimum hourly wage level of $7.25, 28% are in states with a minimum hourly wage between $7.50 and $8.90, and 28% are in states with a minimum hourly wage of $9.00 or more. The impacts of raising the federal minimum wage on nursing homes would be almost completely restricted to increases in wages among nursing assistants, since most of this workforce currently earns at or close to the federal minimum wage. An increase of the federal minimum wage would result in large proportions of nursing assistants gaining a wage increase, thereby increasing direct labor costs to nursing homes.

For more information, see:
- https://aspe.hhs.gov/pdf-report/potential-impacts-minimum-wage-increases-nursing-homes-issue-brief

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Strategy 2.B: Ensure Timely and Accurate Diagnosis

Far too many people with AD/ADRD are not diagnosed until their symptoms have become severe. Timely diagnosis gives people with the condition and their families and caregivers time to plan and prepare for the future, leading to more positive outcomes for both. For some, the inability to access health care due to a lack of insurance or limited finances is a major concern. This is particularly important for individuals with younger-onset disease who may not yet be eligible for Medicare. Even with access to affordable care for individuals, the health care workforce needs tools that can help ensure timely and accurate diagnoses. Research has helped identify some assessment tools that can be used to detect cognitive impairment that may indicate the need for a comprehensive diagnostic evaluation for AD/ADRD. The actions below will facilitate appropriate assessment and give health care providers tools to make timely and accurate diagnoses.

(UPDATED) Action 2.B.1: Identify and disseminate appropriate assessment tools

NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. In 2020, NIA updated its list of free clinical practice tools, training materials and more resources for physicians, nurses, social workers and other professionals as well as a guide that provides information about assessing cognitive impairment in older adults.

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

In 2019, NIA funded two new projects with the goal of producing smartphone applications capable of measuring cognitive status and change on mobile devices. These grants were awarded in response to a specific FOA seeking projects focused on mobile monitoring of cognitive change.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-017.html
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-012.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-050.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-051.html
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9781454&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=4&csb=default&cs=ASC&pball=
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9781463&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=9&csb=default&cs=ASC&pball=

NINDS continues to support Consortium for Detecting Cognitive Impairment, Including Dementia (DetectCID), a national consortium to test and validate clinical paradigms that can be used in

primary health care and other everyday clinical settings. The ultimate goal is to increase detection of cognitive impairment/dementia among high-risk populations, including health disparity populations, and lessen cultural and logistic barriers that currently impede both clinical care and research efforts. Three research teams across the United States are focusing on utilizing assessment tools that are simple to use, standardized, and take 10 minutes or less to administer in a primary care setting.

For more information, see:
- https://www.detectcid.org/
- https://www.ninds.nih.gov/News-Events/News-and-Press-Releases/Press-Releases/NIH-forms-new-consortium-improve-detection
- https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients

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(UPDATED) Action 2.B.2: Educate family and service providers of persons with intellectual and developmental disability about changes that may indicate the onset of dementia

ACL is providing dementia-capability training to paid and unpaid caregivers of persons living with dementia, including individuals living with IDD and dementia or at-risk of developing dementia through grants to states and CBOs. For example, through this grant program approximately 8,000 paid and unpaid caregivers were trained on IDD and dementia with funding from 2014-2017. ACL collaborates closely with the NTG with many grantees participating in their education workshops, becoming affiliated trainers and further disseminating education on IDD and dementia, as well as implementation of their Early Detection Screen for Dementia (NTG-EDSD) tool.

ACL consistently offers educational opportunities/resources in support of both paid and unpaid caregivers of those living with IDD and AD/ADRD or at-risk of developing AD/ADRD. IDD and dementia is consistently included in ACL's annual webinar series, educating attendees on a broad range of topics. Webinars have focused on important topics including early screening, palliative care, family advocacy, and promising practices in care. In 2019, the NADRC published a new guide entitled *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals* which provides background and strategies for professionals working with individuals living with IDD and dementia.

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

CDC, through its National Healthy Brain Initiative, is funding efforts to tailor dementia public health messaging and resources towards persons with IDD. See Action 2.A.3 for information on CDC's funding of the PwIDD-HBI.

For more information, see:
- https://www.cdc.gov/aging/funding/hbi/index.html
- http://aadmd.org/

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(UPDATED) Action 2.B.3: Increase awareness of Alzheimer's disease and related dementias in Tribal and Urban Indian communities and of the availability of services for individuals with dementia and their families

IHS, with ACL and VA, pilot-tested AD/ADRD awareness strategies in communities in which Resources for Enhancing Alzheimer's Caregivers Health (REACH) into Indian Country was successfully implemented, through both health care and aging services settings. The focus of the REACH intervention in its final year was on increasing awareness of AD/ADRD in those communities served by REACH and increasing use of REACH caregiver support services. IHS facilities provide local resources for community-based education and training.

ACL continues to bring awareness to ADRD in Indian Country through participating in educational opportunities including presentations to attendees of ACL's Title VI annual conference and webinars. In 2020, ACL introduced a new ADPI grant program, Dementia Capability in Indian Country. In August 2020, four tribal entities were funded to develop and implement culturally-competent education programs and deliver evidence-based interventions in support of elders living with dementia and their caregivers.

CDC, in partnership with National Council of Urban Indian Health (NCUIH), a communication campaign was developed to raise awareness of AD/ADRD for urban Indian Elders. The campaign includes videos, social media toolkit, flyer and posters, graphics and other resources.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/videos/index.html
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(UPDATED) Action 2.B.4: Increase provider awareness of the need for early diagnosis, and provide tools and resources to enable diagnosis and referral

CDC is funding a special interest project through CDC's Prevention Research Centers (PRCs) in late FY 2020 to improving cognitive impairment detection and referral to resources among older adults by applying the KAER Model to primary care within a health care system.

For more information, see:
- https://www.acpm.org/page/brainhealth
- https://www.cdc.gov/aging/bold/index.html
- https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html
- https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf

Also see Action 1.E.6 for information on the Brain Health Continuing Education course developed by CDC and the American College of Preventive Medicine and Action 2.A.6 for an update on the work of the CDC with support from the BOLD Infrastructure for Alzheimer's Act to create a uniform national public health infrastructure.
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(COMPLETED) Action 2.B.5: Understand the discordance between reported diagnosis, claims, and functional assessment for people with Alzheimer's disease and related dementias

In early 2020, ASPE released two issue briefs on identifying dementia based on self-reported diagnosis, Medicare claims, and/or functional assessment. Although the population identified with dementia should be similar with all three of these methods, there were great differences. The first issue brief compared the characteristics of people identified with each method. For example, of the people whose answer to functional assessment questions indicated probable dementia, only 39.5% had a dementia diagnosis in their Medicare claims data. People identified as having probable dementia based on a cognitive assessment, but not in Medicare claims or with a self-reported diagnosis, were less likely to be White non-Hispanic, more likely to have never married, and had lower levels of education and income than are people with dementia identified in other ways, Their health and functional needs are similar to those of people with dementia identified in other ways.

The second issue brief described the characteristics of people who do not report having a diagnosis of dementia, despite a documented diagnosis by a health care provider, in order to better understand the factors that may contribute to their lack of awareness. Slightly less than one-half (46.8%) of people with a diagnosis in claims data reported they had been told by a doctor that they had dementia. Interestingly, most of these individuals did not show a cognitive assessment consistent with dementia. Only about one-quarter (28.8%) of those who were

unaware of their diagnosis did appear to have probable dementia based on cognitive assessment. This smaller group was more likely to have lower incomes, lower education, and are of a racial or ethnic minority group. The findings have important implications for efforts to use the accuracy of Medicare claims as a source of information on people with dementia, as well as efforts to increase diagnosis and ensure physicians provide information about a diagnosis to patients.

For more information, see:
- https://aspe.hhs.gov/basic-report/implications-alternative-methods-identifying-populations-dementia-issue-brief
- https://aspe.hhs.gov/basic-report/individuals-awareness-dementia-diagnosis-issue-brief

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

Often, even though a physician or another health care provider has identified cognitive impairment, the patient and his/her family and caregivers are not told of the diagnosis. Further, once a diagnosis is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps. This information is important, especially for early-stage individuals who experience positive outcomes when they are involved in planning and receive appropriate services. The actions below will address this gap by educating physicians and other health care providers, incentivizing discussions with people with AD/ADRD and their families, and enhancing the ability of other networks to assist people living with AD/ADRD and their families with addressing their needs.

(ONGOING) Action 2.C.1: 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 increase knowledge of these resources among physicians, nurses, and hospitals, HRSA grantees are working 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, as well as their caregivers. These activities will continue as part of the training in Action 2.A.1.

CMS makes a separate Medicare payment for cognitive assessment and care planning services for individuals with cognitive impairment. A required element of these services is the creation of a care plan, including required referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups), and that the care plan is shared with the patient and/or caregiver with initial education and support.

ACL's state and community ADPI program continues to fund projects that include significant focus on the provision of educational opportunities for physicians and other health care providers. Grantees continue to work toward developing models such as dementia-capable hospitals and federally qualified health centers, including educating providers on the importance of dementia-capable care transitions.

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(UPDATED) Action 2.C.2: Connect American Indian and Alaska Natives to Alzheimer's disease and related dementias resources

The focus on increasing support to caregivers has been through the spread of REACH into Indian Country, with the goal of offering this intervention to those with AD/ADRD and their families. IHS has collaborated with the CDC in the development of the *Brain Health Public Health Road Map*

designed specifically for Tribal Communities. The *Road Map for Indian Country*, co-branded with the Alzheimer's Association, was released and disseminated to multiple stakeholders and Tribal nations. Additionally, CDC developed an infographic describing SCD and related functional limitations, as well as caregiving, in AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country.

Tribal communities continue to benefit from ACL's state and community AD/ADRD grant programs, including development of culturally-competent dementia care specialists, dementia-friendly community education/awareness initiatives and translation of the Music and Memory intervention in Indian Country. ACL's Title VI program has significantly increased the AD/ADRD educational offerings at their annual Title VI Training Conference including increasing awareness of CDC's *Road Map for Indian Country*. In 2020, a new ADPI grant program was introduced, "Dementia Capability in Indian Country"; in August 2020, four Tribal entities were funded to develop and implement culturally-competent education programs and deliver evidence-based interventions in support of elders living with dementia and their caregivers.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html

CDC has partnered with the NCUIH to review, adapt and disseminate existing culturally-appropriate flyers and posters on brain health for an urban AI/AN audience. To accompany the updated materials, NCUIH, with support and feedback from NCUIH staff, created three culturally-appropriate one-minute videos on:
1. Preventing Alzheimer's;
2. Recognizing the signs of Alzheimer's in loved ones; and
3. Healthy living with Alzheimer's.

To ensure maximum exposure, NCUIH will develop and disseminate a healthy brain media kit for use by UIHs and others wanting to raise awareness on AD/ADRD and healthy aging. The media kit will include the updated flyers and posters, links to the videos and social media campaign messaging information. Finally, NCUIH will launch a social media campaign with targeted outreach in cities with the largest AI/AN population (Los Angeles, Phoenix, Tulsa, Oklahoma City, and Anchorage) to disseminate all materials.

Additionally, CDC developed an infographic describing SCD and related functional limitations and caregiving on AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country. These are available in both English and Spanish.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/videos/index.html
- https://www.cdc.gov/aging/data/infographic/2018/american-Indian-alaska-native-cognitive-decline.html
- https://www.cdc.gov/aging/spanish/infographic/2018/aian-cognitive-decline.html
- https://www.cdc.gov/aging/data/infographic/2018/american-indian-adults-caregiving.html
- https://www.cdc.gov/aging/spanish/infographic/2018/ai-adults-caregiving.html

Also see Action 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities, and Action 1.E.4 for information on CDC's partnership with NACDD to develop public health-focused rack cards.

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

Guidelines for the delivery of high-quality care and measures of quality care are needed to ensure that people with AD/ADRD receive high-quality, culturally-competent care in the many different settings where they receive services. These guidelines and measures should be tailored to the stages of the disease, address the physical, cognitive, emotional, and behavioral symptoms of AD/ADRD, and cover the myriad of care settings in which care is delivered. These guidelines should also take into account how care might be modified for diverse populations and in the context of co-occurring chronic conditions in people with AD/ADRD. HHS will seek expert input from public and private entities, and ensure that content builds on existing, evidence-based guidelines. Quality measures should be based on such guidelines and track whether recommended care is being provided. Guidelines and measures need to be free of conflicts of interest. The actions below will advance the development of guidelines and measures of high-quality care, as well as the ability of the provider community to improve the quality of the care they provide. In the future, to facilitate the implementation of quality care guidelines and measurement, HHS will explore development and electronic sharing of clinical decision support interventions in concert with guidelines and measures to provide physicians the information they need at the point of care and ensure continuity between measurement, evaluation, and best practice.

(ONGOING) Action 2.D.1: Explore dementia care guidelines and measures

CMS has included dementia-related measures in the Merit-based Incentives Payment System (MIPS) for Medicare such as cognitive assessment, education and support of caregivers, and others that impact people with dementia. Another area of support is examining and implementing quality and outcome measures and measure concepts for HCBS programs that may serve beneficiaries with dementia.

For more information, see:
- https://qpp.cms.gov/mips/quality-measures
- https://www.medicaid.gov/medicaid/quality-of-care/improvement-initiatives/hcbs/index.html

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(ONGOING) Action 2.D.2: Solicit stakeholder input on meaningful outcomes to drive quality measurement

CMS's "Meaningful Measures" framework identifies the highest priorities for quality measurement and improvement. It involves only assessing those core issues that are the most critical to providing high-quality care and improving individual outcomes. The Meaningful Measure Areas serve as the connectors between CMS's goals and individual measures/initiatives that demonstrate how high-quality outcomes are being achieved across settings of care. CMS also has a "Patients Over Paperwork" initiative to reduce provider burden and increase efficiencies while improving the beneficiary experience.

For more information, see:
- https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page.html
- https://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/PatientsOverPaperwork.html

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(ONGOING) Action 2.D.3: Clarify and disseminate information on privacy, autonomy, and safety issues to physicians

HRSA worked to develop information for physicians on privacy, autonomy, and safety issues around AD/ADRD. These resources are intended to help providers better understand these issues and the balance between safety, privacy, and autonomy. HRSA continues to disseminate this information through the trainings provided by the GWEP awardees.

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(UPDATED) Action 2.D.4: Provide improved training resources to Indian Health Service staff on person-centered goals and strategies for care improvement

IHS collaborated with HRSA to engage the HRSA-funded GWEPs on strategies to improve recognition and diagnosis of dementia. Eleven HRSA GWEPs are currently partnering with federally recognized Tribal organizations. The 11 GWEPs participate in a Native Populations Interest Group for the purpose of exchanging training materials and collaborating regionally on providing education and training to native peoples. The University of Wyoming, in partnership with members of the Eastern Shoshone and Northern Arapaho tribes, completed a culturally-relevant dementia training material for American Indian people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's "Know the 10 Signs: Early Detection Matters". This continues to be disseminated as a national resource.

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

Work is underway at a number of agencies to identify models that provide more effective and efficient care for people with AD/ADRD. Models that improve health and quality of life for people eligible for both Medicaid and Medicare (dually eligible) are also of great importance to the AD/ADRD population, as approximately 19% of the dually eligible population has some form of dementia.

(ONGOING) Action 2.E.1: Evaluate the effectiveness of relevant Innovation Center models for people with Alzheimer's disease and related dementias

CMS's Innovation Center has tested several models that can include testing payment and service delivery models for improving care for Medicare beneficiaries with AD/ADRD. Several early awards under the Innovation Center's Health Care Innovation Awards (HCIA) were focused on people with AD/ADRD and their caregivers.

For more information, see:
- https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/
- https://innovation.cms.gov/initiatives/primary-care-first-model-options/

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(UPDATED) Action 2.E.2: Evaluate the effectiveness of the Independence at Home Demonstration

The Independence at Home Demonstration is testing a payment incentive and service delivery model that uses physicians and nurse practitioners to coordinate HBPC with HCBS. CMS has released the results from Year 5 of the demonstration.

For more information, see:
- https://innovation.cms.gov/files/fact-sheet/iah-yr5-fs.pdf
- https://innovation.cms.gov/initiatives/independence-at-home/

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(ONGOING) Action 2.E.3: Develop a supported decision making model as an alternative to guardianship

ACL continues to support the National Resource Center for Supported Decision-Making (NRC-SDM) which builds on and extends the work of Quality Trust's Jenny Hatch Justice Project by bringing together vast and varied partners to ensure that input is obtained from all relevant stakeholder groups including older adults, people with IDD, family members, advocates, professionals and providers. The NRC-SDM partners bring nationally recognized expertise and leadership on SDM, representing the interests of and receiving input from thousands of older adults and people with IDD. They have applied SDM in groundbreaking legal cases, developed

evidence-based outcome measures, successfully advocated for changes in law, policy and practice to increase self-determination and demonstrated SDM to be a valid, less-restrictive alternative to guardianship.

In September 2020, ACL extended its commitment to keeping supported decision making as a priority with the award of a cooperative agreement to the University of Massachusetts at Boston to implement a national Alternatives to Guardianship (AtG) Youth Resource Center. The AtG is a new initiative focused on diverting high school students with IDD away from guardianship to SDM, which allows individuals with disabilities to make decisions for themselves and choose the level of support they need from people and organizations they trust.

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

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(ONGOING) Action 2.E.4: Understand the role of certified community behavioral health clinics in providing access to care

In April 2014, the Protecting Access to Medicare Act created the Certified Community Behavioral Health Clinic (CCBHC) demonstration. The demonstration establishes a standard definition for CCBHCs and allows states to develop new prospective payment systems (PPS) that reimburse CCBHCs for the total cost of providing comprehensive services to all individuals who seek care. ASPE is managing a 5-year evaluation of this demonstration to answer research questions on how the CCBHCs improve access to care, whether they implement a full scope of services, how they improve the quality of care, whether the PPS covers the full costs of care, and how the demonstration impacts costs and utilization in Medicaid. Reports to Congress are due annually, and interim reports and a final report will be posted on ASPE's website. The first Report to Congress was published in September 2019; an updated Report to Congress and two interim reports were published in September 2020.

For more information, see:
- https://aspe.hhs.gov/report/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2018
- https://aspe.hhs.gov/basic-report/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2019
- https://aspe.hhs.gov/basic-report/preliminary-cost-and-quality-findings-national-evaluation-certified-community-behavioral-health-clinic-demonstration
- https://aspe.hhs.gov/report/implementation-findings-national-evaluation-certified-community-behavioral-health-clinic-demonstration

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(NEW) Action 2.E.5: Expand resources to support person-centered care

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from ACL and CMS that helps states, tribes, and territories implement person-centered thinking, planning, and practice. The NCAPPS supports the provision of technical assistance in the delivery of person-centered care, including dementia care.

For more information, see:
- https://ncapps.acl.gov/home.html

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

People with AD/ADRD have higher rates of emergency room visits and hospitalizations, two settings where they are vulnerable to stress, delirium, and unnecessary complications. A transition between providers and care settings is a complex time of care delivery for all people, but especially for frail elders or people with AD/ADRD who often have multiple chronic conditions. Transitions include moves into acute care hospitals, from hospitals to post-acute care (PAC) settings such as skilled nursing facilities or the home, or from nursing facilities to hospitals. People with AD/ADRD are at high risk of adverse events due to poor communication and other care process deficiencies during transitions and need support to help them determine the best timing for transition and site of care.

(UPDATED) Action 2.F.1: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease and related dementias

CMS's Primary Care First is a set of voluntary Centers for Medicare and Medicaid Innovation (CMMIs) payment model options that reward value and quality by offering innovative payment model structures to support delivery of advanced primary care. One of the Primary Care First payment model options focus on ensuring that seriously ill patients' care is coordinated and that patients are clinically stabilized.

For more information, see:
- https://innovation.cms.gov/initiatives/primary-care-first-model-options/

ACL's state dementia system grants continue to require a care transitions component and an evaluation of the effectiveness of these programs. Numerous evidence-based, evidence-informed, innovative models of care transitions interventions are presently being implemented through ACL's state projects. Information on promising program practices are disseminated through the NADRC.

Through the ADPI state and community grants program, the ACL funds the piloting of innovations in care transitions programs. In Nevada, ACL has funded a successful Hospital2Home intervention to deliver dementia-capable supports as persons living with dementia being discharged from the hospital.

For more information, see:
- https://nadrc.acl.gov
- https://www.integratedcareresourcecenter.com/
- https://www.resourcesforintegratedcare.com/
- http://hospital2home.org/about/

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(ONGOING) Action 2.F.2: Understand facility-initiated involuntary discharges from nursing homes

Facility-initiated involuntary discharges (FIDs) from nursing homes can be unsafe and traumatic, and can result in higher costs of care. This study will examine patterns of discharges using available data to observe the latest trends. The research will explore the prevalence of FIDs and whether it has increased over the years: differences across all states, types of providers (e.g., for profit vs. non-profit; chain vs. non-chain), types of patients (e.g., AD/ADRD, people living with dementia, other disabilities, functional levels), payors (i.e., Medicare, Medicaid, Medicare to Medicaid, other), demographic groups, and duality (eligible for both Medicare and Medicaid). The study will be completed at the end of 2020.

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(NEW) Action 2.F.3: National Center on Advancing Person-Centered Practices and Systems

NCAPPS, an initiative between CMS and ACL to implement person-centered practices, issued a new tool, the Health Care Person-Centered Profile. The template includes essential health information and a format for outlining what is important to the person who may be hospitalized and unable to communicate their wants, needs, and preferences.

For more information, see:
- https://ncapps.acl.gov/covid-19-resources.html

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(NEW) Action 2.F.4: Release of Guide to Billing Codes for Dementia Services

In September of 2020, ACL released, through the NADRC, a new *Guide to Billing Codes for Dementia Services.* Dementia services and supports play an important role in helping people who are living with dementia to remain in the community. Identifying sources of reimbursement for dementia services remains an ongoing challenge. This guide is intended primarily for organizations that have medical billing systems in place and want to understand how to bill for dementia services. It may also be useful for organizations that are considering developing a medical billing system for services.

For more information, see:
- https://nadrc.acl.gov/node/232

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

Coordinating the care received by people with AD/ADRD in different settings by different providers can help reduce duplication and errors and improve outcomes. Despite a general consensus that care coordination is important, more research is needed to determine how best to provide such care in a high-quality and cost-efficient manner. The actions under this strategy will focus on learning from the existing evidence regarding care coordination and using this information to implement and evaluate care coordination models for people with AD/ADRD.

(ONGOING) Action 2.G.1: Implement and evaluate care coordination models

Multiple care coordination models and guidance on care coordination continue across CMS. CMS makes payment for care management and coordination services, including complex and transitional care management. Care coordination models can be a critical component of care in Medicare that can contribute to better health outcomes and higher beneficiary satisfaction.

For more information, see:
- https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html
- https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf

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(UPDATED) Action 2.G.2: Assess the adequacy of health information technology standards to support the needs of persons with Alzheimer's disease and related dementias

HIT is an essential tool to facilitate enhanced care coordination and communication between health care and human service providers that support patients with AD/ADRD. The Office of the National Coordinator for Health Information Technology (ONC) publishes an annual *Interoperability Standards Advisory* to bring public awareness to inter-operability standards and

implementation specifications that can be used by industry, including standards that support care plans and transitions in care, among others.

In September 2019, the standards development organization, Health Level 7 (HL7), published the *eLTSS Fast Healthcare Interoperability Resource* (FHIR) standards which are now available for adoption and implementation by HIT vendors, including those that develop dementia care technology platforms.

For more information, see:

- https://www.healthit.gov/isa/

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(COMPLETED) Action 2.G.3: Study the impacts of managed care on health outcomes and quality

ASPE recently completed a project evaluating the impact of Medicare and Medicaid alignment for individuals eligible for both Medicare and Medicaid on beneficiary outcomes and utilization of acute care services and LTSS. Nineteen percent of all Medicare-Medicaid dually eligible beneficiaries have AD/ADRD. This project focused on one state (Tennessee) that implemented Medicare and Medicaid alignment for dually eligible beneficiaries through a combination of Medicare Advantage Dual Eligible Special Needs Plans (D-SNPs) contracting and Medicaid managed long-term services and supports (MLTSS). This project is testing the hypothesis that the aligned delivery of Medicare and Medicaid-funded services is associated with improved health status and increased efficiency of health care utilization (decreased emergency department utilization, decreased nursing facility utilization, and increased use of HCBS) among full-benefit dually eligible beneficiaries in Tennessee, by evaluating the impact that Tennessee's alignment strategy (pairing D-SNPs with MLTSS) has had on beneficiary outcomes and utilization. In Tennessee, increased aligned plan participation was associated with small decreases in nursing home use and increases in HCBS use among older adults, which is consistent with Tennessee's goal of rebalancing LTSS towards more home and community-based settings. Some data indicates that inpatient and emergency room use initially increased for dually eligible beneficiaries under age 65 as participation in aligned plans increased, but these associations weakened or were no longer present when the analysis include more years of data. The final report will be posted to the ASPE website in late 2020.

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

Some populations are unequally burdened by AD/ADRD, including racial and ethnic minorities and people with IDD. Racial and ethnic minorities are at greater risk for developing AD/ADRD and face barriers to obtaining a diagnosis and services after onset. People with Down syndrome almost always develop AD/ADRD as they age. In addition, because AD/ADRD primarily affects older adults, the population with younger-onset AD/ADRD faces unique challenges with diagnosis, care, and stigma. HHS will undertake the actions below to better understand the unique challenges faced by these groups and create a plan for improving the care that they receive, which will be integrated into the broader efforts to improve care for all people with AD/ADRD.

(UPDATED) Action 2.H.1: Create funding opportunities for organizations to improve care for these specific populations

In 2014, ACL's ADRD traditional funding for state ADSSPs through the Public Health Service Act were supplemented with funds from the Prevention and Public Health Fund. The additional funding allowed ACL to expand programming directly to CBOs. Also in 2014, ACL funded its first ADRD community-based projects, through their ADI-SSS program. In 2019, 29 programs were funded, and in 2020, 16 programs were funded bringing the program total to 108 state and

community program funded in the United States and its territories since 2014. Future grants through ADPI are contingent on availability of funding.

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(UPDATED) Action 2.H.2: Target resources towards the intellectual and developmental disability and dementia population

Through its AD/ADRD grant programs and NADRC, ACL continues to target program resources to the IDD and dementia issue. At the White House Conference on Aging in July 2015, ACL released their *IDD and Dementia Report* on the current state of services and support system for persons with IDD living with dementia. Providing a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers. ACL requires that grantees develop programs that include "improvement of the quality and effectiveness of program and services dedicated to individuals aging with IDD and ADRD or at high risk of developing ADRD". Each year since 2015, the NADRC has included an IDD and dementia-specific webinar in their annual webinar series, all of which can be found online.

In 2019, the NADRC published a new guide entitled *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals* which provides background and strategies for professionals working with individuals living with IDD and dementia.

For more information, see:
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/node/51
- https://nadrc.acl.gov/node/59
- https://nadrc.acl.gov/node/74
- https://nadrc.acl.gov/node/101
- https://nadrc.acl.gov/node/169

Also see Action 2.A.3 for more information on CDC's funding of the PwIDD-HBI.

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(NEW) Action 2.H.3: Review and report on federal programs and initiatives aimed at decreasing health disparities in Alzheimer's.

ASPE will convene federal partners and inventory completed and ongoing programs and initiatives to address racial and ethnic disparities in clinical care, research, and LTSS for people with dementia. As available, ASPE will identify the results of these initiatives and next steps. ASPE will provide a report on this inventory on its website and will present findings at an Advisory Council meeting in 2021.

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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 formal settings such as doctors' offices, hospitals, or nursing homes. Families and other informal 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 caregivers.

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

Caregivers report that they feel unprepared for some of the challenges of caring for a person with AD/ADRD -- for example, caring for a loved one with sleep disturbances, behavioral changes, in need of physical assistance, or advanced dementia can be an enormous challenge. Giving caregivers the information and training that they need in a culturally sensitive manner helps them better prepare for these and other challenges. The actions to achieve this strategy include identifying and addressing areas of training and educational needs, creating culturally-appropriate materials, and distributing these materials widely to caregivers.

(UPDATED) Action 3.A.1: Distribute federally-developed educational materials
NIA's ADEAR Center continues to update and offer free information in English and Spanish on AD/ADRD to caregivers in print and online, as well as through its information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter).

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

ACL's NADRC develops and makes available resources in support of both paid and unpaid caregivers. Examples of such resources includes, but are not limited to:
1. *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals*
2. *Handbook for Helping People Living Alone with Dementia Who Have No Known Support*
3. *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia*
4. *Disaster Planning Toolkit for People Living with Dementia*

The library of NARDC and ACL grantee developed resources for persons living with AD/ADRD and their caregivers can be found online.

For more information, see:
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/node/151
- https://nadrc.acl.gov/node/155
- https://nadrc.acl.gov/node/157
- https://nadrc.acl.gov/node/169

Also see Action 1.E.7 for updates on the Caregiving and SCD infographics, Action 1.E.5 and Action 2.A.5 for information on CDC's weekly newsletter, and Action 1.E.7 for information on CDC's contribution to the Public Health Perspectives on the Family Care Gap textbook.

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(UPDATED) Action 3.A.2: Utilize health information technology for caregivers and persons with Alzheimer's disease and related dementias

Reports from the National Research Council have reinforced the need for HIT applications for caregivers, as well as people with AD/ADRD and providers. Many opportunities exist for using technology to support people with AD/ADRD and their caregivers. Opportunities include assistance with reminders, communications, and monitoring. AHRQ has awarded three grants for integrating information and communication technology to facilitate aging in place.

One grant (1P50HS019917) was awarded and used to create Elder Tree, a suite of electronic services to support older adults and their caregivers. The study was a randomized control trial of adults age 65 and older and their caregivers who had experienced challenges to aging in place. Control group participants were provided usual sources of information and communication, while the intervention group was given access to Elder Tree for 18 months. Findings suggested a positive effect for older adults who are heavy users of health services when they used Elder Tree. Analyses indicated that the system reduced the risk of falls and depression, and improved quality of life and social support for users. The Elder Tree tool is currently being evaluated. So far, 400 people have been recruited to use the suite, and participants were surveyed after use. An analysis is currently underway, and results will be available soon. Elder Tree has been successfully disseminated to 57 counties in Wisconsin and continues to expand.

Another grant (5R18HS022836) was awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD and to study the impact on ability of caregivers to manage family member with AD/ADRD. So far, 60 caregivers have been recruited, out of a goal of 100, and systems are in the process of being installed and caregivers trained.

Finally, a grant (2R21HS026571) was awarded to evaluate the clinical integration of an AD/ADRD support application that provides education, supportive resources, and a platform to share real-time patient-related information with the care team from homes or community settings. The research team has modified based on feedback from stakeholders and is currently implementing the solution into the clinical environment.

For more information, see:
- https://digital.ahrq.gov/ahrq-funded-projects/bringing-communities-and-technology-together-healthy-aginghttps://healthit.ahrq.gov/ahrq-funded-projects/bringing-communities-and-technology-together-healthy-aging
- https://digital.ahrq.gov/ahrq-funded-projects/examining-clinical-workflow-and-outcomes-integrating-health-information

In October 2019, NIA announced three winners in the Improving Care for People with Alzheimer's Disease and Related Dementias Using Technology (iCare-AD/ADRD) Challenge. The winners shared $400,000 in prizes.

The NIH uses prize competitions to spark new ways of thinking, solve tough problems, stimulate innovation, and advance its core mission of turning discovery into health. The iCare-AD/ADRD challenge was launched in 2018 to drive innovation in the dementia care space. The care of people with AD/ADRD is complex, often requiring many care providers and settings. Technologies like mobile applications could be harnessed to help people with dementia, as well as their professional and family caregivers, health care providers, and health care service organizations navigate the system and coordinate care.

The iCare-AD/ADRD Challenge enabled NIA to engage innovators across the country who had a wide range of skill sets and diverse backgrounds, including those who might not typically contribute to NIA research activities. A diverse collection of 33 individuals and teams -- including established aging researchers, start-up companies and biotech firms -- submitted applications to

the Challenge. The technologies submitted ranged from mobile apps to software platforms. From these submissions, a panel of judges selected three innovations for prizes.

The VA Caregiver Center, located at the Memphis VA Medical Center and supported by the VA's Caregiver Support Program, is pilot-testing a supportive texting intervention for caregivers of veterans with dementia. Caregivers will receive information about managing dementia behaviors and their own stress and coping through Annie, the VA's text messaging platform, managed by the Office of Connected Care. National roll-out of the protocol will occur in FY 2021.

For more information, see:
- https://www.nia.nih.gov/icare-ad-adrd-eureka-challenge-winners
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(UPDATED) Action 3.A.3: Increase awareness of the importance of brain health in culturally sensitive ways

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

CDC is working on a training program geared towards African American health professionals. Together with The Balm in Gilead, the CDC will train health professionals on issues affecting cognitive health among African Americans via partnerships with the National Black Nurses Association and National Medical Association.

CDC also supported The Balm in Gilead to develop and implement Memory Sunday, designated as the second Sunday in June, within congregations serving African Americans to provide education on AD/ADRD: prevention, treatment, research studies and caregiving. The purpose of Memory Sunday is to bring national and local attention to the tremendous burden that AD/ADRD is having on the African American community, to utilize the power and influence of the African American pulpit to bring awareness, to distribute the facts about AD/ADRD, to encourage participation in research studies, and to support persons living with AD/ADRD and their caregivers.

CDC developed, using BRFSS data, several fact sheets using the most current data. These resources are made available on the Alzheimer's Association's website and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated.

Through its HBI, CDC will be funding several organizations in FY 2020 to tailor brain health messaging to disproportionately affected populations, including persons with IDD, Hispanics, African Americans, and AI/AN.

For more information, see:
- http://brainhealthcenterforafricanamericans.org/
- https://www.cdc.gov/aging/data/index.htm

Also see Action 2.C.2 for more information on CDC's partnership with NCUIH to develop culturally-appropriate resources on brain health.
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(UPDATED) Action 3.A.4: Increase awareness of the importance of brain health for Tribal communities in culturally sensitive ways

In collaboration with the Alzheimer's Association and numerous partners, the *Road Map for Indian Country* was released and disseminated to multiple stakeholders and Tribal leaders. This *Road Map for Indian Country* has been designed specifically for public health systems serving American Indians, Alaskan Natives, and Native Hawaiians. Additionally, CDC and IHS developed infographics illustrating SCD and related functional limitations, as well as caregiving in AI/AN adults, in order to educate stakeholders and policy makers on brain health and caregiving in Indian Country.

CDC partnered with the ASTHO to develop culturally sensitive materials to educate and empower tribes and Tribal populations about brain health and caregiving. The materials focus on cardiovascular risk factors related to brain health and caregiving issues for Tribal communities.

For more information, see:
- https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html
- https://www.cdc.gov/aging/data/infographic/2017/american-Indian-alaska-native-cognitive-decline.html
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html

Also see Action 2.C.2 for more information on CDC's partnership with NCUIH to develop culturally-appropriate resources on brain health.

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

Even though unpaid caregivers usually prefer to provide care to their loved ones in their home or other community settings, sometimes the round-the-clock care needs of the person with AD/ADRD may necessitate nursing home placement. While they are providing care, supports for families and caregivers can help lessen feelings of depression and stress and help delay or avert institutional care. The actions below will further support informal caregivers by identifying their support needs; developing and disseminating interventions; giving caregivers information they need, particularly in crisis situations; and assisting caregivers in maintaining their health and well-being.

(UPDATED) Action 3.B.1: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and related dementias and their caregivers

NIA is supporting an ongoing project involving AHRQ and NASEM to conduct a systematic review of evidence of care interventions for persons with disabilities (PWD) and their caregivers (AHRQ) and to take stock of the current state of knowledge and inform decision making about which care interventions for PWD and caregivers are ready for dissemination and implementation on a broad scale (NASEM). The NASEM committee held a workshop in April 2020. AHRQ released its final systematic review report in August 2020. A NASEM report that informs decision making about which care interventions are supported by sufficient evidence to be widely disseminated and implemented is forthcoming.

For more information, see:
- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol
- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report

- https://www.nationalacademies.org/event/04-15-2020/care-interventions-for-individuals-with-dementia-and-their-caregivers-phase-two-meeting-1-and-public-workshop
- http://nationalacademies.org/hmd/activities/aging/careinterventionsforindividualswithdementiaandtheircaregivers.aspx

Also in 2019, NIH funded a new effort called the IMPACT Collaboratory to meet the urgent public health need to deliver high-quality, evidence-based care to people living with dementias and their caregivers. Through this effort, researchers will develop and test care interventions in real-world settings such as hospitals, assisted living facilities, nursing homes, and adult day care centers. In general, a "pragmatic clinical trial" means participants are enrolled as part of a real-world setting rather than selected from a broader community-based on narrowly defined criteria. The IMPACT project will bolster the nation's capacity to conduct pragmatic clinical trials of interventions, embedded within health care systems, for people living with dementia and their caregivers. IMPACT supports pilot projects that have the potential to inform the design of larger scale pragmatic trials.

For more information, see:
- https://impactcollaboratory.org/
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-009.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-009.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-018.html
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9774609&icde=51150896&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=

The NIA expanded its Edward R. Roybal Centers for Translational Research to include four new AD/ADRD-specific Roybal Centers for translational intervention development research for AD/ADRD care provider support. The purpose of the Roybal Centers is to develop behavioral interventions that improve the health, well-being and/or capacity of individuals and/or systems that provide care to persons with AD/ADRD.

For more information, see:
- https://grants.nih.gov/grants/guide/RFA-files/RFA-AG-19-007.html
- https://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translational-research-behavioral-and-social-sciences-aging
- https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=14E8C80E4E88C0DF7598B8961CAA4A01A2FFCEB861BF

NIA's ADEAR Center continues to update and offer free information in English and Spanish on AD/ADRD caregiving in print and online, as well as through its information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter). Additionally, the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers provided a platform to disseminate evidence-based interventions for people with AD/ADRD and their caregivers. A total of 58 main research recommendations resulted from nearly 700 recommendations submitted by Summit participants.

For more information, see:
- https://www.nia.nih.gov/2020-dementia-care-summit
- http://www.brainhealth.gov
- https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers
- https://projectreporter.nih.gov/project_info_description.cfm?aid=9860144&icde=51150936&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball=

In addition to these activities, NIA released several FOAs in the past year that call for research to improve the care of persons living with AD/ADRD and their caregivers, and continued to solicit research in this area under several active FOAs that were issued in previous years.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-056.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-026.html
- https://grants.nih.gov/grants/guide/pa-files/PA-18-502.html
- https://grants.nih.gov/grants/guide/pa-files/PAS-17-026.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-186.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-326.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-585.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-587.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-030.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-016.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-037.html
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-20-038.html
- https://www.nia.nih.gov/health/alzheimers/caregiving
- https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=14E8C80E4E8AC1D37598B8961CAA4A01A2FFCEB861BF

ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. All grantees are required to include evidence-based or evidence-informed interventions in their funded programs. In 2019, 29 programs were funded, and in 2020, 16 programs were funded bringing the program total to 108 state and community program funded in the United States and its territories since 2014. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country.

ACL's ADPI and NADRC continue to support the translation and implementation of dementia-specific evidence-based interventions in states and communities across the Nation. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the Nation. For example, NIA funded the research behind SAVVY Caregiver and ACL-funded provider pilot programs that enabled an estimated 20,000 caregivers to receive the intervention.

For more information, see:
- http://nadrc.acl.gov
- https://nadrc.acl.gov/node/110
- https://nadrc.acl.gov/node/140

The U.S. Department of Defense (DoD) has funded REACH Hope, Supporting Caregivers of Veterans with TBI and Alzheimer's Dementia/Mixed Dementia: The REACH Hope Behavioral Intervention, to assist caregivers of veterans who are living with TBI and dementia. The 3-year study, August 2020-August 2023, will combine two behavioral interventions -- Resources for Enhancing All Caregivers Health in the VA (REACH-VA), and the DoD's Virtual Hope Box mobile App -- to support caregivers one-on-one in real-time and as-needed. The study will be conducted by investigators at the VA Caregiver Center at the Memphis VA Medical Center and investigators at Virginia Commonwealth University, and it will be supported by the VA Caregiver Support Program.

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(UPDATED) Action 3.B.2: Provide effective caregiver interventions through Alzheimer's disease and related dementias-capable systems

ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the nation. In 2019, 29 programs were funded, and in 2020, 16 programs were funded bringing the program total to 108 state and community program funded in the United States and its territories since 2014. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country.

For more information, see:
- https://nadrc.acl.gov/node/140

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(UPDATED) Action 3.B.3: Collaborate to share information on long-term services and supports with Tribal providers

HHS uses multiple mechanisms to share information on LTSS and care of the person and family with AD/ADRD with Tribal providers. IHS, ACL, and CMS will develop a joint website on LTSS for Tribal providers. IHS conducts presentations on LTSS for people with AD/ADRD at Indian Country conferences, including the Older Americans Act Title VI annual conference, and conferences for Tribal Health Directors and Planners (NIHB), Tribal Leaders (National Council on American Indians), and Tribal Elders (National Indian Council on Aging). IHS and ACL host joint webinars on addressing the service and supports needs of persons with AD/ADRD. Dissemination of dementia-specific information through presentations occurs at Indian Country meetings and webinars.

In 2020, ACL introduced a new grant program, "ADPI: Dementia Capability in Indian Country". The program is designed to bring culturally-competent ADRD training and education to Indian Country. Four tribes received 3 year awards in August 2020.

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(ONGOING) Action 3.B.4: Continue to promote use of the National Alzheimer's Call Center to provide information, advice and support to people with dementia or their caregivers

ACL continues to provide funding toward and promote use of the National Alzheimer's Call Center to provide information, advice and support about AD/ADRD. The Call Center provides 24-hour access, 7 days a week via a toll free number (1-800-272-3900). Support varies from simple referrals to crisis intervention. Complex and crisis calls are handled by master's level social workers and counselors who provide reflective listening, problem solving, education, action planning, and crisis intervention. The Call Center provides assistance in over 170 languages.

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(ONGOING) Action 3.B.5: Make behavioral symptom management education and training available to caregivers

ACL continues to expand efforts to develop more dementia-capable LTSS systems designed to meet the needs of AD/ADRD caregivers. ACL requires that all ADPI community grants include behavioral symptom management and expert consultations to support caregivers in their programs.

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(UPDATED) Action 3.B.6: Adapt and implement Resources for Enhancing Alzheimer's Caregivers' Health in Tribal communities

The initial phase was completed with 80 REACH certified caregiver support coaches in 56 Tribal communities, serving at least 55 caregivers as of February 2018. The second phase of the effort is focused on strategies to increase penetration of REACH in the communities where there are certified coaches and on building additional, sustainable options for evidence-based caregiver

support services. IHS continues work developing the Extension for Community Healthcare Outcomes project (Project ECHO) model to support Caregiver Coaches in Tribal Communities and to identify additional training for caregiver support through public health nursing. IHS collaborated with the VA Greater Los Angeles GRECC in the development of the IHS ABCD (Addressing Behavioral Challenges in Dementia) training targeted at Public Health Nurses who provide support for caregivers of persons living with dementia.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
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(ONGOING) Action 3.B.7: Develop and disseminate information to caregivers on Alzheimer's disease and related dementias and caregiving

CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD resulting in better quality of life for all care recipients.

CDC has developed a series of web features and podcasts on topics including helping people with AD/ADRD and their caregivers stay physically active, care plans for older adults and their caregivers; and the truth about aging and dementia.

For more information, see:
- https://www.cdc.gov/aging/caregiving/pdf/Complete-Care-Plan-Form-508.pdf
- https://www.cdc.gov/features/caregivers-month/index.html
- https://www.cdc.gov/aging/publications/podcasts.htm

Annually ACL, through the NADRC and its grant programs, continues to develop and make available web content on issues relevant to paid and unpaid caregivers. In addition to hosting ten webinars on a broad range of AD/ADRD topics, the NADRC has developed several resources:
1. *Handbook for Helping People Living Alone with Dementia Who Have No Known Support*
2. *Disaster Planning Toolkit for People Living with Dementia*
3. *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia*

For more information, see:
- https://nadrc.acl.gov/
- https://www.nia.nih.gov/health/alzheimers/caregiving
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(ONGOING) Action 3.B.8: Develop a program to support enhanced financial literacy and preparedness of family caregivers

Family caregivers often lack adequate information and resources to properly manage the financial concerns of their loved ones. ACL introduced a new program to address the need to advance the understanding financial literacy of family caregivers. The program will address that need through development and testing new interventions, as well as identification and dissemination of best practices.
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Strategy 3.C: Assist Families in Planning for Future Care Needs

The vast majority of people do not think about or plan for the LTSS they will need until they experience a disability or AD/ADRD. Many Americans incorrectly believe that Medicare will cover most of the costs of these supportive long-term care services like nursing home care and HCBS. Unfortunately, by the time

care is needed, it is difficult to get coverage in the private long-term care insurance market, and financing options are limited. Educating people about their potential need for LTSS and the significant advantages of planning ahead for these services encourages timely preparation. Planning ahead can help ensure that individuals with AD/ADRD receive care in the setting they prefer, preserve individual and family assets, and maintain dignity.

(COMPLETED) Action 3.C.1: Understand the functional trajectories of people with Alzheimer's disease and related dementias at the end of life

An expert panel on advanced dementia convened by the Institute of Medicine in 2014-2015 highlighted the need to better understand care for people with dementia near the end of life. PWD, whose prognosis is often difficult to determine, may not meet the criteria for hospice or may use hospice services for longer than the 6 months covered by Medicare. In 2020, ASPE released a report and an issue brief describing the differences in functional trajectories in the last 4 years of life between decedents with and without dementia. People with dementia had higher levels of functional impairment throughout the 4 years before death, compared to people without dementia who experienced functional impairment closer to death. In early 2021, ASPE will release the results of similar analyses showing health care service utilization over this time period. Although people with dementia were more likely to use hospice services more than 1 year before death, they were less likely than people without dementia to use these services in the 3 months immediately prior to death. These findings have implications for expanding access to end-of-life services for this population.

For more information, see:
- https://aspe.hhs.gov/basic-report/functional-trajectories-end-life-individuals-dementia-final-report
- https://aspe.hhs.gov/basic-report/functional-trajectories-end-life-individuals-dementia-issue-brief

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(COMPLETED) Action 3.C.2: Understand the use of advance care planning for people with cognitive impairment, including Alzheimer's disease and related dementias

ASPE completed a project evaluating the use of advance care planning (ACP) nationally, which included analyses of the use of billing codes for care planning and cognitive assessment services provided to beneficiaries in traditional Medicare. These billing codes (Healthcare Common Procedure Coding System code G0505 and Current Procedural Terminology code 99483) reimburse providers for assessment of, and care planning for, a patient with cognitive impairment, with one of the required elements being the development, updating or revision, or review of an advance care plan. The study found low use of these billing codes nationally. Experts interviewed for the project suggested potential barriers to uptake include under-diagnosis and under-disclosure of dementia-related diseases, practitioners' lack of training, and patients' fear of losing their independence. The report and issue brief were published in October 2020.

For more information, see:
- https://aspe.hhs.gov/basic-report/advance-care-planning-among-medicare-fee-service-beneficiaries-and-practitioners-research-brief
- https://aspe.hhs.gov/basic-report/advance-care-planning-among-medicare-fee-service-beneficiaries-and-practitioners-final-report

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(COMPLETED) Action 3.C.3: Understand the risks and costs of cognitive impairments

ASPE completed a project to understand the expected lifetime risks and costs of cognitive impairment, including estimates of the value of informal care. The possibility of becoming severely cognitively impaired is among the most consequential risks facing older adults and their families. In addition to the emotional and physical toll associated with dementia, the financial consequences can be overwhelming, as many patients require expensive paid care. Projections

of future care needs and costs are difficult because the older population is changing in ways that will likely shape the course of cognitive impairment. This study uses the Dynamic Simulation of Income Model (DYNASIM) to project the risk and costs of severe cognitive impairment at older ages over the coming decades. Using multiple data sources and sophisticated econometric techniques, DYNASIM simulates the future population and its characteristics, projecting financial resources, disability status, medical conditions, cognitive status, and use of LTSS. Unlike a lot of past research, this study will show how severe cognitive impairment and associated costs vary across the population. The final report will be posted to the ASPE website in late 2020.

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(COMPLETED) Action 3.C.4: Understanding the availability of caregivers for individuals with long-term services and supports needs

ASPE is working on a project to understand widely stated concerns about an impending shortage of informal caregivers and a resulting increase in unmet needs for care as the large Baby Boom cohort enters retirement ages. The project will compile existing evidence in the literature, produce new or updated estimates of current informal caregiving for older people, including alternative arrangements when typical sources of informal care are not available (e.g., a spouse or child), and explore the implications of population aging and other changing demographic characteristics for future met and unmet care needs and reliance on Medicaid LTSS. The final report will be posted to the ASPE website in late 2020.

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(NEW) Action 3.C.5: Empowering people to make better informed health care decisions

CMS launched Care Compare, a streamlined redesign of eight existing CMS health care compare tools, to provide a single user-friendly interface that patients, caregivers, and consumers can use to make informed decisions about health care based on cost, quality of care, volume of services, and other data.

For more information, see:
* https://www.medicare.gov/care-compare/

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(NEW) Action 3.C.6: Expand availability of care planning tools for people with dementia

CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD resulting in better quality of life for all care recipients.

For more information, see:
* https://www.cdc.gov/aging/caregiving/pdf/Complete-Care-Plan-Form-508.pdf

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

People with AD/ADRD are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in care facilities. Reports of elder abuse are handled by state Adult Protective Services (APS), which investigate allegations, provide protective services, and refer cases to law enforcement when appropriate. Not all APS programs cover residents of long-term care facilities. State survey and certification agencies receive funding from CMS to survey Medicare or Medicaid-certified nursing facilities and to investigate abuse complaints in these facilities. State licensing agencies may investigate complaints of abuse in other types of facilities, such as assisted living. State LTCO programs advocate for residents of nursing homes and other adult care facilities, and work to resolve

complaints on behalf of residents, including those related to abuse, neglect, and exploitation. The actions below will help ensure that people with AD/ADRD have their dignity, safety, and rights maintained.

(UPDATED) Action 3.D.1: Monitor, report and reduce inappropriate use of antipsychotics in nursing homes

The National Partnership to Improve Dementia Care in Nursing Homes met its goal of reducing the national prevalence of antipsychotic use in long-stay nursing home residents by 30% by the end of 2016. There was a decrease of 40.1% to a national prevalence of 14.3% in 2019. Success has varied by state and CMS region, with some states and regions having seen a reduction of greater than 45%, with the understanding that there are circumstances where clinical indications for the use of antipsychotic medications are present.

For more information, see:
- https://store.samhsa.gov/system/files/pep19-inappuse-br_0.pdf

CMS continues the Civil Money Penalty Reinvestment Program (CMPRP), an effort to drive improvements in quality of life and quality of care for nursing home residents. CMPRP is funded by the federal portion of civil monetary penalty (CMP) funds to conduct activities that support and protect nursing home residents. This program builds on other CMS initiatives such as the National Partnership. A multi-pronged approach that focuses on those homes that have been identified as late adopters is being utilized. CMS also hosts regular Medicare Learning Network calls, some to address dementia-related issues.

For more information, see:
- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html
- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html
- https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events.html

In the VHA, the Staff Training in Assisted Living Residences-VA (STAR-VA) program in CLCs is related to decreased use of as-needed antipsychotic and benzodiazepine prescriptions. STAR-VA, adapted from the STAR program, is a team-based, behavioral approach for helping CLC staff to understand and manage distressed behaviors among residents with dementia. A VA Quality Enhancement Research Initiative (QUERI) partnered evaluation supported investigation of the impact of STAR-VA on psychotropic medication prescribing, as well as on staff injuries, rates of behavioral symptoms of dementia, and facilitators and barriers to program sustainment.

For more information, see:
- https://www.queri.research.va.gov/qnews/feb20/default.cfm?QnewsMenu=article1
- https://www.mentalhealth.va.gov/healthcare-providers/docs/STAR-VA_Overview.pdf

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(ONGOING) Action 3.D.2: Incorporate elder abuse awareness into Aging Network activities

ACL continues to expand awareness and detection of elder abuse and neglect among the population of people with dementia. ACL will encourage the Eldercare Locator and other Aging Network and prevention program providers to become knowledgeable about warning signs of abuse. These providers will also disseminate information on elder abuse, with a particular focus on the vulnerable population of people with AD/ADRD. The National Center on Elder Abuse (NCEA) is funded by ACL and, through their programs, addresses all facets of elder abuse.

For more information, see:
- https://ncea.acl.gov/

In 2021, the Elder Justice Initiative (EJI) will be providing training to state-level directors of AmeriCorps Seniors (Corporation for National and Community Service) programs throughout the country on recognizing and responding to elder abuse, neglect, and financial exploitation. The training includes a section on the unique aspects of elder abuse when the older adult is a person with AD/ADRD.

For more information, see:
- https://www.nationalservice.gov/programs/senior-corps/what-senior-corps

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(ONGOING) Action 3.D.3: Translate and disseminate information on abuse of people with dementia

ACL, NIH, and the U.S. Department of Justice (DoJ) have funded research to identify the factors associated with elder mistreatment. HHS will work with the private sector to translate these findings into educational materials and resources on abuse of people with dementia.

ACL continues to fund programs designed to address elder abuse. NCEA is funded by ACL and, through their programs, addresses all facets of elder abuse, including the abuse of individuals living with dementia.

For more information, see:
- https://ncea.acl.gov/

NIA produces online and print content on Elder Abuse including a 2019 infographic *Spotting the Signs of Elder Abuse*, to educate the public and disseminate information about types of elder abuse, dealing with caregiver stress, and how to help.

NIA is also actively seeking research in this area with a number of active FOAs. Per NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071, NIA is soliciting research on risk, protective, and resilience factors related to elder mistreatment and interventions to prevent or detect elder mistreatment in informal care settings for individuals with AD/ADRD. Another FOA, RFA-AG-20-00: Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships (R01 Clinical Trial Optional) states, "Even worse, they may deliberately omit important details or provide false information, with the intention of discrediting the patient and misleading the clinician to conceal signs of neglect or abuse" and among the areas of interest to NIA include research on "Interpersonal processes impacted by AD/ADRD symptomology and properties of unhealthy relationships" and "Individual and dyadic-level protective factors and processes that promote resilience in AD/ADRD-affected couples and families and/or modifiable risk factors for unhealthy caregiving relationships". Finally, PAR-18-544 and PAR-18-538 invite applications for basic research to better characterize the affective, cognitive, social, and motivational parameters of impaired and intact decision making in both normal aging and AD/ADRD. Research is sought that will characterize the extent to which basic behavioral and neural processes involved in decision making are differentially impacted in normal aging and AD/ADRD, investigate the influence of social factors on decision making, and investigate the decision making factors that render older adults (with or without cognitive impairment) vulnerable to financial exploitation and other forms of mistreatment and abuse.

For more information, see:
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-538.html
- https://grants.nih.gov/grants/guide/pa-files/par-18-544.html

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html
- https://www.nia.nih.gov/health/elder-abuse

DoJ's National Institute of Justice (NIJ) maintains a webpage featuring NIJ-funded elder abuse research entitled Overview of Elder Abuse, and another page specifically on financial exploitation entitled Financial Exploitation of the Elderly.

For more information, see:
- https://nij.ojp.gov/topics/articles/overview-elder-abuse
- https://nij.ojp.gov/topics/articles/financial-exploitation-elderly

DoJ's EJI website hosts an elder justice Research webpage featuring among other things foundational articles, some of which address elder abuse and dementia.

For more information, see:
- https://www.justice.gov/elderjustice
- https://www.justice.gov/elderjustice/research-related-literature
- https://www.justice.gov/elderjustice/foundational-articles

In addition, EJI's renowned webinar series features several webinars on this topic presented by elder justice experts:
1. *Responding to Elder Abuse Victims with Alzheimer's Disease or Other Dementias*
2. *Increasing Access to Capacity Assessments via New Technologies*
3. *Digging Deeper: When Consent is Not Consent*
4. *Assessing Cognitive Capacity In Elder Abuse Cases*

For more information, see:
- https://www.justice.gov/elderjustice/video/responding-elder-abuse-victims-alzheimer-s-disease-or-other-dementias
- https://ovcttac.adobeconnect.com/px6tzz3q5y94/
- https://www.justice.gov/elderjustice/video/digging-deeper-when-consent-not-consent
- https://www.justice.gov/elderjustice/video/assessing-cognitive-capacity-elder-abuse-cases

The EJI supported the development of *Finding the Right Fit: Decision-Making Supports and Guardianship*, in collaboration with the National Center for State Courts. This online training is designed to assist individuals in exploring ways to help someone who may need assistance in making decisions with informal supports, legal options, and/or adult guardianship. Finding the Right Fit provides a broad overview of decision making supports and guardianship that is not specific to state laws or rules.

For more information, see:
- https://eji.courtlms.org/catalog/info/id:140?eType=EmailBlastContent&eId=78fc945e-be1f-4cdb-8474-cfd9b72ca056

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(ONGOING) Action 3.D.4: Improve the ability of legal services to address the needs of people with Alzheimer's disease and related dementias

ACL has a number of related activities underway to improve legal services for people with AD/ADRD. The ACL National Legal Resource Center (NLRC) website includes a special section addressing advance planning and end-of-life issues, a resource for legal and aging/disability service professionals and family caregivers assisting people with AD/ADRD or other causes of diminished capacity.

ACL-funded state and community grants programs include pilot programs designed to make dementia-capable legal services available to persons with dementia and their caregivers.

Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

ACL grants to states and communities include pilot programs designed to make dementia-capable legal services available to persons with dementia and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

In 2018, the NADRC partnered with the American Bar Association (ABA) Commission on Law and Aging to develop *The Handbook for Helping People Living Alone with Dementia Who Have No Known Support.* Among other things it provides practical guidance as well as tools for helping a person living alone who does not have informal supports. The Handbook includes practical strategies for identifying people who are living alone without support, assessing risk, building trust, identifying family and friends willing to help, determining decision making capacity, options for helping the person maintain their independence, and the basics of guardianship or conservatorship.

For more information, see:
- http://www.nlrc.aoa.gov/NLRC/Index.aspx
- https://nadrc.acl.gov/node/137

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(ONGOING) Action 3.D.5: Educate law enforcement and other first responders about interacting with Alzheimer's disease and related dementias

DoJ will continue to educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD, and provide current information and resources to help law enforcement agencies and the communities they serve. The education will include how to prevent persons with AD/ADRD from wandering and becoming lost, as well as information on locating those who do wander and become lost. The training and resources are provided through projects funded by the Office of Justice Programs' Bureau of Justice Assistance.

As part of their funded grants, several ACL ADI-SSS community projects are training law enforcement and other first responders. One grantee created a series of well-received law enforcement training videos to address wandering, driving and encountering disoriented individuals on "house calls".

For more information, see:
- https://youtu.be/cQbmcq7rC7A

The EJI continues its commitment to ensuring law enforcement has the training and tools to robustly and appropriately respond to victims of elder abuse, including persons with ADRD. For example, EJI currently hosts relevant resources on the law enforcement webpage, including:
1. *Safe Return: Alzheimer's Disease Guide for Law Enforcement* (Alzheimer's Association)
2. *A Booming Problem: Alzheimer's, Dementia, and Elder Abuse* (COPS Office)
3. *Approaching Alzheimer's: First Responder Training Program* (Alzheimer's Association)
4. *Communicating with Someone with Dementia* (Alzheimer's Association)

For more information, see:
- https://www.justice.gov/elderjustice/law-enforcement-1
- http://www.alz.org/national/documents/SafeReturn_lawenforcement.pdf
- http://cops.usdoj.gov/html/dispatch/05-2015/alzheimers_dementia_elder_abuse.asp
- http://www.alz.org/care/alzheimers-first-responder.asp
- https://www.alz.org/help-support/caregiving/daily-care/communications

In FY 2021, the EJI is collaborating with the FBI to support the development of curriculum for forensic interviewing with older adults. This is an advanced forensic interviewing certificate curriculum for established forensic interviewers with previous basic certification and extensive experience in forensic interviewing and or working with older adults and adults with ADRD. The advanced forensic interview certificate curriculum is designed to support forensic interviewers to gather information from alleged victims in the most reliable and legally defensible manner. From this in-depth curriculum, a supplemental curriculum for front line responders and another one for elder justice professionals also will be developed. This project builds upon a previous (December, 2017) EJI-hosted webinar on *Forensic Interviewing With Older Adults*, featuring aspects of dementia as part of this training that remains available for professionals to download.

For more information, see:
- https://www.justice.gov/elderjustice/video/forensic-interviewing-older-adults

The EJI is collaborating with the University of Southern California to develop The Enhanced AIM Judicial Review Tool. This is a standardized framework and pragmatic tool based upon the Abuse Intervention Model (AIM) for judges, court officers, and investigators to better evaluate and assimilate evidence related to capacity and the risk for elder mistreatment, including aspects of ADRD.

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(ONGOING) Action 3.D.6: Work with communities to develop best practices for protecting people with Alzheimer's disease and related dementias

ACL, NADRC and dementia grantees continue to make the provision of dementia-specific education of first responders a priority in their funded programs. NADRC developed a guide for first responders entitled *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia*. The guide helps community organizations collaborate with first responders to better serve people living with dementia, a need increasingly recognized by first responder agencies. This guide explains why this issue is gaining attention, provides strategies for building successful partnerships, and describes the types of programs that can benefit people living with dementia. Also included are resources such as training materials, sample policies, tip sheets and more.

In addition to the guide, ACL grantees developed a training session on the basics of dementia for first responders which includes descriptions of dementia, the changes that accompany dementia (e.g., communication, behavior), and important safety and wandering issues related to dementia. Alzheimer's San Diego created a referral form that law enforcement can use. To refer an individual or family member to Alzheimer's San Diego for support or education. A complement to these resources are the four-part training series of videos developed by Alzheimer's Orange County which present educational vignettes to address wandering, driving and encountering disoriented individuals on "house calls" involving actual first responders and actors portraying people living with dementia and reminders about how to handle the interactions and any follow-up.

For more information, see:
- https://nadrc.acl.gov/node/155
- https://nadrc.acl.gov/node/196
- https://www.youtube.com/playlist?list=PLyUU5QfNKxwhm7NTgcmUGUsfKxs_qCb20

The EJI's Multidisciplinary Team Technical Assistance Center (MDT TAC) provides educational offerings and technical assistance to elder abuse MDTs on the topic of detecting and providing appropriately tailored elder abuse interventions for older adults with AD/ADRD.

For more information, see:
- https://www.justice.gov/elderjustice/mdt-tac

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

Stable housing is essential to helping people with AD/ADRD remain in the community, particularly as they experience an increasing need for services and supports as the disease progresses. Housing is a crucial platform for delivering the necessary health and supportive services. Recognizing these links, HHS and the U.S. Department of Housing and Urban Development (HUD) are working together to improve health outcomes and housing stability through supportive services for vulnerable populations including people with AD/ADRD. Through the actions below, HHS will assess the availability of services in the settings where people with AD/ADRD live. This information will form the basis of future actions to further link housing with services for people with AD/ADRD.

(COMPLETED) Action 3.E.1: Evaluate the Support And Services at Home program

ASPE and HUD completed an evaluation of the Support And Services at Home (SASH) program for the first years of the program (2010-2016). The SASH program in Vermont is an approach to providing support services and care coordination to older adults and individuals with disabilities, using affordable housing properties as a platform for service delivery. Under contract from HHS and HUD, RTI International conducted a mixed-methods evaluation of the SASH program.

SASH appears to be a promising model of providing care coordination within housing sites with concentrations of older adults. However, health care utilization outcomes varied between different types of SASH sites (whether rural or urban; or primarily serving housing residents (i.e., site-based) or the wider community [community-based]). Growth in average annual Medicaid expenditures for long-term institutional care was $400 slower for dually eligible SASH participants in site-based panels and in rural panels. Analysis of Medicaid claims data indicates that the SASH program had a favorable impact on Medicaid expenditures for long-term institutional care for dually eligible SASH participants over age 65. While the program as a whole did not reduce growth in Medicare spending, the SASH program had a favorable impact on the Medicare expenditures for participants in urban areas. The impact of the SASH program on the growth of Medicare expenditures varied across different types of panels. The participants in urban panels experienced growth in Medicare expenditures that were slower by $1,400 per beneficiary per year. These impacts on total Medicare expenditures were driven by statistically significant slower growth in Medicare expenditures for hospital stays, emergency room visits, and specialist physicians, which is consistent with the SASH program goal of preventing unnecessary high-cost care.

For more information, see:
- https://aspe.hhs.gov/pdf-report/support-and-services-home-sash-evaluation-highlights-evaluation-program-outcomes-2010-2016
- https://aspe.hhs.gov/pdf-report/support-and-services-home-sash-evaluation-sash-evaluation-findings-2010-2016
- https://www.huduser.gov/portal/periodicals/cityscpe/vol20num2/ch1.pdf

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(ONGOING) Action 3.E.2: Assess utilization of home health benefits

ASPE continues to study the growth in use of the Medicare home health benefit by community-admitted users (those individuals for whom home health episodes are not preceded by a hospitalization or PAC stay). The Medicare home health payment policy for fee-for-service has undergone several changes in the past decades. There have also been overall increases in Medicare home health utilization. Growth in utilization has been particularly strong for community-

admitted users. The Medicare Payment Advisory Commission has suggested that this might be an indication that some beneficiaries are using the home health benefit as a long-term care benefit. Several alternative explanations for the growth of the community-admitted users are plausible. Indeed, a recent Academy Health meeting on PAC noted that as the American population ages, those with chronic conditions will likely cycle between PAC and chronic care services. Our research indicates that there are many important differences between patients based on the length of their home health care use, not just based on their source of admission, and that the source of admission may be a more important differentiator among patients who use home health care for longer periods. The study also found that use of the home health care benefit is changing -- use of home health aide care has declined and use of physical therapy services has increased, even for longer periods of care. ASPE is now working on research to better understand trends in home health care use in Medicare Advantage compared to traditional Medicare.

For more information, see:
- https://aspe.hhs.gov/pdf-report/patterns-care-and-home-health-utilization-community-admitted-medicare-patients

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(NEW) Action 3.E.3: Understand contributing factors to and policy implications of nursing facility closures

In fall 2020, ASPE began an evaluation of nursing facility closures over the last decade. Nursing facility closures can have negative effects on residents and affect access to care in this setting. Although a certain proportion of nursing facility closures is expected and may be considered an appropriate market response to poor performance or oversupply, stakeholders are concerned with recent news of increases in the number of closures and how that may limit access to necessary long-term care services in some circumstances. This study will explore the incidence rate of nursing facility closures per year over the last decade and describe factors that may be contributing to those closures. The study will contribute to HHS's general understanding of changes in the nursing facility industry and how recent closures may impact access for the aging population.

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Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of AD/ADRD; more than 85% of people surveyed can identify the disease and its symptoms. AD/ADRD is also one of the most feared health conditions, yet there are widespread and significant public misperceptions about diagnosis and clinical management. Misperceptions 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 and Related Dementias

Greater public awareness of AD/ADRD can encourage families to seek assessment, reduce isolation and misunderstanding felt by caregivers, and help link people in need to accurate information, resources and services.

(UPDATED) Action 4.A.1: Enhance public outreach about Alzheimer's disease and related dementias

Through its grant and resource center programs, ACL continues to build awareness of AD/ADRD. All ACL grantees include awareness and outreach in their programs. Numerous grantee programs include dementia-friendly community activities in their projects, partnering with established AD/ADRD stakeholders, as well as training volunteer educators of community organizations including, but not limited to, faith-based organizations, business leaders and grass roots volunteer organizations like Rotary clubs.

ACL's NADRC website is an established hub for resources to support community outreach and education efforts. The website offers a broad range of resources to support the development and implementation of community-based AD/ADRD education programs.

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 AD/ADRD, participation in clinical trials, and caregiving is freely available. NIA disseminates ADEAR's resources through outreach in the research and care communities and through 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 its part, CDC's Alzheimer's Disease and Health Aging Program publishes web features, a series of podcasts, weekly newsletters (67,000 subscribers), and social media to increase awareness and engagement by the public and its stakeholders about AD/ADRD. Web features for 2019-2020 include:
1. **Web Features**
    - Healthy Body, Healthy Brain
    - Loneliness and Social Isolation in Older Adults
    - Caring for Yourself When Caring for Another
    - Minorities and Women Are at Greater Risk for Alzheimer's Disease

2. **Podcasts** (Aging and Health Matters Series)
   - Healthy Body, Healthy Brain
   - Loneliness Puts Older Adults at Risk for Serious Medical Problems
   - What About the Caregivers?
   - The Importance of Physical Activity for Older Adults
   - Alzheimer's Disease -- Genes Do Not Equal Destiny

For more information, see:
- https://www.cdc.gov/aging/publications/features/healthy-body-brain.html
- https://www.cdc.gov/aging/publications/features/lonely-older-adults.html
- https://www.cdc.gov/aging/publications/features/caring-for-yourself.html
- https://www.cdc.gov/aging/publications/features/Alz-Greater-Risk.html
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/407659
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/406088
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/405188
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/402234

Also in 2019-2020, AD+HAP launched on its website a new Communication Center and Resources and Publications hub.

CDC has participated in the *Did You Know?* feature offered by CDC's Center for State, Tribal, Local, and Territorial Support to promote prevention activities. Featured topics have included: brain health, memory loss, chronic conditions in relation to memory loss, and how dementia disproportionately effects minorities and women.

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

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(UPDATED) Action 4.A.2: Facilitate translation of data and surveillance to inform the public

In 2019, CDC translated the national caregiving and SCD infographics into Spanish and develop corresponding infographics for African American, AI/AN, Asian/Pacific Islander, Hispanic, Women, Men, Rural, LGBT, and Veterans. These infographics can be used to educate the public and aid in making decisions on how to allocate resources and funding.

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

Additionally, CDC developed infographics co-branded with the Alzheimer's Association and IHS. These resources are marketed on the Alzheimer's Association website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers.

State of Aging and Health in America: Data Brief Series are topic-specific documents focusing on public health issues related to older adults, developed by CDC and the NACDD. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

For more information, see:
- https://www.cdc.gov/aging/publications/briefs.htm

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

Also see Action 1.E.7 for information on resources developed using BRFSS data.

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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 and Related Dementias Awareness and Readiness across the Government

State, Tribal, and local governments are working to help address challenges faced by people with AD/ADRD and their caregivers. Nineteen states and a handful of local entities have published plans to address AD/ADRD that cover many of the same issues as the National Plan. Leveraging the available resources and programs across these levels of government will aid in the success of these efforts.

(ONGOING) Action 4.B.1: Continue to convene federal partners

The Interagency Group on Alzheimer's Disease and Related Dementias, convened on an ongoing basis since April 2011, provides a forum for discussion of AD/ADRD efforts across federal departments and agencies. Participants in this group have gained a better understanding of the roles and responsibilities of other departments and agencies for addressing AD/ADRD. Together, the group has identified existing resources and new opportunities for collaboration, best practices, and initiatives. HHS will continue to convene federal partners to collaborate on AD/ADRD. The group will share research findings, innovative or best practices, and information about new or upcoming initiatives.

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(ONGOING) Action 4.B.2: Build upon lessons learned to improve the dementia-capacity of state and local service systems

HHS will improve the dementia-capability of state and community service systems through the ACL's ADPI, and the NADRC. ACL and the NADRC have developed the Dementia Capability Assessment Tool designed to measure the dementia-capability of the LTSS in various organizations and measure improvement over time.

ADPI grantees, partners and other collaborators will work in peer-led groups on specific activities to make state and local-level improvements related to dementia-capability. The peer-led groups will develop practical tools to promote the adoption of dementia-capable practices at the state and local-levels. HHS will help states and communities meet the needs of people with AD/ADRD through an expanded Dementia Capability Toolkit and other, related resources. Additional materials will result from similar program activities.

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

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(ONGOING) Action 4.B.3: Get Tribal input on Alzheimer's disease and related dementias and support improved coordination between Indian Health Service, Tribal, and Urban Indian Health programs and the Tribal aging network

HHS will solicit input from Tribal leaders on the impact of AD/ADRD on Indian Country during the annual Tribal Consultation process and through broader meetings and convenings. HHS will use these opportunities to convene leaders and solicit input on the needs related to recognition, diagnosis, and support for individuals with dementia and their families.

The Alzheimer's Association has started meetings with the United South and Eastern tribes and with the Northwest Portland Area Indian Health Board. There has been increased Tribal representation on the Alzheimer's Association/CDC HBI *Road Map for Indian Country* work.

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(ONGOING) Action 4.B.4: Develop and update a public health Road Map for assisting state, Tribal, and local health departments in prioritizing actions

CDC supported the Alzheimer's Association to co-develop the third in a series of HBI Road Maps to advance cognitive health as an integral component of public health, the HBI *State and Local Public Health Partnerships to Address Dementia. The 2018-2023 Road Map* outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Twenty-five specific actions are proposed in four traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

In collaboration with the Alzheimer's Association and numerous partners, the *Road Map for Indian Country* was released in 2019 and disseminated to multiple stakeholders and Tribal leaders. This Road Map has been designed specifically for public health systems serving American Indians, Alaskan Natives, and Native Hawaiians.

For more information, see:
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
- https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html
- https://www.cdc.gov/aging/healthybrain/roadmap.htm

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(UPDATED) Action 4.B.5: Facilitate translation of findings into public health practice in Tribal communities

In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the *Public Health Road Map for Tribal Communities*, the HBI *Road Map for Indian Country*. The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion *Road Map for Indian Country* has been designed specifically for public health systems serving AI/AN adults. Additionally, there are several companion materials to support brain health in Tribal communities developed by CDC in partnership with ASTHO and the Alzheimer's Association. CDC and the Alzheimer's Association, in collaboration with IHS, also produced infographics sharing data from the 2015-2018 BRFSS describing caregiving and SCD among AI/AN adults.

State of Aging and Health in America: Data Brief Series, developed in collaboration with NACDD and CDC are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic

conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

For more information, see:
- https://www.cdc.gov/aging/data/index.htm
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
- https://www.cdc.gov/aging/publications/briefs.htm

Also see Action 2.C.2 for information on CDC's partnership with NCUIH to develop culturally-appropriate resources on brain health and Action 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

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

Many nations have developed dementia plans of their own that involve improved care and supports for people with AD/ADRD and their caregivers, as well as enhanced research and public awareness. In implementing the actions in this Plan, HHS and its federal partners will coordinate with global partners to enhance these plans, avoid duplication of effort, and optimize existing resources.

(UPDATED) Action 4.C.1: Work with global partners to enhance collaboration

The United States participated in the World Health Organization's (WHO's) Global Dementia Observatory (GDO) in 2019. The GDO is an information exchange platform that collects information from countries on dementia policy, service delivery, and information and research. As of August 2019, 21 other countries had submitted information to the GDO.

The HRS: HCAP initiative is an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide. The primary aim of the HRS, funded by NIA and SSA, is to collect and distribute multi-disciplinary data for research on aging. To provide the worldwide research community with new and richer data to study the prevalence, predictors, and outcomes of cognitive impairment and dementia. NIH first supported HCAP during in 2016 when investigators administered a supplemental in-home, 1-hour battery of cognitive tests to about 3,200 randomly selected HRS respondents age 65 and older, along with a 20-minute informant interview. The data from that 2016 assessment have been made publicly-available to the scientific community, and analyses are underway. HCAP 2020, a follow-up to the original, is now being planned. Researchers will readminister the same in-home cognitive assessment and seek an informant report from all surviving members of the original HCAP sample and from a new random sample of those age 65-68 in 2020. HCAP 2020 will provide extensive new data to better assess trajectories of cognitive decline. These data afford an unprecedented opportunity to more clearly describe trends in the incidence and prevalence of dementia around the world. HCAP is also being administered in other developed and developing countries, where HRS-like representative population surveys are conducted, including in China, England, India, Mexico, South Africa, and parts of the EU. In most of these studies, important biomarker data, including DNA for genotyping and future sequencing, is also being collected.

For more information, see:
- https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology
- https://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.118334926.654419972.1601312536-181621991.1601312536

NIA also supports an international team of researchers that has made more progress in explaining the genetic component of AD/ADRD. Their analysis, involving data from more than 35,000 individuals with LOAD, has identified variants in five new genes that put people at greater risk of AD/ADRD. It also points to molecular pathways involved in AD/ADRD as possible avenues for prevention, and offers further confirmation of 20 other genes that had been implicated previously in AD/ADRD. The results of this largest-ever genomic study of AD/ADRD suggests key roles for genes involved in the processing of beta-amyloid peptides, which form plaques in the brain recognized as an important early indicator of AD/ADRD. They also offer the first evidence for a genetic link to proteins that bind tau, the protein responsible for telltale tangles in the AD/ADRD brain that track closely with a person's cognitive decline. The new findings are the latest from the International Genomics of Alzheimer's Project (IGAP) consortium. The effort, spanning four consortia focused on AD/ADRD in the United States and Europe, was launched in 2011 with the aim of discovering and mapping all the genes that contribute to AD/ADRD.

For more information, see:
- https://www.nih.gov/news-events/news-releases/data-sharing-uncovers-five-new-risk-genes-alzheimers-disease

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Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding AD/ADRD and its impact on PWD, 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, low income populations, rural residents, and sexual and gender 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

The Federal Government needs improved data on people with AD/ADRD, their caregivers, and the care and supports that they use to address policy questions and plan and evaluate new initiatives. HHS and its partners will identify the policy questions that cannot be answered with existing data, as well as questions likely to arise in the future. These questions will provide a mechanism for identifying gaps, challenges, and changes or additions to data collection.

(ONGOING) Action 5.A.1: Identify needed changes or additions to data

HHS will work with federal partners and researchers to identify the data and data infrastructure needed to address new policy issues. These changes or additions may include new or improved measures, new data collection efforts, or links between existing datasets.

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(ONGOING) Action 5.A.2: Make needed improvements to data

HHS will address the identified data needs or possible improvements and develop questions to be fielded for data collection. These questions may be added to existing studies, be part of supplements to existing studies, or form the basis of a new study.

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(UPDATED) Action 5.A.3: Summarize data on cognitive impairment across states

CDC continues to summarize and provide infographics from data on cognitive impairment across states. See Action 1.D.3 for a full overview of work on BRFSS and NHANES and Action 4.A.2 for a description of the *State of Aging and Health in America: Data Brief Series*, developed by CDC in collaboration with NACDD.

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(COMPLETED) Action 5.A.4: Develop and disseminate measures of awareness of Alzheimer's disease and related dementias

CDC examined the validity of subjective cognitive questions used in national surveys by comparing self-rated perceptions of cognitive functioning to functional measures. The report, using NHANES cognitive performance testing data, was released in fall 2019 in collaboration with the National Center for Health Statistics (NCHS).

For more information, see:
• https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf

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(UPDATED) Action 5.A.5: Summarize existing data on people with Alzheimer's disease and related dementias and their caregivers

CDC, NIA, and ACL provided new data benchmarks and goals related to AD/ADRD through Healthy People 2020 and Healthy People 2030. During the Healthy People 2020 close-out, more

recent data was provided for "DIA-1: Increase the proportion of adults aged 65 years and older with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis" and "DIA-2: Reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed Alzheimer's disease and other dementias". For Healthy People 2030, the dementia workgroup successfully retained DIA-1 and DIA-2 and added a third core objective "DIA-3: Increase the proportion of adults with SCD who have discussed their confusion or memory loss with a health care professional". These three objectives each set new and ambitious targets to be achieved during the next decade to improve health and quality of life for people with dementia, including AD/ADRD.

For more information, see:
- https://www.cdc.gov/aging/publications/healthy-people-2030/index.html

Also see Action 1.D.3 for full overview of work on BRFSS, Action 4.A.2 for a description of the *State of Aging and Health in America: Data Brief Series* developed by CDC in collaboration with NACDD, and Action 1.E.7 for update on the Caregiving and SCD infographics.

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(UPDATED) Action 5.A.6: Provide analysis of Behavioral Risk Factor Surveillance System data on Alzheimer's disease and related dementias and their caregivers in user-friendly formats

CDC partnered with NACDD to create a series of data briefs addressing topic-specific public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions including the importance of brain health, the management of chronic conditions, and caregiving burdens so as to help identify needs and mitigate the future effects of a growing population of older adults. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

For more information, see:
- https://www.cdc.gov/aging/publications/briefs.htm

Also see Action 1.D.3 for full overview of work on BRFSS, including information on the Cognitive Decline and Caregiver Optional Modules.

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Strategy 5.B: Monitor Progress on the National Plan

The National Plan is intended to be a Road Map for accomplishing its five goals. It is a document that is designed to be updated regularly. HHS is committed to tracking progress and incorporating findings into an updated National Plan.

(ONGOING) Action 5.B.1: Track National Plan progress

HHS will monitor progress to determine whether actions are being completed as stated in the National Plan and the extent to which implemented actions contribute to the desired outcomes and changes associated with each strategy. HHS and its federal partners will identify challenges to the successful completion of strategies and actions, and make recommendations for how they can be addressed. For each strategy, HHS will monitor available population-based data, such as the National Health and Aging Trends Survey (NHATS), Medicare Current Beneficiary Survey, or the BRFSS to assess the extent to which progress is being made. HHS will use data from both the public and private sectors, as appropriate, to track progress on the National Plan. Additionally, HHS will work to incorporate measures related to AD/ADRD into other surveillance efforts to

monitor population health, such as Healthy People 2020 and Healthy People 2030 which incorporate objectives related to AD/ADRD.

For each *Action*, HHS will track implementation to determine whether actions are completed in a timely and successful manner. Appendix 2 provides a timeline, method of action, and identifies lead and partner agencies for each action step in the Plan. Progress on each of these actions will be reported to the Advisory Council.

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(ONGOING) Action 5.B.2: Update the National Plan annually

Tracking progress will help HHS and the Advisory Council monitor progress towards the goals of the National Plan and make recommendations for priority actions and updates to the National Plan. HHS will incorporate its findings and the recommendations of the Advisory Council to update the National Plan on an annual basis.

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(ONGOING) Action 5.B.3: Identify key indicators of progress on the National Plan

ASPE convened federal partners to identify key indicators of progress on the National Plan to Address Alzheimer's Disease. These indicators should be meaningful for the policy makers, program staff as well as the public and enhance our understanding of the impact of the activities described within the framework of the National Plan. Indicators may be available from federal program data or other sources. As a next step, ASPE will host a discussion of this work and gather in form members at a meeting of the Advisory Council on Alzheimer's Research, Care, and Services.

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Appendix 1: List of Participating Departments and Agencies

Administration for Children and Families (ACF)
Administration for Community Living (ACL)
Administration on Aging (AoA)
Administration on Intellectual and Developmental Disabilities (ADD)
Agency for Healthcare Research and Quality (AHRQ)

Centers for Disease Control and Prevention (CDC)
Centers for Medicare & Medicaid Services (CMS)
Consumer Finance Protection Bureau (CFPB)

Department of Defense (DoD)
Department of Health and Human Services (HHS)
Department of Housing and Urban Development (HUD)
Department of Veterans Affairs (VA)

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Food and Drug Administration (FDA)

Health Resources and Services Administration (HRSA)

Indian Health Service (IHS)

National Institute of Neurological Disorders and Stroke (NINDS)
National Institute on Aging (NIA)
National Institute on Minority Health and Health Disparities (NIMHD)
National Institutes of Health (NIH)
National Science Foundation (NSF)

Office of Global Affairs (OGA)
Office of Intergovernmental and External Affairs (IEA)
Office of the Assistant Secretary for Health (OASH)
Office of the Assistant Secretary for Public Affairs (ASPA)
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
Office of the National Coordinator of Health Information Technology (ONC)
Office of the Surgeon General (OSG)
Office on Disability (OD)

Substance Abuse and Mental Health Services Administration (SAMHSA)

Appendix 2: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
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 2018. Summit scheduled for 2021.	NIH/NIA	National and international experts, public and private stakeholders, Research Subgroup, academia, industry, professional and advocacy groups	Ongoing Past Summits: 2012, 2015, 2018 Fourth Summit TBD 2021	2018 AD Research Summit • https://www.nia.nih.gov/research/nih-ad-summit-2018-program-agenda • https://www.nia.nih.gov/research/milestones Planning is underway for an AD Research Summit in spring 2021
1.A.2	Solicit diverse community input on AD research priorities.	Developed recommendations and milestones from 2018 AD Research Summit based on feedback from external stakeholders. Presented recommendations and milestones during IADRFC calls.	NIH/NIA		Updated Recommendations and Milestones were updated following the May 2018 Summit	2018 AD Summit Recommendations • https://www.nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018 2020 National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers • https://www.nia.nih.gov/2020-dementia-care-summit Updated AD Research Implementation Milestones • https://www.nia.nih.gov/research/milestones As of July 2020, the Milestone database now includes better tracking of progress including success criteria and specific implementation activities.
1.A.3	Regularly update the National Plan and refine Goal 1 strategies and action items based on diverse feedback and input.	Update Goal 1 elements of the National Plan to reflect new insights and diverse input from the community.	ASPE	Advisory Council, NIH/NIA, Research Subgroup	Ongoing	
1.A.4	Update research priorities and milestones.	Updated research priorities and milestones.	ASPE	Advisory Council, NIH/NIA, Research Subgroup	Ongoing	
1.A.5	Create a timeline with milestones for achieving Goal 1.	Create and update milestone document.	NIH/NIA, NIH/NINDS		Ongoing	AD/ADRD Research Implementation Milestones comprehensively updated in 2019 to cover progress toward information obtained from AD, ADRD, and Care and Services Summits, including funding initiatives, research programs and resources, and research highlights. Full set of milestones through 2025 • https://www.nia.nih.gov/research/milestones 2020 Milestones • https://www.nia.nih.gov/sites/default/files/2018-07/fy2020-milestones-chart.pdf

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
1.A.6	Regularly convene an ADRD Summit to review progress on research recommendations, and refine and add new recommendations to be considered by the broad scientific community as appropriate, based on recent scientific discoveries.	Convened third Summit in 2019.	NIH/NINDS	Research Subgroup, academia, industry, professional and advocacy groups	Updated Past Summits: 2013, 2016, 2019 Future Summit planned for 2022	The third ADRD Summit was on March 14-15, 2019. Final research recommendations from the ADRD Summit 2019 were adopted by the NINDS Advisory Council in September 2019 and were accepted as new/refined ADRD research milestones by the NAPA Advisory Council in January 2020. • https://www.ninds.nih.gov/sites/default/files/2019_adrd_summit_recommendations_508c.pdf • https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2019-prioritized-research-milestones • https://www.ninds.nih.gov/News-Events/Events-Proceedings/Events/Alzheimers-Disease-Related-Dementias-Summit-2019
1.A.7	Regularly convene a Research Summit on Care, Services, and Supports for PWD and their Caregivers.	Second Care Summit held as virtual Summit series in July and August 2020.	ASPE, NIH	NAPA Advisory Council, academia, industry, professional and advocacy groups	Updated Past Summits: 2017, 2020	The 2017 Summit final report was released in April 2018 • https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report 2020 NIA-hosted Summit recordings, draft research gaps and opportunities, and other information are publicly-available: • https://www.nia.nih.gov/2020-dementia-care-summit • https://www.nia.nih.gov/2020-dementia-care-summit#Materials • https://www.nia.nih.gov/research/summit-gaps-opportunities • https://twitter.com/search?q=%23DementiaCareSummit&src=typeahead_click&f=live
1.A.8	Create and implement a strategic plan for CDMRP PRARP.	Release Strategic Plan.	DoD		New	In 2019, PRARP will release an updated Strategic Plan that identifies the high-impact research goals in the areas of TBIs and AD/ADRD. The Strategic Plan summarizes research funding and findings through the PRARP program since 2011, identified short, medium, and long-term goals for the program. • https://cdmrp.army.mil/prarp/default
1.A.9	Develop and administer a scientific landscape survey for the CDMRP PRARP.	Develop, administer, and analyze results of survey.	DoD			The CDMRP PRARP is administering a survey to the general public regarding future research directions for dementia subsequent to TBI. The survey requests input regarding future research directions for: (1) basic and translational science; (2) quality of life and caregiving research; and (3) efforts regarding future pre-clinical and clinical research. • https://cdmrp.army/mil/prarp/pdfs/PRARP%20Survey%20For%20Distro_FY20.pdf
Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease and Related Dementias						
1.B.1	Expand research to identify the molecular and cellular mechanisms underlying AD/ADRD, and translate this information into potential targets for intervention.	Develop an integrated interdisciplinary basic science research agenda to enable the identification and selection of therapeutic targets.	NIH/NIA, NIH/NINDS	Potential research partners in the public and private sectors	Updated	Ongoing and newly released NIH FOAs: • PAR-17-029: Dynamic Interactions between Systemic or Non-Neuronal Systems and the Brain in Aging and in AD https://grants.nih.gov/grants/guide/pa-files/PAR-17-029.html

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1.B.1 (*continued*)						• PAR-17-031: Role of Age-Associated Metabolic Changes in AD https://grants.nih.gov/grants/guide/pa-files/PAR-17-031.html • PAR-17-033: Integrative Research to Understand the Impact of Sex Differences on the Molecular Determinants of AD Risk and Responsiveness to Treatment https://grants.nih.gov/grants/guide/pa-files/PAR-17-033.html • PAR-17-039: Comparative Biology of Neurodegeneration https://grants.nih.gov/grants/guide/pa-files/PAR-17-039.html • PAR-17-047: Selective Cell and Network Vulnerability in Aging and AD https://grants.nih.gov/grants/guide/pa-files/PAR-17-047.html • PAR-18-029: Clarifying the Relationship between Delirium and AD/ADRD https://grants.nih.gov/grants/guide/pa-files/PAR-18-029.html • PAR-18-497: Sleep disorders and circadian clock disruption in AD/ADRD of aging https://grants.nih.gov/grants/guide/pa-files/PAR-18-497.html • PAR-18-512: Testing Lifespan/Healthspan-Extension Interventions in the Models of AD https://grants.nih.gov/grants/guide/pa-files/PAR-18-512.html • PAR-18-516: Human Cell Biology of AD Genetic Variants https://grants.nih.gov/grants/guide/pa-files/PAR-18-516.html • PAR-18-519: Sensory and motor system changes as predictors of preclinical AD https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html • PAR-18-544: Basic and Translational Research on Decision Making in Aging and AD https://grants.nih.gov/grants/guide/pa-files/PAR-18-544.html • PAR-18-760: In Vivo Synaptic Function in AD/ADRD https://grants.nih.gov/grants/guide/pa-files/PAR-18-760.html • RFA-NS-19-013: LBD CWOW https://grants.nih.gov/grants/guide/rfa-files/rfa-ns-19-013.html • RFA-AG-19-025: Development of Personalized In Vitro Assays to Quantitatively Assess Age-related Changes in Cellular Resiliencies to Physiologic Stressors (R43/R44) https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-19-025.html • RFA-AG-19-026: Development of Personalized In Vitro Assays to Quantitatively Assess Age-related Changes in Cellular Resiliencies to Physiologic Stressors (R41/R42) https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-19-026.html • RFA-NS-19-027: Human 3-Dimensional Cell Model Systems for ADRD https://grants.nih.gov/grants/guide/rfa-files/rfa-ns-19-027.html

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1.B.1 (continued)						• RFA-NS-19-030: NATBI CWOW (U54 Clinical Trial Not Allowed) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-030.html • RFA-NS-19-039: Mechanistic Basis of Diffuse White Matter Disease in VCID (R01) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-039.html • PAR-19-070: Research on Current Topics in ADRD (R01) https://grants.nih.gov/grants/guide/pa-files/PAR-19-070.html • PAR-19-071: Research on Current Topics in ADRD (R21) https://grants.nih.gov/grants/guide/pa-files/PAR-19-071.html • PAR-19-167: Development and Validation of Advanced Mammalian Models for ADRD https://grants.nih.gov/grants/guide/pa-files/par-19-167.html • RFA-NS-20-004: Molecular Mechanisms of Blood-Brain Barrier Function and Dysfunction in AD/ADRD (R01) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-004.html • RFA-NS-20-005: Mechanistic Basis of TDP-43-Dependent Pathobiology in Common Dementias (R01) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-005.html • RFA-AG-20-016: Lucidity in Dementia https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-016.html • RFA-AG-20-025: Understanding Senescence in Brain Aging and AD https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-025.html • RFA-AG-20-040: Oscillatory Patterns of Gene Expression in Aging and AD https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-040.html • RFA-AG-20-041: Regulation of Brain Regional and Cell Type Specific Proteome Dynamics in AD https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-041.html • RFA-NS-21-003: CWOW for Molecular Mechanisms of Neurodegeneration in FTD https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-003.html • RFA-NS-21-006: Mechanisms of Pathological Spread of Abnormal Proteins in LBD and FTD (R01 Clinical Trial Not Allowed) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-006.html • RFA-NS-21-007: Mechanisms of Selective Vulnerability in LBD and FTD (R01 Clinical Trial Not Allowed) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-007.html

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1.B.1 (*continued*)						AMP-AD Activities are also relevant • https://www.nia.nih.gov/alzheimers/amp-ad Established TREAT-AD consortium in 2019 • https://www.nia.nih.gov/news/nih-funded-translational-research-centers-speed-diversify-alzheimers-drug-discovery Continue to support efforts through Tau CWOW • http://tau-center-without-walls.org/east-cwow/overview
1.B.2	Expand genetic epidemiologic research to identify risk and 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, NIH/NINDS	Potential research partners in the public and private sectors	Updated	Ongoing and newly released FOAs: • PAR-17-214: Limited Competition: Analysis of Data from NIA's ADSP Follow-Up Study https://grants.nih.gov/grants/guide/pa-files/PAR-17-214.html • PAR-16-371: Phenotypic and Functional Characterization of ApoE2 to Inform Translation Strategies for Aging-Related Conditions https://grants.nih.gov/grants/guide/pa-files/PAR-16-371.html • PAR-16-205: NIA LOAD Family-Based Study https://grants.nih.gov/grants/guide/pa-files/PAR-16-205.html • PAR-16-406: Limited Competition: Additional Sequencing for the ADSP https://grants.nih.gov/grants/guide/pa-files/PAR-16-406.html • NOT-NS-18-082: Notice of the NINDS' Participation in PAR-18-296 and interest in Clinical Trial readiness applications for FTD by NIA and NINDS https://grants.nih.gov/grants/guide/notice-files/NOT-NS-18-082.html • PAR-18-889: Limited Competition: Renewal of, and Revisions to the AD Genetics Consortium https://grants.nih.gov/grants/guide/pa-files/PAR-18-889.html • RFA-NS-19-012: Post-Stroke VCID in the US Including in Health Disparities Populations (U19) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html • RFA-NS-19-013: LBD CWOW (U54) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-013.html • PAR-19-234: Limited Competition: Additional Sequencing for the ADSP https://grants.nih.gov/grants/guide/pa-files/PAR-19-234.html • PAR-19-269: Cognitive Systems Analysis of AD Genetic and Phenotypic Data https://grants.nih.gov/grants/guide/pa-files/PAR-19-269.html

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1.B.2 (*continued*)						• RFA-NS-20-013: White Matter Disease Etiology of Dementia in the US Including in Health Disparities Populations https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-013.html • RFA-NS-21-003: CWOW for Molecular Mechanisms of Neurodegeneration in FTD https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-21-003.html Continue to support efforts through: ADSP • https://www.niagads.org/adsp/content/home NIAGADS • https://www.niagads.org/ FTD Sequencing Consortium • https://www.allftd.org/ In 2020, VA launched a new research partnership initiative with NIA for AD/ADRD called AD-VANCE initiative. The inaugural major collaborative effort under the AD-VANCE initiative is the VA-NIA Genetics Initiative for AD, which leverages veterans' data from the VA MVP to understand genetic risk factors for AD/ADRD.
1.B.3	Increase enrollment in clinical trials and other clinical research through community, national, and international outreach.	Identify approaches and coordination points for these efforts; develop an action plan that incorporates these ideas; collaborate to increase awareness among health and social service providers.	NIH/NIA, ACL, CDC, VA	FDA, VA, CDC, HRSA, CMS, in partnership with the private sector	Updated	Culminating from the efforts of expert working groups, steering committee, and crowdsourced public input, and with facilitation by the Alzheimer's Association, NIA produced the National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research, which was presented to the NAPA Advisory Council in October 2018. • https://www.nia.nih.gov/research/recruitment-strategy In 2019, NIA launched ADORE, an online repository of planning tools, best practices, and materials to support researchers' recruitment and retention efforts. NIA is currently developing a web-based communication tool that will enable health care professionals in the community to easily produce a "package" of tailored materials and strategies that can be branded locally to increase participant recruitment for clinical studies. • https://www.nia.nih.gov/research/adore • https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources

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1.B.3 (*continued*)						NIA is currently investing in the expansion of its clinical trial data infrastructure to more seamlessly track enrollment to NIA-funded clinical studies. • https://www.nia.nih.gov/alzheimers/clinical-trials NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through our ADEAR website portal; clinical trials listing and monthly e-alert to more than 16,000 subscribers; social media messages through Facebook and Twitter; promotion of ADORE materials; and collaboration with federal agencies and advocacy organizations to encourage research participation among older adults, including through the Focus on Aging interagency webinar series. • https://www.nia.nih.gov/news/focus-aging-federal-partners-webinar-series Ongoing released FOAs: • PAR-18-749: Examining Diversity, Recruitment and Retention in Aging Research https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.htm The 2019 HRSA GWEP Notice of Funding Opportunity included language to educate and train patients, families, caregivers, direct care workers, health care providers, and health professions students, faculty, residents, and fellows on when it is appropriate to recruit older adults into research. • https://bhw.hrsa.gov/fundingopportunities/default.aspx?id=4c8ee9ff-617a-495e-ae78-917847db86a9 In 2020, VA is one of the recruitment networks for the NIA-funded PREVENTABLE trial, which aims to determine whether statin can prevent dementia and disability in addition to heart disease and other cardiovascular-related deaths. The VA CSP Pharmacy Coordinating Center serves as the central pharmacy for the trial to distribute medications to study participants.
1.B.4	Monitor and identify strategies to increase enrollment of racial and ethnic minorities in AD/ADRD studies.	Track enrollment in NIH AD/ADRD studies; identify and implement next steps for engaging and enhancing research participation by racial and ethnic minorities; raise awareness of need for participation.	NIH/NIA, NIH/NIMHD	ACL	Updated	See 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in AD Clinical Research released in fall 2018. This strategy includes approaches to increase enrollment of racial and ethnic minorities in AD/ADRD studies outlined in recommendations of the National Strategy Group's Local, Diverse Working Group which have been transformed into the AD/ADRD Clinical Studies Recruitment Planning Guide. • https://www.nia.nih.gov/research/recruitment-strategy • https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf

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1.B.4 (*continued*)						NIMHD has begun a new clinical trial on "Addressing the Knowledge and Recruitment Gap in AD-PM among Native People". An innovative pragmatic Randomized Controlled Trial with 4,000 AI/AN enrollees. • https://projectreporter.nih.gov/project_info_description.cfm?aid=9570695&icde=41152371&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball= • https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-047.html • https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=15EEC10D4C8DC5D37598B8961CAA4A01A2FFCEB861BF The NIA-funded ACTC will develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations and establish a new minority outreach and recruitment team. • https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias ADRCs also enhance and promote diversity of research participants. ADRCs have set up a Latino interest group. This group is helping to ensure that materials are available in Spanish, addressing the needs of Spanish speaking participants, and assuring research capacity (with both materials and staff training) for assessment in Spanish. • https://www.nia.nih.gov/research/adc Ongoing FOAs: • PAR-18-749: Examining Diversity, Recruitment and Retention in Aging Research https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html • NOT-AG-18-047: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 Health Disparities and AD https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-047.html • RFA-AG-20-023: Exploratory ADRCs (P20 Clinical Trial Not Allowed) https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-20-023.html

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1.B.5	Conduct clinical trials on the most promising pharmacologic interventions.	Identify partnerships with private sector participants to voluntary share information about new and ongoing clinical trials. Develop partnerships to better coordinate federal and private sector review of the status and progress of the trials and emerging opportunities. Review the status and progress of clinical trials annually.	NIH/NIA	VA	Updated	FOAs for clinical trials have been released: • PAR-18-513: ACTC Clinical Trials (R01 Clinical Trial Required) https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html • RFA-AG-20-029: Pragmatic Trials of Managing Multimorbidity in AD https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html • PAR-18-877: Early Stage Clinical Trials for the Spectrum of AD and Age-related Cognitive Decline (R01 Clinical Trial Optional) https://grants.nih.gov/grants/guide/pa-files/par-18-877.html • PAR-18-878: Late Stage Clinical Trials for the Spectrum of AD and Age-related Cognitive Decline (R01 Clinical Trial Required) https://grants.nih.gov/grants/guide/pa-files/PAR-18-878.html Launched in 2017, a new clinical trials consortium funded by NIA is expected to accelerate and expand studies for therapies in AD/ADRD. ACTC is a "next-generation" infrastructure designed to harness best practices and latest methods for AD trials. • https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias • https://www.nia.nih.gov/research/ongoing-AD-trials Coordination of federal, non-federal, and international AD/ADRD research, including clinical trials, can be found in the IADRP • http://iadrp.nia.nih.gov/
1.B.6	Continue clinical trials on the most promising lifestyle interventions.	Conduct annual reviews of the status and progress of clinical trials.	NIH/NIA	VA	Updated	FOAs for clinical trials have been released: • PAR-18-513: ACTC Clinical Trials (R01 Clinical Trial Required) https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html • RFA-AG-20-029: Pragmatic Trials of Managing Multimorbidity in AD https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html See 1.B.5 for updates regarding ACTC and ongoing clinical trials supported by NIA. Many of the approximately 140 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD include testing lifestyle interventions such as diet and exercise. • https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias • https://www.nia.nih.gov/research/ongoing-AD-trials

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1.B.6 (*continued*)						The INFINITY trial indicated that, after 3 years of treatment, intensive lowering of blood pressure slowed white-matter disease in adults age 75 and older with high blood pressure. • https://www.nia.nih.gov/news/intensive-blood-pressure-control-slowed-white-matter-disease-adults-age-75-and-older IADRP facilitates tracking research efforts, including treatment studies • http://iadrp.nia.nih.gov/cadro-web/
1.B.7	Expand research focused on needs related to the intersection of Down syndrome and AD/ADRD.	Develop a research agenda from basic to clinical studies that aims to better understand the interplay between Down syndrome and AD/ADRD.	NIH		Updated	INCLUDE project was launched in June 2018. • https://www.nih.gov/include-project ACTC-DSN • https://projectreporter.nih.gov/project_info_description.cfm?aid=9749625&icde=46135063&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball= • https://projectreporter.nih.gov/project_info_description.cfm?aid=9893363&icde=46762199 AD Biomarker Consortium--Down Syndrome aims to identify biomarkers that indicate AD is developing or progressing and track the AD process in people with Down syndrome. • https://www.nia.nih.gov/research/abc-ds • https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx Additionally, NIA and NICHD collaborated to produce and disseminate information for people with Down syndrome and their families on the interplay of these conditions and the importance of participating in research. Efforts include a fact sheet, AD in People with Down Syndrome, and outreach via email and social media. • https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome
1.B.8	Issue a joint VA-NIA career development award for physician scientists new to the area of dementia research.	Collaborate with NIA on a Mentored Physician Scientist Award in Alzheimer's Disease and Related Dementias.	VA		Updated	In FY 2020, VA received several research proposals in response to the early career physician-scientist mentored research in AD/ADRD funding announcement. Funds have been committed to supporting the meritorious awards. This program has been approved for another year.

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1.B.9	Expand research for care and support of individuals with cognitive and behavioral symptomatology related to both TBI and dementia.	Release funding announcements and award grants for research on patient-centered approaches to address cognitive and behavioral symptomatology.	DoD		New	The InCASA was offered for the first time for the CDMRP PRARP in 2019. The InCASA supports innovative research that improves the quality of life and care for individuals living with the common symptoms of TBI and/or AD/ADRD and/or their families and care providers. For this funding opportunity, applicants were encouraged to propose work that should challenge existing research paradigms, or exhibit high levels of creativity. The RPA mechanism was also offered as a multi-partnered funding opportunity. The RPA requires partners from diverse backgrounds to come together and work on a project that neither individual investigator alone could achieve. Applications to this mechanism were required to demonstrate long and short-term benefits of their projects. Applications to the RPA were also required to show how the efforts will ultimately benefit individuals affected by AD/ADRD, their caregivers, and their families. Copies of the most recent PRARP Program Funding Opportunities available online. • https://cdmrp.army.mil/funding/archive/prarparchive
Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias						
1.C.1	Identify imaging and biomarkers to monitor disease progression.	Conduct annual reviews of ADNI to identify and monitor disease progression.	NIH/NIA, NIH/NINDS	ADNI partners, AMP partners	Updated	Ongoing reporting and monitoring of ADNI activities, continuing on an annual basis, along with provision of research funding on developing and testing diagnostic tools. ADNI's activities are and will continue to be monitored and reviewed on an annual basis • http://adni.loni.usc.edu/ AMP-AD • https://www.nia.nih.gov/alzheimers/amp-ad • https://amp-pd.org/ In 2019 and early 2020, NIH-supported scientists reported advances in the development of blood-based tests that could enable rapid screening of volunteers who wish to enroll in studies. In addition to blood tests, other NIH-supported research projects are designed to look beyond current measures to identify people with dementia earlier in the disease process. • https://www.nia.nih.gov/news/nia-small-business-funding-seeks-find-blood-based-diagnostic-alzheimers-disease • https://www.nia.nih.gov/news/blood-test-shows-promise-predicting-presymptomatic-disease-progression-people-risk-familial • https://www.nia.nih.gov/news/blood-test-method-may-predict-amyloid-deposits-brain-potentially-indicating-alzheimers-disease

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1.C.1 (*continued*)						• PAR-18-519: Sensory and motor system changes as predictors of pre-clinical AD https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html • RFA-NS-19-012: Post-Stroke VCID in the US Including in Health Disparities Populations (U19 Clinical Trial Not Allowed) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html To enable better patient stratification, diagnosis, and tracking of disease progression in LBD, FTD, VCID, and dementias with mixed etiologies, NINDS has released several funding opportunities to support the development of biomarkers, including imaging ligands, for ADRD. • NOT-NS-18-082: Notice of the NINDS' Participation in PAR-18-296 and interest in Clinical Trial readiness applications for FTD by NIA and NINDS https://grants.nih.gov/grants/guide/notice-files/NOT-NS-18-082.html • PAS-19-210: Progression Markers for Cognitive Impairment in Parkinson's Disease Dementia (R01) https://grants.nih.gov/grants/guide/pa-files/PAS-19-210.html • RFA-NS-16-022: Biomarkers for the LBD (U01) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-022.html • RFA-NS-17-016: Leveraging Existing Resources for Research on LBD (R03) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-016.html • RFA-NS-19-014: CWOW for PET Ligand Development for ADRD (U19) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-014.html • PAR-19-170: Progression Markers for Cognitive Impairment in Parkinson's Disease Dementia (R01) https://grants.nih.gov/grants/guide/pa-files/PAR-19-170.html • RFA-NS-20-012: VCID Biomarker and Interventional Clinical Trials Planning https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-012.html • RFA-NS-20-014: Peripheral Pathology in the LBD https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-014.html

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1.C.1 (*continued*)						NIH continues to support a small vessel VCID Biomarkers Consortium (MarkVCID) to develop and validate candidate human biomarkers for small vessel disease in the brain that would enable more accurate identification of those at-risk for long-term cognitive decline and tracking of disease progression in individuals already affected by cognitive impairment and dementia • https://markvcid.partners.org/ Ongoing and newly released FOAs include: • RFA-NS-19-026: Clinical and Biological Measures of TBI-related dementia including CTE (R01) https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-026.html • NOT-AG-18-048: Notice to Specify High-Priority Research Topics for PAR-19-070 and PAR-19-071 Novel Approaches to Characterizing and Diagnosing AD/ADRD https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html
1.C.2	Maximize collaboration among federal agencies and with the private sector.	Identify additional partnership opportunities with the private sector and facilitate collaborative efforts to enhance identification of risk factors and early biomarkers.	NIH/NIA, NIH/NINDS	FDA, AMP partners	Updated	AMP-AD is an NIH-supported precompetitive partnership among government, industry, and non-profit organizations that focuses on discovering novel, clinically relevant therapeutic targets and on developing biomarkers to help validate existing therapeutic targets. The program brings together geneticists, epidemiologists, biologists, data scientists and drug discovery experts across many academic institutions and 4 pharmaceutical industry organizations. AMP-AD (Projects A and B) • http://www.nia.nih.gov/research/amp-ad • https://amp-pd.org/ ADNI is also a public-private partnership between NIH, the Canadian government, and over 20 biopharmaceutical companies and non-profit organizations. ADNI is in collaboration with the ADSP • http://adni.loni.usc.edu/about/funding/ IADRP facilitates tracking research efforts in the public and private sector. • https://iadrp.nia.nih.gov/

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1.C.2 (*continued*)						CAP is a public-private partnership that brings together research groups to harmonize biomarker, clinical, and cognitive measures and align data-sharing and sample-sharing approaches used in certain trials so that findings can inform the entire research community. CAP includes researchers from 3 trials co-funded by NIH, industry, and foundations • https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847536/ • https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5111162/ NIH-funded Tau CWOW is a multi-center, interdisciplinary program that was established in FY 2016 to investigate the molecular mechanisms of tau toxicity in FTD. One of the requirements of this program is to have ongoing collaborative partnerships with non-profit non-governmental organizations and philanthropic entities, such as AFTD, CurePSP, and the Rainwater Charitable Foundation. • https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-16-023.html
Strategy 1.D: Coordinate Research with International Public and Private Entities						
1.D.1	Inventory AD/ADRD research investments.	International AD Research Database launched July 2012 and continually updated. It was relaunched as the International AD/ADRD Dementias Research Portfolio in July 2018 and continually updated.	NIH/NIA		Updated	IADRP now includes data from over 40 public and private funding organizations across more than 10 countries. • https://iadrp.nia.nih.gov/ In 2018, the IADRP database was relaunched with a number of changes to CADRO, including greater specificity in the coding of FTD, LBD, and VCID. • https://iadrp.nia.nih.gov/about/cadro
1.D.2	Expand international outreach to enhance collaboration.	Invite international colleagues to meet and discuss AD/ADRD research priorities and collaboration through regular meetings in-person and via teleconference.	NIH/NIA		Updated	In collaboration with the EU JPND, NIH is participating in the upcoming EU mapping exercise that invites 20+ countries to submit their recently funded neurodegenerative research (notably AD/ADRD). • http://www.neurodegenerationresearch.eu/initiatives/mapping-excercise/data-collected/ • https://www.neurodegenerationresearch.eu/wp-content/uploads/2018/07/JPND-Mapping-Exercise-Report-28Final2912072018.pdf Alzheimer's Disease Funders' meeting held during the 2020 AAIC; quarterly funders' calls led by NIA and Alzheimer's Association. Also, IADRP which includes data from over 40 public and private funding organizations across more than 10 countries is publicly-available for use. • https://iadrp.nia.nih.gov/

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1.D.2 (*continued*)						HRS: HCAP is being administered in the US and other developed and developing countries, where HRS-like representative population surveys are conducted, including in China, England, India, Mexico, South Africa, and parts of the EU. Data is currently available from the US, England, and Mexico with data release scheduled for India, South Africa, and China by the end of 2020. In 2019, HCAP studies were also begun in the Caribbean basin and Chile. NIA funded in 2019 a research network to support the continued harmonization of the HCAP studies and a related project focused on harmonizing cognitive assessments in Irish, English, and American longitudinal studies to support cross-national research on the epidemiology of dementia. • https://hrs.isr.umich.edu/welcome-health-and-retirement-study • https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/ • https://projectreporter.nih.gov/project_info_description.cfm?aid=9618704&icde=42939202 • https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-016.html • https://grants.nih.gov/grants/guide/pa-files/PAS-17-028.html • https://projectreporter.nih.gov/project_info_description.cfm?aid=10003934&icde=51152035&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball= • https://projectreporter.nih.gov/project_info_description.cfm?aid=10017122&icde=51152035&ddparam=&ddvalue=&ddsub=&cr=3&csb=default&cs=ASC&pball= • https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology • http://hrsonline.isr.umich.edu/index.php?p=shoavail&iyear=ZU&_ga=2.3082800.1242911673.1556821900-1050997585.1555960426 • http://www.mhasweb.org/Data.aspx In 2019, the NIA funded a research network to support the continued harmonization of the HCAP studies and a related project focused on harmonizing cognitive assessments in Irish, English, and American longitudinal studies to support cross-national research on the epidemiology of dementia.

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1.D.3	Identify research priorities via surveys tracking health conditions and risk factors.	Use BRFSS optional modules on SCD and Caregiving to measure burden and determine priority areas for action.	CDC		Updated	BRFSS is the world's largest, ongoing telephone health survey system, tracking health conditions and risk behaviors in the US yearly since 1984. It is conducted by all states under the direction of CDC with state public health authorities. There are 2 optional modules that states can include in their annual BRFSS survey on the topics of caregiving and cognitive decline. The Caregiver Module from 2015-2018 has been administered in 44 states, the DC, and Puerto Rico; while the Cognitive Decline Module was administered in 50 states, DC, and Puerto Rico in 2015-2016. Collecting and analyzing this data allows the study of burden, impact, and trends and is used by decision makers to decide course of action for research as well as interventions. In August 2020, CDC released a Technical Assistance Document for both the Caregiving and Cognitive Decline modules designed to assist data users through the analytic process. The data are available in a searchable data portal, data briefs, and infographics with national estimates, by state, sex, rural status, veteran status, and race/ethnicity. • https://www.cdc.gov/aging/publications/BRFSS-caregiver-brief-508.pdf • https://www.cdc.gov/aging/agingdata/index.html • https://www.cdc.gov/aging/data/index.htm • https://www.cdc.gov/aging/healthybrain/brfss-faq.htm • https://www.cdc.gov/aging/publications/briefs.htm • https://www.cdc.gov/brfss/index.html Cognitive Performance and SCD are included on the NHANES. NHANES is designed to assess the health and nutritional status of adults and children in the US. Conducted since 1960, the survey includes both interview and physical examination components. The survey examines a nationally representative sample of about 5,000 persons each year. The NHANES interview includes demographic, socioeconomic, dietary, and health-related questions. The examination component consists of medical, dental, and physiological measurements, as well as laboratory tests administered by highly trained medical personnel. • https://www.cdc.gov/nchs/nhanes/ • https://wwwdev.cdc.gov/nchs/nhanes/ Data on Cognitive Performance and SCD in adults aged 60 years and older were collected from 2011-2014. Assessments conducted included: • SCD • 10-item word list learning with both immediate and delayed recall • Animal Fluency • Digit Symbol Substitution

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1.D.3 (*continued*)						NHANES Cognitive Performance and SCD data from 2011-2014 are publicly accessible and available at the NHANES website. All data for cognitive performance can be found under Questionnaire Data. SCD data are in the Medical Conditions data file, and data for the cognitive functioning assessments are in the Cognitive Functioning data file. For an example of an analysis conducted using these data and a more detailed description of NHANES and the cognitive variables are in an online article. • https://wwwdev.cdc.gov/nchs/nhanes/ • https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf Data on Cognitive Performance and SCD in adults aged 60 years and older were collected from 2019-2020. Assessments conducted included: • SCD • MoCA NHANES Cognitive Performance and SCD data from 2019-2020 are anticipated to publicly accessible and available at the NHANES website in 2021. • https://wwwdev.cdc.gov/nchs/nhanes/ • https://www.cdc.gov/aging/agingdata/index.html • https://www.cdc.gov/aging/publications/nhanes/index.html • https://www.cdc.gov/nchs/nhanes/
Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs						
1.E.1	Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings.	Disseminate research findings through various media and in partnership with organizations, particularly those involving interventions in treatment and care.	NIH/NIA	FDA, ACL, CDC, partner organizations	Ongoing	NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. • https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals NIA supports the AMP-AD Target Discovery Project, which has generated a wealth of molecular data from over 3,000 human brain and plasma samples collected in several NIA-supported AD cohorts and brain banks. The project makes these datasets available to the greater research community through the AMP-AD Knowledge Portal.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
1.E.1 (*continued*)						In 2018, these novel target predictions, along with the data and analyses that led to their discovery, were made available via a new AMP-AD data resource, the AGORA platform. This web-based, interactive platform will enable researchers in academia and biotech and pharmaceutical communities to leverage AMP-AD analyses and results to enhance their own work and build on the AMP-AD discoveries. • https://www.nia.nih.gov/research/amp-ad • https://ampadportal.org/
1.E.2	Continue to promote use of the ADEAR Center to provide evidence-based information on AD/ADRD to the public and others.	Prepare and disseminate regular reports on AD/ADRD research findings.	NIH/NIA	ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations	Updated	NIA's ADEAR Center routinely disseminates information on AD/ADRD research findings through our website, regular weekly and monthly email alerts to more than 16,000 subscribers, and social media (Twitter and Facebook). • https://www.nia.nih.gov/alzheimers Progress in AD research is also reported in the annual Bypass Budget proposal. • https://www.nia.nih.gov/about/bypass-budget-proposal-archive In FY 2019, 1 GWEP grant recipient (University of Southern California) is partnering with 3 ADCs. The remaining 47 are encouraged to work with nearby ADCs.
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	• https://www.fda.gov/media/110903/download • https://www.fda.gov/regulatory-information/search-fda-guidance-documents/clinical-considerations-investigational-device-exemptions-ides-neurological-devices-targeting
1.E.4	Expand and disseminate research on co-occurring conditions and dementias.	Literature review to be disseminated through CDC's public health network, AoA's Aging Network, and NIA research network.	CDC	ACL, NIH/NIA	Updated	The third HBI Road Map for State and Local Public Health was released in late 2018 identifying 25 actions for public health professionals related to cognitive health, including cognitive impairment and caregiving for persons with a cognitive impairment, through 2023. In 2019, the first Road Map for Indian Country was released identifying 8 priority actions for Indian Country. • https://www.cdc.gov/aging/healthybrain/roadmap.htm • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html

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1.E.4 (*continued*)						CDC published a peer-reviewed paper of co-occurring chronic health conditions and a companion data brief and podcast (English and Spanish) in 2020. Additionally, CDC has partnered with NACDD to develop a series of rack cards for distribution at public health and other medical clinics and other appropriate areas, including health fairs or other health promotional events. These rack cards are designed to educate about risk reduction practices related to AD/ADRD, including the importance of physical activity, healthy diet, blood pressure control, blood sugar management, and smoking cessation. These risk reduction messages can then be integrated alongside existing health promotion messaging among states and other partners. • https://academic.oup.com/innovateage/article/4/1/igz045/5687172 • https://www.cdc.gov/aging/publications/chronic-diseases-brief.html • https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892 • https://tools.cdc.gov/medialibrary/index.aspx#/media/id/410065 NIA and NINDS jointly produce and disseminate content on AD/ADRD, including FTD, LBD, and VCID. • https://www.nia.nih.gov/health/alzheimers/related-dementias • https://www.ninds.nih.gov/current-research/focus-disorders/alzheimers-related-dementias • https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Frontotemporal-Dementia-FTD • https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Lewy-Body-Dementia-LBD-Research • https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Vascular-Contributions-Cognitive • https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias/Focus-Mixed-Etiology-Dementias-MED
1.E.5	Provide information to the public on brain health.	Develop and disseminate a brain health resource to aging, disability, and public health professionals.	ACL, NIH/NIA, NIH/NINDS, CDC	CMS, HRSA, VA, private partners	Updated	On February 2, 2016, NINDS launched a public health campaign on link between hypertension and cognitive decline for integration with the HHS Million Hearts Campaign. • https://mindyourrisks.nih.gov/

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1.E.5 (*continued*)						NIA also maintains a web portal on Cognitive Health and Older Adults. • https://www.nia.nih.gov/health/cognitive-health The campaign What is Brain Health? formerly managed by ACL was transferred to NIA in 2017. • https://brainhealth.nia.nih.gov/ In 2020, the VA posted information about brain health on its Office of Geriatrics and Extended Care website. The information was developed by the VA GRECC program. For information, see: • https://www.va.gov/geriatrics/brain/ • https://www.va.gov/GERIATRICS/docs/GRECCBrainHealthBooklet.pdf In 2019, all of the 48 HRSA-funded GWEPs were educating and training the public on brain health including sharing resources. CDC disseminates a weekly newsletter to more than 67,000 subscribers. It is a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health. • https://tools.cdc.gov/campaignproxyservice/subscriptions.aspx?email=YOUREMAILHERE@youremail.com&topic_id=USCDC_944&origin=&pop=t CDC recently launched a series of podcasts titled "Aging and Health Matters" that includes short discussions on issues in older adult health, including ADRD and caregiving. Topics include: "Healthy Body, Healthy Brain", "AD-Genes do not equal Destiny", and "Memory Problems? Talk to your Doctor" among others. • https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101 ACL's ADPI grantees embed brain health education in their funded activities. Through partnerships with private non-profit educational entities grantees are bringing a broad range of brain health resources to the communities they serve. ADPI-funded activities include, but are not limited to, brain health educational opportunities as a means to introducing opportunities for ADRD screening/assessments and benefits counseling.

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1.E.5 (*continued*)						ACL continues to maintain their brain health curriculum Brain Health: You Can Make a Difference! Brain Health Basics. The resource offers a PowerPoint presentation for professionals to use in educating older adults and adults with disabilities about brain health as we age, and a related handout for consumers. • https://acl.gov/brain-health
1.E.6	Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings.	Develop a 1-1.5 hour(s) CME/MOC module on the benefits of blood pressure management as a potential mechanism to reduce cognitive decline and dementia.	CDC	Private partners	Completed	CDC in collaboration with the American College of Preventive Medicine developed a Brain Health Continuing Education Course and resource page to increase physician and health care professionals' awareness of brain health as a serious health condition and to increase the number of physicians and health care professionals acting to address, diagnose, and refer patients with brain health issues to care and community support programs. The module was included as an elective in the Lifestyle Medicine Core Competencies Online Program in December 2018. • https://www.acpm.org/page/brainhealth
1.E.7	Facilitate translation of findings into public health practice.	Develop and update a Public Health Road Map.	CDC	Public and private partners	Updated Released in fall 2018	CDC provided funds to the Alzheimer's Association to co-develop the third in a series of HBI Road Maps to advance cognitive health as an integral component of public health. This HBI State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map was co-authored by experts in public health and brain health, including scientists at CDC. The Road Map outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. 25 specific actions are proposed in 4 traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate. Additionally, CDC has developed a series of 5 Issue Maps that highlight specific sets of Road Map actions related to caregiving, risk reduction, early detection of AD/ADRD, and the education of health professionals. The associated planning tool was developed to guide state and local public health professionals through quick steps in selected Road Map items and getting started with implementation in their jurisdictions. 2 podcasts were also produced discussing the updated Road Map. In 2019, the first Road Map for Indian Country was released identifying 8 priority actions for Indian Country. • https://www.cdc.gov/aging/healthybrain/roadmap.htm • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html

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1.E.7 (*continued*)						• https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html • https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html • https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html • https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html • https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html • https://www.cdc.gov/aging/publications/podcasts.htm The BOLD Infrastructure for Alzheimer's Act was passed into law on December 31, 2018 (P.L. 115-406), and amends the Public Health Service Act (Section 398A; 42 U.S.C. 280c-3-4) is designed to facilitate the translation of findings into public health practice. The activities outlined in BOLD are designed to create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It is designed to promote implementation of CDC's HBI State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map and the HBI Road Map for Indian Country. • https://uscode.house.gov/statutes/pl/115/406.pdf • https://www.cdc.gov/aging/healthybrain/roadmap.htm • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html Specifically, the BOLD Infrastructure for AD Act directs CDC to: • Establish ADRD PHCOE • Provide Funds to Support Public Health Departments • Increase Data Analysis and Timely Reporting CDC will announce the first recipients of the BOLD PHCOE and BOLD Public Health Programs awards in late FY 2020. • https://www.cdc.gov/aging/bold/index.html

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1.E.7 (*continued*)						CDC is partnering with ASTHO to produce a series of products to support public health agencies in identifying priorities, areas of synergy within existing or upcoming jurisdictional plans, and opportunities for integrating cognitive health into public health efforts as guided by the HBI Road Maps. Products designed to facilitate implementation of the HBI Road Maps include a series of HBI Action Institutes across the country in each HHS region, Health communication materials for AI/AN communities, and a series of recorded webinars to promote the importance of public health in addressing brain health.
						• https://www.astho.org/Healthy-Aging/
						See 1.E.4 for information on CDC's partnership with NACDD to develop public health-focused rack cards.
						Additionally, CDC has partnered with The Balm in Gilead and the NBHCAA to address the higher prevalence of dementias and disparities in dementia diagnosis and treatment among African Americans through strategic and culturally tailored public health approaches. In partnership with CDC, The Balm in Gilead over the past year has garnered more than 25,000 social media impressions during week long "Road to Memory Sunday" campaign; 1000+ viewers participated in the Facebook Live Memory Sunday Townhall, with over 300 shares including 73 Facebook Watch Parties, distributed over 1,700 copies of the Book of AD and Memory Sunday Toolkit to congregations and community partners. Furthermore, they have produced a 4-part virtual web series is to engage public health, health care providers, and other key stakeholders working to address today's challenges of brain health and AD among African Americans and communities of color. Each session within the series aims to connect public health issues of aging with a cultural understanding of faith and spirituality. Through insightful and evidence-based discussion, participants will learn how effectively connect faith and public health approaches to raise awareness about the impacts of AD/ADRD and mobilize communities in a deliberate way to improve brain health equity.
						CDC updated technical assistance documents meant to provide guidance for BRFSS coordinators and researchers who would like to conduct analyses of the data collected through the 2018 BRFSS Caregiver Optional Module and the 2018 BRFSS Cognitive Decline Module. These documents provide basic computer code for analyzing the data with a goal to enable consistency in analytic methods and results reported.

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1.E.7 (*continued*)						CDC is partnering with the NIHB to expand knowledge of public health practice within AI/AN communities. NIHB is expanding website content aimed at health practitioners, as well as conducting a virtual Brain Health Action Institute for Tribal Nations. This institute, facilitated by NIHB, will support tribes and Tribal organizations in using the HBI Road Map for Indian Country to start conversations, as well as develop and plan strategies for improving brain health in their own communities. The Road Map for Indian Country is the first-ever public health guide focused on dementia in AI/AN communities. CDC contributed to the Public Health Perspectives on the Family Care Gap textbook with a book chapter that illustrates a public health approach to supporting caregivers of people with dementia using the HBI State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. It is framed using essential public health services and identifies 25 strategies for public health action to support caregivers. It also addresses the anticipated family care gap and urges the collaboration of public health systems to collect data and equitably implement evidence-based policies and programs that support people providing care in their communities. This book will be published in 2021. CDC has updated the Caregiving and SCD infographic series. The infographics were developed using 2015-2018 BRFSS data from the Caregiving and SCD modules. The infographic populations include: National Combined Data, African American, AI/AN, Asian/Pacific Islander, Hispanic, Women, Men, Rural, LGBT, and Veterans. These infographics can be used to educate the public and aid in making decisions on how to allocate resources and funding. • https://www.cdc.gov/aging/healthybrain/brfss-faq.htm • https://www.cdc.gov/aging/publications/briefs.htm The National Combined Data, African American, AI/AN, Asian/Pacific Islander, Hispanic, Women, and Men populations have been translated to Spanish. • https://www.cdc.gov/aging/data/index.htm

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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 GWEP about how to: (1) work with people with the disease, and their families; (2) link people to support services in the community, identify signs of caregiver burden and depression; and (3) detect cognitive impairment and assess/diagnose AD/ADRD.	HRSA	CMS, NIH/NIA, CDC, ACL collaboration	Updated	In FY 2019, HRSA competed the GWEP and made 48 awards. All GWEP awardees are educating and training the workforce on how to care for persons living with dementia. Of the $35.7 million GWEP budget, $8.7 million was for dementia education and training activities. In Academic Year 2018-2019 (latest available data), GWEP grantee provided 445 AD/ADRD courses and trained 73,115 health care providers and 24,434 caregivers in ADRD. In FY 2019, HRSA also competed the GACA program and made 26 awards totaling $1.9 million. GACA grant recipients are encouraged to provide dementia education to the health professions workforce. ACL ADPI-funded programs dedicate significant resources to the training of professionals, developing and implementing curriculum designed to increase the dementia capability of health care professionals. Several funded programs partner with GWEP grantees to maximize the impact that both funding streams can have in the communities they support. • https://alzpossible.org/training/ • https://nadrc.acl.gov/ NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. • https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals NIA disseminates Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians and Managing Older Patients with Cognitive Impairment. • http://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients • https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment In 2020, the NIA ACTC (described in 1.B.5) launched the IMPACT-AD course that aims to educate and promote diversity among research professionals and future researchers in the AD/ADRD field. • https://impact-ad.org/about/

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2.A.1 (*continued*)						Newly Released FOA: • RFA-AG-19-002: Small Research Grant Program for the Next Generation of Clinical Researchers in AD/ADRD Research https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-002.html Additionally, NIA currently supports over 60 clinical trials aimed at testing interventions to improve care for persons with dementia and their caregivers. • https://www.nia.nih.gov/research/ongoing-AD-trials#section5 VA's Geriatric Scholars program offers staff training to integrate geriatrics into primary care practices, including RITT. VA Geriatric Scholars includes a wide variety of training activities, many of which include or are focused on dementia training. Examples of FY 2020 training activities included webinars on differential diagnosis of delirium, dementia, and depression; outpatient management of behaviors in dementia; behavioral strategies to optimize self-care for clients living with dementia; understanding daily risk of abusive and neglectful behaviors in dementia family caregiving. VA's EES makes the webinars available for external audiences through the TRAIN interagency sharing platform.
2.A.2	Encourage providers to pursue careers in geriatric specialties.	Educate providers about opportunities through the HRSA GWEP.	HRSA		Updated	In Academic Year 2016-2017 (latest available data), GWEP awardees trained 638 individuals in geriatrics fellowships and 136 advanced education nursing students in advanced practice adult-gerontology nursing programs. As part of their training, these individuals received education in AD/ADRD.
2.A.3	Strengthen state aging, public health, and IDD workforces.	Educate the workforces through various means including online training, webinars, fact sheets and other tools.	ACL	HRSA	Updated	HHS will coordinate with states to develop workforces trained in aging, public health, and IDD that are AD-capable and culturally-competent. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network. ACL, through NADRC, continues to offer an annual dementia-specific webinar series, attracting as many as 1,300 attendees to a single session. The series targets ADRD professionals, attracting family caregivers as well, and includes information on related dementias, innovative interventions and a wide variety of caregiving topics. CEUs are available to attendees, and the webinars are archived on the resource center web page. • https://nadrc.acl.gov

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2.A.3 (*continued*)						Each year, in support of paid and unpaid caregivers, NADRC develops tools and issue briefs on dementia-specific topics. New materials developed are disseminated through the ACL grant programs, as well as at professional conferences and the center web page. ACL is constantly adding new tools and issue briefs to its growing library. Topics of materials developed by NADRC include, but are not limited to, advance planning, living alone, compendiums of dementia-specific interventions and outcome measures.
						The NADRC website is home to the materials delivered through the ADPI grant program. The ADSSP, ADI-SSS, and ADPI program deliverables determined to be potential resources for the non-grantee community are posted for review and utilization by the dementia service provider community.
						In 2017, ACL received OMB authority to collect data on professionals trained through ADPI grant funding. Since receiving approval to collect training data, ACL grantees have trained in excess of 70,000 professional in the many facets of working with persons living with dementia and their caregivers.
						In 2019, the 48 HRSA GWEP grantees collaborated with 50 AAAs and 7 QIOs to strengthen state aging, public health, and IDD workforces. In addition, 19 of the HRSA 48 GWEPs collaborated with VA to assist with training on dementia.

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2.A.3 (*continued*)						CDC funded the University of Illinois at Chicago in FY 2021 as part of the National Healthy Brain Initiative. Their focus will be the PwIDD-HBI addresses stigma, early diagnosis, and culturally-relevant care to engage decades of collaboration with a robust network of people with IDD, their caregivers, health care providers, and CBOs that are supporting people with IDD. Guided by the HBI Road Map Series and the NTG "My Thinker's Not Working" National Strategy for people with IDD, PwIDD-HBI will develop and implement public health strategies to improve the quality of life of people with IDD by raising awareness of ADRD among people with IDD as a public health issue and support caregivers to care for people with IDD and care for themselves. The purpose of this project is to concentrate current efforts in ADRD and people with IDD fields into 1 community of practice for people with IDD, caregivers (paid and unpaid), health care providers, public health and policy stakeholders. A healthy brain community of practice for people with IDD will be a "one-stop space" that offers products, trainings, and materials to raise awareness of ADRD among people with IDD decrease disparities for those experiencing ADRD and improve people with IDD and caregiver's quality of life. • https://www.cdc.gov/aging/funding/hbi/index.html
2.A.4	Develop and disseminate a unified primary care AD/ADRD curriculum for clinical professionals and caregivers.	Develop a voluntary curriculum for primary care practitioners.	HRSA	CMS, NIH/NIA, VA	Updated	From FY 2015-FY 2017, HRSA partnered with federal staff at ACL, CDC, CMS, OWH, and VA on a contract to develop a Dementia Curriculum for Health Care Professionals and Caregivers. The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. The curriculum was first made available in 2017. From December 2017 to August 2020, there were 57,663 page views on the AD curriculum page. It continues to be a valuable resource for clinicians, families, and caregivers. • https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

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2.A.4 (*continued*)						CMS's RIC, which partners with health plans and providers, also offers a Geriatric-Competent Care Webinar Series designed to help health professionals in all settings and disciplines expand their knowledge and skills in the unique aspects of caring for older adults and in working with their caregivers, with some focus on dementia. The webinars are intended for front line community partners and delivery staff such as care managers, member service representatives, and home care providers. Recent topics have included supporting people with dementia and their caregivers during the COVID-19 pandemic, empowering unpaid caregivers of older adults during times of stress and isolation, preparing the workforce to be more disability-competent, and how to use person-centered language. • https://www.resourcesforintegratedcare.com/
2.A.5	Ensure aging and 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, National Alzheimer's Call Center and Elder Locator, Alzheimers.gov and other federal partners to ensure aging and public health workforces receive recent, updated and culturally-competent information.	ACL, NIH/NIA	CDC, AHRQ, NASEM	Updated	As mentioned in 1.E.5, CDC has developed a weekly newsletter that is sent out to over 67,000 subscribers. The newsletter focuses on a variety of topics that are applicable to the Alzheimer's Disease and Healthy Aging. Some of the foundational topics include: Caregiving, SCD, general health, emergencies, care planning, and COVID-19 guidance (Since March 2020). The newsletters are a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health. • https://tools.cdc.gov/campaignproxyservice/subscriptions.aspx?email=YOUREMAILHERE@youremail.com&topic_id=USCDC_944&origin=&pop=t NIH initiated a project involving AHRQ and NASEM, to conduct a systematic review of the evidence on prevention of clinical AD-type dementia, MCI, and age-related cognitive decline (AHRQ), and to shape these findings into a set of recommendations for public health practice and research (NASEM). The NASEM report, detailing recommendations for public health messaging based on findings were released in June 2017. • http://nationalacademies.org/hmd/reports/2017/preventing-cognitive-decline-and-dementia-a-way-forward.aspx

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2.A.5 (*continued*)						In 2018, NIA commissioned a second systematic evidence review by AHRQ of care and caregiving interventions for dementia to determine which of these interventions have an evidence base that is sufficient to support widespread dissemination. Findings from the evidence review released in August 2020, as well as a later set of recommendations, will inform NIA's future research investments and activities. One example is NIA's IMPACT Collaboratory. The goal is to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems for people living with dementia and their caregivers. Any research gaps identified in the evidence review can be considered by the Collaboratory researchers for additional exploration within its framework. • https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol • https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers • https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-twohttps://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report See 1.E.6 for information on the Brain Health Continuing Education course developed by CDC and the American College of Preventive Medicine. NIA continues to expand its efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. In 2020, NIA updated its list of cognitive screening tools and Alzheimer's and dementia resources for professionals. • https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals • https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients

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2.A.5 (*continued*)						In 2020, NIA, ACL, CDC and HRSA revived their annual webinar series Focus on Aging: Federal Partners' Webinar Series. The webinar series addresses important topics for public health and health care professionals, aging services organizations, the research community, and other stakeholders in aging. In addition to general topics of interest for older adults and those who work with them, each webinar will include information specific to individuals with ADRD, as well as their caregivers. • https://www.nia.nih.gov/news/focus-aging-federal-partners-webinar-series
2.A.6	Engage the public health workforce on brain health.	Conduct briefings with federal, state, and local public and private partners regarding the HBI: The Public Health Road Map for State and National Partnerships, 2013-2018.	CDC	ACL, NIH/NIA, public and private partners	Updated	CDC has developed a "Public Health Curriculum" in partnership with the Alzheimer's Association and Emory University. The Public Health Curriculum is a comprehensive course designed to educate public health students about the growing issues related to AD/ADRD and is tied to the "Core Competencies for Public Health Professionals". It includes slides, teacher notes, and other elements to create a complete course for educators to use in the classroom. The curriculum is also relevant to other audiences for broader reach. The course was available in late 2019 with additional enhancements in 2020, such as video modules. • https://www.cdc.gov/aging/aginginfo/alzheimers.htm See 1.E.7 for an update on CDC's partnership with ASTHO. See 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities. See 1.E.4 for information on CDC's partnership with NACDD to develop public health-focused rack cards. CDC, with support from the BOLD Infrastructure for AD Act is creating a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It's designed to promote implementation of CDC's HBI State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map and the HBI Road Map for Indian Country. In October 2020, CDC will fund 3 PHCOE in dementia and 16 state, local and tribal cooperative agreements to increase education of public health officials and others on brain health, promote risk reduction, early detection and preventing avoidable hospitalizations, decreasing health disparities and supporting caregiving and planning for people living with the disease.

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2.A.6 (continued)						• https://www.cdc.gov/aging/aginginfo/alzheimers.htm • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html • https://www.cdc.gov/aging/healthybrain/issue-maps/data-evidence-for-action.html • https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html • https://www.cdc.gov/aging/healthybrain/issue-maps/educating-training-professionals.html • https://www.cdc.gov/aging/healthybrain/issue-maps/risk-reduction.html • https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html • https://www.cdc.gov/aging/healthybrain/roadmap.htm • https://www.cdc.gov/aging/bold/index.html
2.A.7	Strengthen the ability of primary care teams in Indian Country to meet the needs of people with AD/ADRD and their caregivers.	Incorporate training for AD/ADRD into the online continuing education curriculum for IHS/Tribal/ Urban Indian Health program nursing.	IHS, CDC	Public and private partners	Updated	IHS incorporated training for AD/ADRD into the online continuing education curriculum for IHS/Tribal/Urban Indian Health program nursing. A web-based course on AD/ADRD was provided in April-June 2016 at the IHS Clinical Rounds. Results were addressed at the IHS Nursing Leadership meeting on May 17, 2016. A clinical training on diagnosis and management of AD/ADRD for an ACL/IHS/CMS LTSS conference was delivered in November 2016. There is an ongoing collaboration with the VA Greater Los Angeles GRECC and the VA Geriatric Scholars Program in team training in diagnosis and management of ADRD through the RITT for rural IHS and Tribal facilities and in training for support of caregivers through the IHS-ABCD program. See 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.
2.A.8	Develop a baseline understanding of self-reported competence and confidence of IHS, Tribal and Urban Indian Health nursing staff in care of individuals with AD/ADRD.	Assess nursing in IHS, Tribal, and Urban Indian Health programs on self-reported competence, confidence, and recent training specific to care for individuals with dementia.	IHS		Ongoing	Survey pilot-tested at 1 Tribal site.
2.A.9	Improve educational resources for primary care staff in Tribal communities caring for individuals with AD/ADRD and their families.	Pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, and Urban Indian Health Programs.	IHS	HRSA, ACL	Updated	In process of adding to online nursing educational curriculum. In 2020, ACL introduced a new grant program, ADPI: Dementia Capability in Indian Country. The program designed to bring culturally-competent ADRD training and education to Indian Country. Four tribes received 3 year awards in August of 2020.

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2.A.10	Provide decision support for clinicians in Tribal communities.	Develop and pilot-test decision support tools for clinicians using the IHS EHR.	IHS		Ongoing	Development of templates to support AWV (with cognitive assessment) and CCM.
2.A.11	Provide interdisciplinary team training in recognition, assessment, and management of AD/ADRD in small rural Indian Health facilities.	Provide the VA RITT to 10 IHS and Tribal sites with a focus on dementia care.	IHS	VA	Ongoing	15 RITT Trainings completed. These include webinars that are accredited through EES and TRAIN for VA and community clinicians: PTSD and Memory (January 24, 2018). Training continued in 2019 and the first quarter of 2020, and in March 2020 included the newly developed ABCD training to support public health nursing in their role of caregiver support. Geriatric Scholars Toolkits: Dementia • http://www.gerischolars.org/course/view.php?id=29
2.A.12	Strengthen states' ability to provide and sustain dementia-capable HCBS.	Grants to states and technical assistance on high-quality person-centered dementia care. Develop learning collaboration and tool to evaluate dementia-capability.	ACL	CMS	Ongoing	ACL's ADPI program continues to make funds available to states to develop and implement dementia-capable HCBS. Through the ADPI program, states are able to pilot programs in support of persons living with AD/ADRD and their caregivers in an effort to develop evidence for sustainability post-grant funding. • https://nadrc.acl.gov In 2017 ACL rolled out its dementia-capability assessment tool for implementation through the ACL state and community grant program. The tool assesses program partners over the course of a grant to measure the improvement in dementia-capability over time. The tool is available for non-grantees on the NADRC website. • https://nadrc.acl.gov/sites/default/files/uploads/docs/NADRC_Dementia_capability_assessment_public_posting-508.docx
2.A.13	Fill service gaps in dementia-capable systems by expanding the availability of specialized services and supports to target previously under-served populations.	Grants to states and localities.	ACL	CMS	Updated	In 2014, ACL began funding community programs designed to fill service gaps in existing dementia-capable systems. Funded programs are required to target program activities to providing effective supportive services to persons living alone with AD/ADRD, improving quality and effectiveness of services for individuals aging with IDD and AD/ADRD or those at high risk and delivery of behavioral symptom management training and expert consultations for family caregivers. In 2019, 29 programs were funded and in 2020 16 programs were funded bringing the program total to 108 state and community program funded in the US and its territories since 2014.

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2.A.13 (*continued*)						Medicare Advantage organizations may consider an item or service as a supplemental benefit if it is used to diagnose, compensate for physical impairments, acts to ameliorate the functionality/ psychological impact of injuries or health conditions, or reduces avoidable emergency and health care utilization. This permits the plans to optionally offer supplemental benefits such as adult day health, meal delivery or transportation for non-medical needs like grocery shopping, environmental modifications, palliative care, and in-home supports that could support certain beneficiaries with dementia.
2.A.14	Improve HCBS provided through state Medicaid waivers.	Hold webinars, national calls, and provide information to key stakeholders.	CMS		Updated	CMS continues to hold webinars, national calls, and provide information to key stakeholders on HCBS topics. For example, CMS is supporting state Medicaid agencies in topics like electronic visit verification and conflict of interest. CMS also recently worked with its partners at ACL to address person-centered planning and practice, culminating in a 2020 report that describes facilitator core competencies, a framework for measurement, and strategies for meaningful engagement. • http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx • https://www.medicaid.gov/medicaid/hcbs/training/index.html
2.A.15	Train future public health professionals on AD/ADRD.	Develop a public health curriculum for use in university settings.	CDC	Private partners	Ongoing	The Public Health Curriculum, developed in partnership with the Alzheimer's Association and Emory University, is a comprehensive course designed to educate public health students about the growing issues related to AD/ADRD and is tied to the Core Competencies for Public Health Professionals. It includes slides, teacher notes, and other elements to create a complete course for educators to use in the classroom. The curriculum is also relevant to other audiences for broader reach. The course was available in late 2019 with additional enhancements in 2020, such as video modules. • https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum

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2.A.16	Understand the impacts of minimum wage increases on nursing homes.	Analyze data from DoL and CMS.	ASPE		Completed	Nursing homes employ large proportions of their workforce at the minimum wage. This project sought to understand the potential impacts of federal minimum wage increases on nursing staff hours and labor costs of nursing homes. In 2017, approximately 44% of nursing homes are in states that use the federal minimum hourly wage level of $7.25, 28% are in states with a minimum hourly wage between $7.50 and $8.90, and 28% are in states with a minimum hourly wage of $9.00 or more. The impacts of raising the federal minimum wage on nursing homes would be almost completely restricted to increases in wages among nursing assistants, since most of this workforce currently earns at or close to the federal minimum wage. An increase of the federal minimum wage would result in large proportions of nursing assistants gaining a wage increase, thereby increasing direct labor costs to nursing homes. These results are based on national estimates. • https://aspe.hhs.gov/pdf-report/potential-impacts-minimum-wage-increases-nursing-homes-issue-brief
Strategy 2.B: Ensure Timely and Accurate Diagnosis						
2.B.1	Identify and disseminate appropriate assessment tools.	Identify a variety of appropriate assessment tools that can be used in a variety of outpatient settings, including the Medicare AWV, to assess cognition. Complete the development of the "toolbox" of cognitive assessment tools. Disseminate recommended tools to practitioners.	NIH/NIA	CDC	Updated	NIA continues to expand our efforts to educate clinicians about recent research findings; clinical practice tools for assessment, diagnosis and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources, which are available online in a mini-portal of resources for professionals. • https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals NIA funded 2 projects that seek to produce Apps capable of measuring cognitive status and change on mobile devices in response to RFA-AG-18-012 Mobile Monitoring of Cognitive Change (U2C). Researcher availability of the developed Apps (both iOS and Android) will begin in 2022. • https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-012.html • https://projectreporter.nih.gov/project_info_description.cfm?aid=9781454&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=4&csb=default&cs=ASC&pball= • https://projectreporter.nih.gov/project_info_description.cfm?aid=9781463&icde=46515933&ddparam=&ddvalue=&ddsub=&cr=9&csb=default&cs=ASC&pball=

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
2.B.1 (*continued*)						Low-cost detection of cognitive decline in clinical settings (RFA-AG-20-050 and RFA-AG-20-051). • https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-050.html • https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-051.html Notice of Special Interest: Digital Technology for Early Detection of ADRD. • https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-017.html NINDS continues to support DetectCID, a national consortium to test and validate clinical paradigms that can be used in primary health care and other everyday clinical settings. The ultimate goal is to increase detection of cognitive impairment/dementia among high-risk populations, including health disparity populations, and lessen cultural and logistic barriers that currently impede both clinical care and research efforts. Three research teams across the US are focusing on utilizing assessment tools that are simple to use, standardized, and take 10 minutes or less to administer in a primary care setting. • https://www.detectcid.org/ • https://www.ninds.nih.gov/News-Events/News-and-Press-Releases/Press-Releases/NIH-forms-new-consortium-improve-detection • https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients NIA updated its list of free clinical practice tools, training materials and more resources for physicians, nurses, social workers, and other professionals as well as a guide that provides information about assessing cognitive impairment in older adults. • https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals

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2.B.2	Educate family service providers of persons with IDD about changes that may indicate the onset of dementia.	Develop fact sheets and tools to aid in identifying the onset of dementia.	ACL/AIDD	NTG	Updated	ACL, through their AD/ADRD grants to states and communities are providing dementia-capability training to paid and unpaid caregivers of PWD, including individuals living with IDD and dementia or at-risk of developing dementia. For example, in response to a spring 2018 poll of IDD program providers grantees reported training close to 8,000 paid and unpaid caregivers in IDD and dementia, through their IDD-specific service gap activities since 2014. ACL collaborates closely with NTG with many grantees participating in their education workshops, becoming affiliated trainers and further disseminating education on IDD and dementia, as well as implementation of their NTG-EDSD tool. ACL consistently offers educational opportunities/resources in support of both paid and unpaid caregivers of those living with IDD and AD/ADRD or at-risk of developing AD/ADRD. • https://nadrc.acl.gov • http://aadmd.org/ CDC, through its National Healthy Brain Initiative, is funding efforts to tailor dementia public health messaging and resources towards persons with IDD. See 2.A.3 for information on CDC's funding of the PwIDD-HBI. • https://www.cdc.gov/aging/funding/hbi/index.html
2.B.3	Increase awareness of AD/ADRD in Tribal and Urban Indian communities and of the availability of services for individuals with dementia and their families.	Pilot-test AD/ADRD awareness strategies in communities in which REACH into Indian Country is implemented, through both health care and aging services settings.	IHS	ACL	Updated	The focus of the REACH intervention in its final year was on increasing awareness of AD/ADRD in those communities served by REACH and increasing use of REACH caregiver support services. IHS facilities provided local resources for community-based education and training. ACL continues to bring awareness to AD/ADRD in Indian Country through participating in educational opportunities including presentations to attendees of ACL's Title VI annual conference and webinars. In 2020, ACL introduced a new ADPI grant program, Dementia Capability in Indian Country. In August 2020, 4 tribal entities were funded to develop and implement culturally-competent education programs and deliver evidence-based interventions in support of elders living with dementia and their caregivers. CDC in partnership with NCUIH is developing a video and materials to increase awareness of ADRD in Urban Indian communities which will be released in late FY 2020.

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2.B.4	Increase provider awareness of the need for early diagnosis, and provide tools and resources to enable diagnosis and referral.	Develop a 1-1.5 hour(s) CME/MOC module on the benefits of blood pressure management as a potential mechanism to reduce cognitive decline and dementia.	CDC	Private partners	Updated	See 1.E.6 for information on the Brain Health Continuing Education course developed by CDC and the American College of Preventive Medicine. • https://www.acpm.org/page/brainhealth See 2.A.6 for update on the work of the CDC with support from the BOLD Infrastructure for AD Act to create a uniform national public health infrastructure. • https://www.cdc.gov/aging/bold/index.html • https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html • https://www.acpm.org/page/brainhealth CDC is funding a special interest project through CDC's PRCs in late FY 2020 to improving cognitive impairment detection and referral to resources among older adults by applying the KAER Model to primary care within a health care system. • https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf
2.B.5	Understand the discordance between reported diagnosis, claims, and functional assessment for people with AD/ADRD.	Analyze NHATS data on reported diagnosis and cognitive functioning assessments linked to Medicare claims data.	ASPE		Completed	In early 2020, ASPE released 2 issue briefs on identifying dementia based on self-reported diagnosis, Medicare claims, and/or functional assessment. Although the population identified with dementia should be similar with all 3 of these methods, there were great differences. The first issue brief compared the characteristics of people identified with each method. For example, of the people whose answer to functional assessment questions indicated probable dementia, only 39.5% had a dementia diagnosis in their Medicare claims. People identified as having probable based on a cognitive assessment, but not in Medicare claims or with a self-reported diagnosis, were less likely to be White non-Hispanic, more likely to have never married, and had lower levels of education and income than are people with dementia identified in other ways, Their health and functional needs are similar to those of people with dementia identified in other ways.

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2.B.5 (*continued*)						The second issue brief described the characteristics of people who do not report having a diagnosis of dementia, despite a documented diagnosis by a health care provider, in order to better understand the factors that may contribute to their lack of awareness. Slightly less than one-half (46.8%) of people with a diagnosis in claims data reported they had been told by a doctor that they had dementia. Interestingly, most of these individuals did not show a cognitive assessment consistent with dementia. Only about one-quarter (28.8%) of those who were unaware of their diagnosis did appear to have probable dementia based on cognitive assessment. This smaller group was more likely to have lower incomes, lower education, and are of a racial or ethnic minority group. The findings have important implications for efforts the accuracy of Medicare claims as a source of information on people with dementia, as well as efforts to increase diagnosis and ensure physicians provide information about a diagnosis to patients. • https://aspe.hhs.gov/basic-report/implications-alternative-methods-identifying-populations-dementia-issue-brief • https://aspe.hhs.gov/basic-report/individuals-awareness-dementia-diagnosis-issue-brief
Strategy 2.C: Educate and Support People with Alzheimer's Disease and Related Dementias and Their Families upon Diagnosis						
2.C.1	Educate physicians and other health care providers about accessing LTSS.	Increase knowledge of available resources among doctors, nurses, and hospitals.	HRSA	CMS, VA, ACL	Ongoing	HRSA's grantees are 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, as well as their caregivers. CMS makes separate payments in Medicare for cognitive assessment and care planning services for individuals with cognitive impairment. In Medicare, a required element of these services is the creation of a care plan, including requires referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups), and that the care plan is shared with the patient and/or caregiver with initial education and support. ACL's state and community ADPI program continues to fund projects that include significant focus on the provision of educational opportunities for physicians and other health care providers. Grantees continue to work toward developing models such as dementia-capable hospitals and federally qualified health centers, including educating providers on the importance of dementia-capable care transitions.

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2.C.2	Connect AI/AN to AD/ADRD resources.	As new resources become available, they will be distributed through a variety of venues to Indian Country.	IHS	ACL, CDC	Updated	The focus on increasing support to caregivers has been through the spread of REACH into Indian Country, with the goal of offering this intervention to those with AD/ADRD and their families. IHS has collaborated with CDC in the development of the Brain Health Public Health Road Map designed specifically for Tribal Communities. The Road Map for Indian Country, co-branded with the Alzheimer's Association, was released and disseminated to multiple stakeholders and Tribal nations. Tribal communities continue to benefit from ACL's state and community AD/ADRD grant programs, including development of culturally-competent dementia care specialists, dementia-friendly community education/awareness initiatives and translation of the Music and Memory intervention in Indian Country. ACL's Title VI program has significantly increased the AD/ADRD educational offerings at their annual Title VI Training Conference including increasing awareness of CDC's Road Map for Indian Country. In 2020, ACL introduced a new ADPI grant program, Dementia Capability in Indian Country, in August 2020 4 tribal entities were funded to develop and implement culturally-competent education programs and deliver evidence-based interventions in support of elders living with dementia and their caregivers. See 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities. • https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html See 1.E.4 for information on CDC's partnership with NACDD to develop public health-focused rack cards.

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2.C.2 (*continued*)						CDC has partnered with the NCUIH to review, adapt and disseminate existing culturally-appropriate flyers and posters on brain health for an urban AI/AN audience. To accompany the updated materials, NCUIH, with support and feedback from UIH staff, created 3 culturally-appropriate 1-minute videos on: (1) Preventing Alzheimer's; (2) Recognizing the signs of AD in loved ones; (3) Healthy living with AD. Finally, to ensure maximum exposure, NCUIH will develop and disseminate a healthy brain media kit for use by UIHs and others wanting to raise awareness on AD and healthy aging. The media kit will include the updated flyers and posters, links to the videos and social media campaign messaging information. Finally, NCUIH will launch a social media campaign with targeted outreach in cities with the largest AI/AN population (LA, Phoenix, Tulsa, Oklahoma City, and Anchorage) to disseminate all materials. Additionally, CDC developed an infographic describing SCD and related functional limitations and caregiving on AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country. These are available in both English and Spanish. • https://www.cdc.gov/aging/data/infographic/2018/american-Indian-alaska-native-cognitive-decline.html • https://www.cdc.gov/aging/spanish/infographic/2018/aian-cognitive-decline.html • https://www.cdc.gov/aging/data/infographic/2018/american-indian-adults-caregiving.html • https://www.cdc.gov/aging/spanish/infographic/2018/ai-adults-caregiving.html
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 and private organizations to discuss dementia care practices; develop/identify 3-5 evidence-based guidelines of best dementia practices;; disseminate guidelines to consumer and clinical stakeholders, as well as quality measure developers.	CMS	ASPE	Ongoing	CMS has included dementia-related measures in the MIPS for Medicare such as cognitive assessment, education and support of caregivers, etc. • https://qpp.cms.gov/mips/quality-measures Another area of support is examining and implementing quality and outcome measures and measure concepts for HCBS programs. • https://www.medicaid.gov/medicaid/quality-of-care/improvement-initiatives/hcbs/index.html

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2.D.2	Solicit stakeholder input on meaningful outcomes to drive quality measurement.	Convene listening sessions with relevant stakeholders.	CMS	ASPE	Ongoing	CMS's Meaningful Measures framework is a new initiative that identifies the highest priorities for quality measurement and improvement. It involves only assessing those core issues that are the most critical to providing high-quality care and improving individual outcomes. The Meaningful Measure areas serve as the connectors between CMS's goals and individual measures/initiatives that demonstrate how high-quality outcomes are being achieved across settings of care. • https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page.html
2.D.3	Clarify and disseminate information on privacy, autonomy, and safety issues for physicians.	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.	HRSA		Ongoing	HHS continues to disseminate this information through the trainings provided by the GWEP grant recipients.
2.D.4	Provide improved training resources to IHS staff on person-centered goals and strategies for care improvement.	Review of training resources for IHS nursing staff highlighting person-centered goals and strategies for improving care for PWD.	IHS	HRSA	Updated	IHS collaborated with HRSA to engage the HRSA-funded GWEPs in strategies to improve recognition and diagnosis of dementia. In FY 2019, 11 HRSA GWEPs partnered with federally recognized Tribal organizations. 11 GWEPs participate in a Native Populations Interest Group in preparation for exchanging training materials. The University of Wyoming, in partnership with members of the Eastern Shoshone and Northern Arapaho tribes, created culturally-relevant dementia training material for AI people on the Wind River Reservation with a pictorial version of the Alzheimer's Association's Know the 10 Signs: Early Detection Matters. The other members of the Interest Group are discussing how/whether to adopt similar materials. This continues to be disseminated nationally.
Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease and Related Dementias						
2.E.1	Evaluate the effectiveness of relevant CMMI models for people with AD/ADRD.	Examine changes in care quality and care coordination among people with AD/ADRD.	CMS/CMMI	NIH/NIA, Johns Hopkins University	Ongoing	HCIAs Round 1 have ended. Information about the evaluation of these projects can be found at the links below. • https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/ • https://innovation.cms.gov/initiatives/primary-care-first-model-options/ HCIA R2 has also ended, and CMS is in the process of completing the evaluation.

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2.E.2	Evaluate the effectiveness of the Independence at Home Demonstration.	Examine whether health and functional status outcomes are improved among people with AD/ADRD in this demonstration.	CMS/CMMI		Updated	CMS has released the results from Year 5 of the demonstration. • https://innovation.cms.gov/files/fact-sheet/iah-yr5-fs.pdf • https://innovation.cms.gov/initiatives/independence-at-home/
2.E.3	Develop a SDM model as an alternative to guardianship.	Support a national training, technical assistance, and resource center to explore and develop SDM as an alternative to guardianship.	ACL		Ongoing Started in 2015, expected completion in 2019	ACL continues to support the NRC-SDM which builds on and extends the work of Quality Trust's Jenny Hatch Justice Project. The NRC-SDM partners bring nationally recognized expertise and leadership on SDM, representing the interests of and receiving input from thousands of older adults and people with IDD. They have applied SDM in groundbreaking legal cases, developed evidence-based outcome measures, successfully advocated for changes in law, policy and practice to increase self-determination and demonstrated SDM to be a valid, less-restrictive alternative to guardianship. In September 2020, ACL extended its commitment to keeping supported decision making as a priority with the award of a cooperative agreement to the University of Massachusetts at Boston to implement a national AtG Youth Resource Center. The AtG is a new initiative focused on diverting high school students with IDD away from guardianship to SDM, which allows individuals with disabilities to make decisions for themselves and choose the level of support they need from people and organizations they trust. • http://www.supporteddecisionmaking.org
2.E.4	Understand the role of CCBHC in providing access to care.	Conduct an evaluation of CCHBC demonstration to determine improvements in accessibility, quality, and outcomes of ambulatory care.	ASPE		Ongoing	ASPE is managing a 5-year evaluation of this demonstration. Current reports include: • https://aspe.hhs.gov/report/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2018 • https://aspe.hhs.gov/basic-report/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2019 • https://aspe.hhs.gov/basic-report/preliminary-cost-and-quality-findings-national-evaluation-certified-community-behavioral-health-clinic-demonstration • https://aspe.hhs.gov/report/implementation-findings-national-evaluation-certified-community-behavioral-health-clinic-demonstration
2.E.5	Fund a resource center to support person-centered care.	Support the provision of technical assistance to states, tribes and territories in the delivery of person-centered care.	ACL		New	NCAPPS is an initiative from ACL and CMS that helps states, tribes, and territories implement person-centered thinking, planning, and practice. • https://ncapps.acl.gov/home.html

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Strategy 2.F: Ensure that People with Alzheimer's Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems						
2.F.1	Implement and evaluate new care models to support effective care transitions for people with AD/ADRD.	Evaluate care transition demonstration programs.	CMS	ACL	Updated	CMS's Primary Care First is a set of voluntary CMMIs payment model options that reward value and quality by offering innovative payment model structures to support delivery of advanced primary care. One of the Primary Care First payment model options focus on ensuring that seriously ill patients' care is coordinated and that patients are clinically stabilized. • https://www.integratedcareresourcecenter.com/ • https://www.resourcesforintegratedcare.com/ • http://hospital2home.org/about/ Through the ADPI program, the ACL funds the piloting of innovations in care transitions programs. In Nevada ACL has funded a successful Hospital2Home intervention to deliver dementia-capable supports as persons living with dementia being discharged from the hospital. • https://nadrc.acl.gov
2.F.2	Understand FIDs from nursing homes.	Analyze Medicare and Medicaid data.	ASPE		Ongoing	The research will explore the prevalence of FIDs and whether it has increased over the years; and, differences across all states, types of providers (e.g., for profit vs. non-profit; chain vs. non-chain), types of patients (e.g., AD, PWD, other disabilities, functional levels), payors (i.e., Medicare, Medicaid, Medicare to Medicaid, other), demographic groups, and duality (eligible for both Medicare and Medicaid). The study will be completed at the end of 2020.
2.F.3	National Center on Advancing Person-Centered Practices and Systems.	Implement person-centered practices	CMS	ACL	New	NCAPPS, an initiative between CMS and ACL to implement person-centered practices, issued a new tool, the Health Care Person-Centered Profile. The template includes essential health information and a format for outlining what is important to the person who may be hospitalized and unable to communicate their wants, needs, and preferences. • https://ncapps.acl.gov/covid-19-resources.html
2.F.4	Release of Guide to Billing Codes for Dementia Services.	Support organizations providing supports and services to individuals with dementia.	ACL		New	In September 2020, ACL released, through the NADRC, a new Guide to Billing Codes for Dementia Services. Dementia services and supports play an important role in helping people who are living with dementia to remain in the community. Identifying sources of reimbursement for dementia services remains an ongoing challenge. This guide is intended primarily for organizations that have medical billing systems in place and want to understand how to bill for dementia services. It may also be useful for organizations that are considering developing a medical billing system for services. • https://nadrc.acl.gov/node/232

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Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People Living with Alzheimer's Disease and Related Dementias						
2.G.1	Implement and evaluate care coordination models.	Implement and evaluate care coordination models.	CMS		Ongoing	CMS makes payment for care management and coordination services. Care coordination models can be a critical component of care in Medicare that can contribute to better health outcomes and higher beneficiary satisfaction. • https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/chronic-care-management.html • https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf
2.G.2	Assess the adequacy of HIT standards to support the needs of persons with AD/ADRD.	Convene partners to explore feasibility and timing.	ONC	CMS, ASPE	Updated	ONC publishes an annual Inter-operability Standards Advisory to bring public awareness to inter-operability standards and implementation specifications that can be used by industry, including standards that support care plans and transitions in care, among others. • https://www.healthit.gov/isa/ In September 2019, the standards development organization, HL7, published the eLTSS FHIR standards which are now available for adoption and implementation by HIT vendors, including those that develop dementia care technology platforms.
2.G.3	Study impacts of managed care on health outcomes and quality.	Examine the Medicare-Medicaid alignment programs in Tennessee.	ASPE		Completed	ASPE recently completed a project evaluating the impact of Medicare and Medicaid alignment for individuals eligible for both Medicare and Medicaid on beneficiary outcomes and utilization of acute care services and LTSS. 19% of all Medicare-Medicaid dually eligible beneficiaries have AD/ADRD. This project is testing the hypothesis that the aligned delivery of Medicare and Medicaid-funded services to full-benefit dually eligible beneficiaries is associated with improved health status and increased efficiency of health care utilization (decreased emergency department utilization, decreased nursing facility utilization, and increased use of HCBS) among full-benefit dually eligible beneficiaries in Tennessee. Some data indicates that inpatient and emergency room use initially increased for dually eligible beneficiaries under age 65 as participation in aligned plans increased, but these associations weakened or were no longer present when the analysis include more years of data. The final report will be posted to the ASPE website in late 2020.

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Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and Related Dementias, and for Populations Facing Care Challenges						
2.H.1	Create funding opportunities for organizations to improve care for these specific populations.	Fund dementia-capable systems to implement new programs designed to provide more effective services to: (1) individuals living alone in the community with dementia; (2) individuals with IDD who have or are at-risk of developing dementia; and (3) caregivers who need behavioral symptom management training or expert consultations to help them care for family members.	ACL		Updated	In 2019, 29 programs were funded, and in 2020, 16 programs were funded bringing the program total to 108 state and community program funded in the US and its territories since 2014. Future grants are contingent on availability of funding.
2.H.2	Target resources towards the IDD and dementia population.	Develop workforces in aging, public health, and IDD that are dementia-capable and culturally-competent. Develop programs that include improvement of the quality and effectiveness of program and services dedicated to individuals aging with IDD and AD/ADRD or at high risk of developing AD/ADRD.	ACL		Updated	Through its AD/ADRD grant programs and NADRC, ACL continues to target program resources to the IDD and dementia issue. At the White House Conference on Aging in July 2015, ACL released their IDD and Dementia Report on the current state of services and support system for persons with IDD living with dementia. Providing a broad overview of the services and support system for persons with IDD affected by dementia and their caregivers. ACL requires that grantees develop programs that include "improvement of the quality and effectiveness of program and services dedicated to individuals aging with IDD and ADRD or at high risk of developing ADRD". Each year since 2015, NADRC has included an IDD and dementia-specific webinar in their annual webinar series. • https://nadrc.acl.gov/ In 2019, NADRC published a new guide entitled IDD and Dementia: Practical Strategies for Professionals: Practical Strategies for Professionals which provides background and strategies for professionals working with individuals living with IDD and dementia. • https://nadrc.acl.gov/node/169 • https://nadrc.acl.gov/node/51 • https://nadrc.acl.gov/node/59 • https://nadrc.acl.gov/node/74 • https://nadrc.acl.gov/node/101 See 2.A.3 for information on CDC's funding of the PwIDD-HBI. • https://www.cdc.gov/aging/funding/hbi/index.html

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2.H.3	Review and report on federal programs and initiatives aimed at decreasing health disparities in Alzheimer's.	Convene federal partners.	ASPE		New	ASPE will convene federal partners and to inventory completed and ongoing programs and initiatives to that address racial and ethnic disparities in clinical care, research, and LTSS for people with dementia. As available, ASPE will identify the results of these initiatives and next steps. The results of this inventory will be reported at an Advisory Council meeting. ASPE will then draft a special report to the Advisory Council by April 1, 2021, on these initiatives, current results, and further steps to be taken.
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 federally-developed educational materials.	Distribute training and education materials through federal agencies and state and local networks.	ACL	NIH/NIA, ADEAR	Update	ACL's NADRC develops and makes available resources in support of both paid and unpaid caregivers. Examples of such resources includes, but is not limited to: • IDD and Dementia: Practical Strategies for Professionals https://nadrc.acl.gov/node/169 • Handbook for Helping People Living Alone with Dementia Who Have No Known Support https://nadrc.acl.gov/node/157 • Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia https://nadrc.acl.gov/node/155 • Disaster Planning Toolkit for People Living with Dementia https://nadrc.acl.gov/node/151 The library of NARDC and ACL grantee developed resources for persons living with AD/ADRD and their caregivers. • https://nadrc.acl.gov/ Fact sheets • https://eldercare.acl.gov/Public/Resources/Topic/Alzheimer_Disease.aspx NIA's ADEAR Center continues to update and offer free information in English and Spanish on AD/ADRD caregiving in print and online, as well as through our information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter). • https://www.nia.nih.gov/health/alzheimers/caregiving See 1.E.7 for updates on the Caregiving and SCD infographics. See 1.E.5 and 2.A.5 for information on CDC's weekly newsletter. See 1.E.7 for information on CDC's contribution to the Public Health Perspectives on the Family Care Gap textbook.

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3.A.2	Utilize HIT for caregivers and persons with AD/ADRD.	Identify tools, evaluate, and disseminate findings.	AHRQ		Updated	AHRQ has awarded 3 grants for integrating information and communication technology to facilitate aging in place. One grant (1P50HS019917) was awarded and used to create Elder Tree, a suite of electronic services to support older adults and their caregivers. The study was a randomized control trial of adults age 65 and older and their caregivers who had experienced challenges to aging in place. Control group participants were provided usual sources of information and communication, while the intervention group was given access to Elder Tree for 18 months. Findings suggested a positive effect for older adults who are heavy users of health services when they used Elder Tree. Analyses indicated that the system reduced the risk of falls and depression, and improved quality of life and social support for users. The Elder Tree tool is currently being evaluated. So far, 400 people have been recruited to use the suite, and participants were surveyed after use. An analysis is currently underway, and results will be available soon. Elder Tree has been successfully disseminated to 57 counties in Wisconsin and continues to expand. Another grant (5R18HS022836) was awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD and to study the impact on ability of caregivers to manage family member with AD/ADRD. So far, 60 caregivers have been recruited, out of a goal of 100, and systems are in the process of being installed and caregivers trained. Finally, a grant (2R21HS026571) was awarded to evaluate the clinical integration of an AD/ADRD support application that provides education, supportive resources, and a platform to share real-time patient-related information with the care team from homes or community settings. The research team has modified based on feedback from stakeholders and is currently implementing the solution into the clinical environment. • https://digital.ahrq.gov/ahrq-funded-projects/examining-clinical-workflow-and-outcomes-integrating-health-information • https://healthit.ahrq.gov/ahrq-funded-projects/bringing-communities-and-technology-together-healthy-aging In October 2019, NIA announced 3 winners in the iCare-AD/ADRD Challenge. The winners shared $400,000 in prizes. • https://www.nia.nih.gov/icare-ad-adrd-eureka-challenge-winners

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3.A.2 (*continued*)						The VA Caregiver Center, located at the Memphis VA Medical Center and supported by the VA's Caregiver Support Program, is pilot-testing a supportive texting intervention for caregivers of veterans with dementia. Caregivers will receive information about managing dementia behaviors and their own stress and coping through Annie, the VA's text messaging platform, managed by the Office of Connected Care. National roll-out of the protocol will occur in FY 2021.
3.A.3	Increase awareness of the importance of brain health in culturally sensitive ways.	Increase awareness of brain health, specifically AD/ADRD and caregiving among African Americans.	CDC	ACL	Updated	CDC supported the development of NBHCAA. The mission of NBHCAA is to raise awareness of the issues of cognitive health among African Americans by working through networks of faith-based institutions, and by establishing partnerships with organizations and individuals dedicated to NBHCAA's mission. The 3 areas of focus are brain health education, mobilization and advocacy, and networking. NBHCAA serves as an information hub on the human brain that can be shared throughout all networks that reach and touch approximately 40 million African Americans living in the US.

CDC is working on a training program geared towards African American health professionals. Together with The Balm in Gilead, the CDC will train health professionals on issues affecting cognitive health among African Americans via partnerships with the National Black Nurses Association and National Medical Association.

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

CDC developed, using BRFSS data, several fact sheets using the most current data. These resources are made available on the Alzheimer's Association's website and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers. These resources are updated annually, as new data becomes available. By creating easy-to-read, visually appealing materials, uptake of knowledge is facilitated. |

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
3.A.3 (*continued*)						Through its HBI, CDC will be funding several organizations in FY 2020 to tailor brain health messaging to disproportionately affected populations, including persons with IDD, Hispanics, African Americans, and AI/AN. See 2.C.2 for information on CDC's partnership with NCUIH to develop culturally-appropriate resources on brain health. • http://brainhealthcenterforafricanamericans.org/ • https://www.cdc.gov/aging/data/index.htm
3.A.4	Increase awareness of the importance of brain health for Tribal communities in culturally sensitive ways.	Develop materials to support implementation of the Public Health Road Map in Tribal Communities.	CDC	Private partners	Updated	In conjunction with the Alzheimer's Association and other partners, the Road Map for Indian Country was released and disseminated to multiple stakeholders and Tribal nations. This Road Map for Indian Country has been designed specifically for public health systems serving AI/ANs and Native Hawaiians. Additionally, CDC developed infographics illustrating SCD and related functional limitations in AI/AN adults in order to education stakeholders and policy makers on brain health in Indian Country. • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html CDC supported ASTHO to develop culturally sensitive materials to educate and empower tribes and Tribal populations about brain health and caregiving. The materials focus on cardiovascular risk factors related to brain health and caregiving issues for Tribal communities. See 2.C.2 for information on CDC's partnership with NCUIH to develop culturally-appropriate resources on brain health. • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html • https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html • https://www.cdc.gov/aging/data/infographic/2017/american-Indian-alaska-native-cognitive-decline.html • https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html

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Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being
3.B.1	Develop and disseminate evidence-based interventions for people with AD/ADRD and 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	Updated	NIA is supporting an ongoing project involving AHRQ and NASEM, to conduct a systematic review of evidence of care interventions for persons living with dementia and their caregivers (AHRQ), and to take stock of the current state of knowledge and inform decision making about which care interventions for PWD and caregivers are ready for dissemination and implementation on a broad scale (NASEM). AHRQ released a draft report in March 2020 and the NASEM committee held a workshop in April 2020. AHRQ released a Prepublication Final Report July 31, 2020. AHRQ dementia care evidence review • https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol • https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report NASEM workshop • https://www.nationalacademies.org/event/04-15-2020/care-interventions-for-individuals-with-dementia-and-their-caregivers-phase-two-meeting-1-and-public-workshop Also in 2019, NIH funded a new effort called the IMPACT Collaboratory to meet the urgent public health need to deliver high-quality, evidence-based care to people living with dementias and their caregivers. Through this effort, researchers will develop and test care interventions in real-world settings such as hospitals, assisted living facilities, nursing homes, and adult day care centers. In general, a "pragmatic clinical trial" means participants are enrolled as part of a real-world setting rather than selected from a broader community-based on narrowly defined criteria. The IMPACT project will bolster the nation's capacity to conduct pragmatic clinical trials of interventions, embedded within health care systems, for people living with dementia and their caregivers. IMPACT supports pilot projects that have the potential to inform the design of larger scale pragmatic trials. • https://impactcollaboratory.org/ • https://projectreporter.nih.gov/project_info_description.cfm?aid=9774609&icde=51150896&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=

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3.B.1 (*continued*)						The NIA expanded its Edward R. Roybal Centers for Translational Research to include 4 new AD/ADRD-specific Roybal Centers for translational intervention development research for AD/ADRD care provider support. The purpose of the Roybal Centers is to develop behavioral interventions that improve the health, well-being and/or capacity of individuals and/or systems that provide care to persons with AD/ADRD. • https://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translational-research-behavioral-and-social-sciences-aging • https://grants.nih.gov/grants/guide/RFA-files/RFA-AG-19-007.html • https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=14E8C80E4E88C0DF7598B8961CAA4A01A2FFCEB861BF ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. All grantees are required to include evidence-based or evidence-informed interventions in their funded programs In 2019, 29 programs were funded, and in 2020, 16 programs were funded bringing the program total to 108 state and community program funded in the US and its territories since 2014. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country. ACL's ADPI and the NADRC continue to support the translation and implementation of dementia-specific evidence-based interventions in states and communities across the nation. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the nation. For example, NIA funded the research behind SAVVY Caregiver and ACL-funded provider pilot programs that enabled an estimated 20,000 caregivers to receive the intervention. Grantee-Implemented Evidence-Based and Evidence-Informed Interventions • https://nadrc.acl.gov/node/140 ACL-funded SPECIAL EDITION of ASA Generations: Supporting People with Dementia and Their Caregivers in the Community. • https://nadrc.acl.gov/node/110 • https://nadrc.acl.gov/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
3.B.1 (*continued*)						NIA's ADEAR Center continues to update and offer free information in English and Spanish on AD/ADRD caregiving in print and online, as well as through its information and referral helpline, a weekly email alert specifically on caregiving issues, and social media (Facebook and Twitter). Additionally, the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers provided a platform to disseminate evidence-based interventions for people with AD/ADRD and their caregivers. A total of 58 main research recommendations resulted from nearly 700 recommendations submitted by Summit participants. • https://www.nia.nih.gov/2020-dementia-care-summit • http://www.brainhealth.gov • https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers • https://projectreporter.nih.gov/project_info_description.cfm?aid=9860144&icde=51150936&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball= Ongoing and newly released FOAs and NOSIs: • RFA-AG-20-037 and RFA-AG-20-038: Dementia Care: HCBS https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-037.html • https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-20-038.html • RFA-AG-19-007: Roybal Centers for Translational Research on Dementia Care Provider Support https://grants.nih.gov/grants/guide/RFA-files/RFA-AG-19-007.html • RFA-AG-19-009: NIA AD/ADRD Health Care Systems Research Collaboratory https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-009.html • RFA-AG-19-016: High-Priority Behavioral and Social Research Networks in AD/ADRD https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-19-016.html • RFA-AG-21-009: Artificial Intelligence and Technology Collaboratories for Aging Research https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-009.html • RFA-AG-21-018: Artificial Intelligence and Technology Collaboratories for Aging Research Coordinating Center https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-018.html

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
3.B.1 (*continued*)						• PAS-17-026: Improving Quality of Care and Quality of Life for Persons with AD/ADRD at the End of Life https://grants.nih.gov/grants/guide/pa-files/PAS-17-026.html • PAR-18-186: Development of Socially-assistive Robots to Engage Persons with AD/ADRD, and their Caregivers https://grants.nih.gov/grants/guide/pa-files/PAR-18-186.html • PA-18-502: Advancing the Science of Geriatric Palliative Care https://grants.nih.gov/grants/guide/pa-files/PA-18-502.html • PAR-18-585: Pragmatic Trials for Dementia Care in LTSS Settings https://grants.nih.gov/grants/guide/pa-files/PAR-18-585.html • RFA-AG-20-006: Interpersonal Processes in AD/ADRD Clinical Interactions and Care Partnerships https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html • PAR-18-326: Technology to Detect, Monitor and Assess Daily Functions in Individuals with Cognitive Decline, AD and/or AD/ADRD https://grants.nih.gov/grants/guide/pa-files/PAR-18-326.html • RFA-AG-18-030: Dementia Care and Caregiver Support Interventions https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-18-030.html • PAR-18-587 and PAR-18-588: Assistive Technology for Persons with AD/ADRD and Their Caregivers https://grants.nih.gov/grants/guide/pa-files/PAR-18-587.html • NOT-AG-20-026: Notice of Special Interest: Dementia Care Workforce for Those Living with AD/ADRD https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-026.html • NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 Behavioral and Social Science Priority Areas in Dementia Caregiver Research https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html • https://projectreporter.nih.gov/reporter_searchresults.cfm?redir=sh&sl=14E8C80E4E8AC1D37598B8961CAA4A01A2FFCEB861BF&icde=51150774&hsid=74802641&shQID=0&go2=

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
3.B.1 (*continued*)						DoD has funded REACH Hope, Supporting Caregivers of Veterans with TBI and AD/Mixed Dementia: The REACH Hope Behavioral Intervention, to assist caregivers of veterans who are living with TBI and dementia. The 3-year study, August 2020-August 2023, will combine 2 behavioral interventions--REACH-VA, and the DoD's Virtual Hope Box mobile app--to support caregivers 1-on-1 in real-time and as-needed. The study will be conducted by investigators at the VA Caregiver Center, located at the Memphis VA Medical Center, and will be supported by the VA's Caregiver Support Program and Virginia Commonwealth University.
3.B.2	Provide effective caregiver interventions through AD/ADRD-capable systems.	Work with states and communities to identify caregiver interventions for dissemination.	ACL		Updated	ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. ACL programs have supported the implementation of 15 evidence-based interventions, preparing some to be taken to scale across the nation. In 2019, 29 programs were funded, and in 2020, 16 programs were funded bringing the program total to 108 state and community program funded in the US and its territories since 2014. Subject to appropriations, ACL anticipates continuing the program to increase the availability of evidence-based interventions across the country. Grantee-Implemented Evidence-Based and Evidence-Informed Interventions. • https://nadrc.acl.gov/node/140
3.B.3	Collaborate to share information on LTSS with Tribal providers.	Various dissemination mechanisms such as webinars and sharing materials with relevant networks.	ACL	IHS, CMS	Ongoing	In 2020, ACL introduced a new grant program, ADPI: Dementia Capability in Indian Country. The program designed to bring culturally-competent ADRD training and education to Indian Country. Four tribes received 3 year awards in August 2020. HHS uses multiple mechanisms to share information on LTSS and care of the person and family with AD/ADRD with Tribal providers. IHS, ACL, and CMS will develop a joint website on LTSS for Tribal providers. IHS conducts presentations on LTSS for people with AD/ADRD at Indian Country conferences, including the Older Americans Act Title VI annual conference, and conferences for Tribal Health Directors and Planners (NIHB), Tribal Leaders (National Council on American Indians), and Tribal Elders (National Indian Council on Aging). IHS and ACL host joint webinars on addressing the service and supports needs of persons with AD/ADRD. Dissemination of dementia-specific information through presentations occurs at Indian Country meetings and webinars.

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3.B.4	Continue to promote use of the National Alzheimer's Call Center to provide information, advice, and support to people with dementia or their caregivers.	ACL will continue to contribute funding to this public-private effort.	ACL	Private Partner	Ongoing	ACL continues to contribute funding to this public-private effort.
3.B.5	Make behavioral symptom management education and training available to caregivers.	Award grants.	ACL	CMS	Ongoing	ACL continues to expand efforts to develop more dementia-capable LTSS systems designed to meet the needs of AD/ADRD caregivers. ACL requires that all ADPI community grants include behavioral symptom management and expert consultations to support caregivers in their programs.
3.B.6	Adapt and implement REACH in Tribal communities.	Working in partnership with ACL, the University of Tennessee Health Sciences Center, and the Rx Foundation implement the REACH intervention as REACH into Indian Country.	IHS	ACL, VA, University of Tennessee Health Sciences Center	Updated	Initial phase completed with 80 REACH certified caregiver support coaches in 56 Tribal communities, serving at least 55 caregivers as of February 2018. Second phase of the effort is focused on strategies to increase penetration of REACH in the communities where there are certified coaches and on building additional, sustainable options for evidence-based caregiver support services. IHS continues work developing the Project ECHO model to support Caregiver Coaches in Tribal Communities and to identify additional training for caregiver support through public health nursing. IHS collaborated with the VA Greater Los Angeles GRECC in the development of the IHS-ABCD (Addressing Behavioral Challenges in Dementia) training targeted at Public Health Nurses who provide support for caregivers of persons living with dementia. • https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
3.B.7	Develop and disseminate information to caregivers on AD/ADRD and caregiving.	Develop up-to-date, relevant web content on a variety of issues to support caregivers in their role and to stay healthy.	CDC	ACL	Updated	CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD resulting in better quality of life for all care recipients. CDC has developed a series of web features and podcasts on topics including helping people with AD/ADRD and their caregivers stay physically active, care plans for older adults and their caregivers; and the truth about aging and dementia. • https://www.cdc.gov/aging/caregiving/pdf/Complete-Care-Plan-Form-508.pdf • https://www.cdc.gov/features/caregivers-month/index.html • https://www.cdc.gov/aging/publications/podcasts.htm

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
3.B.7 (*continued*)						Annually ACL, through NADRC and its grant programs, continues to develop and make available web content on issues relevant to paid and unpaid caregivers. In addition to hosting 10 webinars on a broad range of AD/ADRD topics, NADRC has developed several resources: • Handbook for Helping People Living Alone with Dementia Who Have No Known Support • Disaster Planning Toolkit for People Living with Dementia • Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia Available resources • https://nadrc.acl.gov/
3.B.8	Develop a program to support enhanced financial literacy and preparedness of family caregivers.	The program will address that need through development and testing new interventions, as well as identification and dissemination of best practices.	ACL	Private partner	Ongoing	Family caregivers often lack adequate information and resources to properly manage the financial concerns of their loved ones. ACL introduced a new program to address the need to advance the understanding financial literacy of family caregivers. The program will address that need through development and testing new interventions, as well as identification and dissemination of best practices.
Strategy 3.C: Assist Families in Planning for Future Care Needs						
3.C.1	Understand the functional trajectories of people with AD/ADRD at the end of life.	Understand better the trajectory of people with AD/ADRD, who tend to cycle in and out of hospice care at the end of life, and how numerous variables affect the trajectory.	ASPE		Completed	An expert panel on advanced dementia convened by the Institute of Medicine in 2014-2015 highlighted the need to better understand care for people with dementia near the end of life. PWD, whose prognosis is often difficult to determine, may not meet the criteria for hospice or may use hospice services for longer than the 6 months covered by Medicare. In 2020, ASPE released a report and an issue brief describing the differences in functional trajectories in the last 4 years of life between decedents with and without dementia. People with dementia had higher levels of functional impairment throughout the 4 years before death, compared to people without dementia who experienced functional impairment closer to death. In early 2021, ASPE will release the results of similar analyses showing health care service utilization over this time period. Although people with dementia were more likely to use hospice services more than 1 year before death, they were less likely than people without dementia to use these services in the 3 months immediately prior to death. These findings have implications for expanding access to end-of-life services for this population. • https://aspe.hhs.gov/pdf-report/functional-trajectories-end-life-individuals-dementia-final-report • https://aspe.hhs.gov/basic-report/functional-trajectories-end-life-individuals-dementia-issue-brief

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3.C.2	Understand the use of ACP for people with cognitive impairment, including AD/ADRD.	Understand better the characteristics of providers billing for and beneficiaries with cognitive impairment receiving ACP services.	ASPE		Completed	ASPE completed a project evaluating the use of ACP nationally, which included analyses of the use of billing codes for care planning and cognitive assessment services provided to beneficiaries in traditional Medicare. These billing codes (Healthcare Common Procedure Coding System code G0505 and Current Procedural Terminology code 99483) reimburse providers for assessment of, and care planning for, a patient with cognitive impairment, with one of the required elements being the development, updating or revision, or review of an advance care plan. The study found low use of these billing codes nationally. Experts interviewed for the project suggested potential barriers to uptake include under-diagnosis and under-disclosure of dementia-related diseases, practitioners' lack of training, and patients' fear of losing their independence. The report and issue brief were published in October 2020. • https://aspe.hhs.gov/basic-report/advance-care-planning-among-medicare-fee-service-beneficiaries-and-practitioners-research-brief • https://aspe.hhs.gov/basic-report/advance-care-planning-among-medicare-fee-service-beneficiaries-and-practitioners-final-report
3.C.3	Understand the risks and costs of cognitive impairments.	Use micro-simulation modeling to project the risks and costs of cognitive impairment.	ASPE		Completed	ASPE completed a project to understand the expected lifetime risks and costs of cognitive impairment, including estimates of the value of informal care. This study uses the DYNASIM to project the risk and costs of severe cognitive impairment at older ages over the coming decades. Unlike a lot of past research, this study will show how severe cognitive impairment and associated costs vary across the population. The final report will be posted to the ASPE website in late 2020.
3.C.4	Understanding the availability of caregivers for individuals with LTSS needs.	Conduct data analyses and micro-simulation modeling to understand the future availability of caregivers.	ASPE		Completed	ASPE is working on a project to understand widely stated concerns about an impending shortage of informal caregivers and a resulting increase in unmet needs for care as the large Baby Boom cohort enters retirement ages. The final report will be posted to the ASPE website in late 2020.
3.C.5	Empowering people to make better informed health care decisions.	Empowering people to make better informed health care decisions.	CMS		New	CMS launched Care Compare, a streamlined redesign of 8 existing CMS health care compare tools, to provide a single user-friendly interface that patients, caregivers, and consumers can use to make informed decisions about health care based on cost, quality of care, volume of services, and other data. • https://www.medicare.gov/care-compare/

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3.C.6	Expand availability of care planning tools for people with dementia.		CDC		New	CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD resulting in better quality of life for all care recipients. • https://www.cdc.gov/aging/caregiving/pdf/Complete-Care-Plan Form-508.pdf
Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease and Related Dementias						
3.D.1	Monitor, report, and reduce inappropriate use of antipsychotics in nursing homes.	National Partnership to Improve Dementia Care.	CMS	ACL, NORC	Updated	The Partnership met its goal of reducing the national prevalence of antipsychotic use in long-stay nursing home residents by 30% by the end of 2016. There was a decrease of 40.1% to a national prevalence of 14.3% in 2019. Success has varied by state and CMS region, with some states and regions having seen a reduction of greater than 45%, with the understanding that there are circumstances where clinical indications for the use of antipsychotic medications are present. • https://store.samhsa.gov/system/files/pep19-inappuse-br_0.pdf In the VHA, the STAR-VA training program in CLCs is related to decreased use of as-needed antipsychotic and benzodiazepine prescriptions. STAR-VA, adapted from the STAR program, is a team-based, behavioral approach for helping CLC staff to understand and manage distressed behaviors among residents with dementia. A VA QUERI partnered evaluation supported investigation of the impact of STAR-VA on psychotropic medication prescribing, as well as on staff injuries, rates of behavioral symptoms of dementia, and facilitators and barriers to program sustainment. • https://www.queri.research.va.gov/qnews/feb20/default.cfm?QnewsMenu=article1 • https://www.mentalhealth.va.gov/healthcare-providers/docs/STAR-VA_Overview.pdf CMS continues CMPRP, an effort to drive improvements in quality of life and quality of care for nursing home residents. CMPRP is funded by the federal portion of CMP funds to conduct activities that support and protect nursing home residents. This program builds on other CMS initiatives such as the National Partnership. A multi-pronged approach that focuses on those homes that have been identified as late adopters is being utilized. CMS also hosts regular Medicare Learning Network calls, some to address dementia-related issues.

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3.D.1 (*continued*)						• https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html • https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html • https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events.html
3.D.2	Incorporate elder abuse awareness into Aging Network activities.	Eldercare Locator and other Aging Network and prevention programs providers to recognize warning signs of abuse.	ACL	Private partner/grantees	Ongoing	ACL continues to fund programs designed to address elder abuse. NCEA is funded by ACL and, through their programs, addresses all facets of elder abuse. • https://ncea.acl.gov
3.D.3	Translate and disseminate information on abuse of people with dementia.	Create and disseminate research briefs, fact sheets and webinars.	ACL	NIH/NIA, DoJ, private partners	Ongoing	ACL continues to fund programs designed to address elder abuse. NCEA is funded by ACL and, through their programs, addresses all facets of elder abuse, including the abuse of individuals living with dementia. • https://ncea.acl.gov NIA produces online and print content on Elder Abuse including a new infographic to educate the public and disseminate information about types of elder abuse, dealing with caregiver stress, and how to help. • https://www.nia.nih.gov/health/elder-abuse NIA is actively seeking research in this area. New and ongoing FOAs: • NOT-AG-18-057: Notice to Specify High-Priority Research Topic for PAR-19-070 and PAR-19-071 https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html • RFA-AG-20-00: Interpersonal Processes in AD/ADRD Clinical Interactions and Care Partnerships https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html • PAR-18-544 (R01); PAR-18-538 (R21): Basic and Translational Research on Decision Making in Aging and AD https://grants.nih.gov/grants/guide/pa-files/par-18-544.html DoJ's NIJ maintains a webpage featuring NIJ-funded elder abuse research entitled Overview of Elder Abuse, and another page specifically on financial exploitation entitled Financial Exploitation of the Elderly.

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3.D.3 (*continued*)						• https://nij.ojp.gov/topics/articles/overview-elder-abuse • https://nij.ojp.gov/topics/articles/financial-exploitation-elderly EJI website hosts an elder justice Research webpage featuring among other things foundational articles, some of which address elder abuse and dementia. • https://www.justice.gov/elderjustice • https://www.justice.gov/elderjustice/research-related-literature • https://www.justice.gov/elderjustice/foundational-articles In addition, EJI's renowned webinar series features several webinars on this topic presented by elder justice experts: • Responding to Elder Abuse Victims with Alzheimer's Disease or Other Dementias https://www.justice.gov/elderjustice/video/responding-elder-abuse-victims-alzheimer-s-disease-or-other-dementias • Increasing Access to Capacity Assessments via New Technologies https://ovcttac.adobeconnect.com/px6tzz3q5y94/ • Digging Deeper: When Consent is Not Consent https://www.justice.gov/elderjustice/video/digging-deeper-when-consent-not-consent • Assessing Cognitive Capacity In Elder Abuse Cases https://www.justice.gov/elderjustice/video/assessing-cognitive-capacity-elder-abuse-cases The EJI supported the development of Finding the Right Fit: Decision-Making Supports and Guardianship, in collaboration with the National Center for State Courts. This online training is designed to assist individuals in exploring ways to help someone who may need assistance in making decisions with informal supports, legal options, and/or adult guardianship. Finding the Right Fit provides a broad overview of decision making supports and guardianship that is not specific to state laws or rules. • https://eji.courtlms.org/catalog/info/id:140?eType=EmailBlastContent&eId=78fc945e-be1f-4cdb-8474-cfd9b72ca056
3.D.4	Improve the ability of legal services to address the needs of people with AD/ADRD.	Award, monitor, and report on demonstration grants. Revise NLRC website.	ACL	Legal assistance developers, NLRC	Ongoing	ACL grants to states and communities include pilot programs designed to make dementia-capable legal services available to persons with dementia and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

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3.D.4 (*continued*)						In 2018, NADRC partnered with the ABA Commission on Law and Aging to develop the Handbook for Helping People Living Alone with Dementia Who Have No Known Support. Among other things it provides practical guidance as well as tools for helping a person living alone who does not have informal supports. The Handbook includes practical strategies for identifying people who are living alone without support, assessing risk, building trust, identifying family and friends willing to help, determining decision making capacity, options for helping the person maintain their independence, and the basics of guardianship or conservatorship. In 2017, NADRC designed and published Living with Dementia: Advance Planning Guides (4 guides) for Persons with Dementia and Caregivers. • https://nadrc.acl.gov/node/137 ACL's NADRC continues to work closely with the ABA's Commission on Law and Aging in the development of resources that support persons with dementia and their caregivers in legal matters. ACL funds the National Center on Law and Elder Rights and grants under the Model Approaches program. • http://www.nlrc.aoa.gov/NLRC/Index.aspx
3.D.5	Educate law enforcement and other first responders about interacting with AD/ADRD.	Educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD.	DoJ		Ongoing	DoJ will continue to educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD, and provide current information and resources to help law enforcement agencies and the communities they serve. The education will include how to prevent persons with AD/ADRD from wandering and becoming lost, as well as information on locating those who do wander and become lost. The training and resources are provided through projects funded by the Office of Justice Programs' Bureau of Justice Assistance. As part of their funded grants, several ACL ADI-SSS community projects are training law enforcement and other first responders. One grantee created a series of well-received law enforcement training videos to address wandering, driving and encountering disoriented individuals on "house calls". • https://youtu.be/cQbmcq7rC7A

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3.D.5 (*continued*)						The EJI continues its commitment to ensuring law enforcement has the training and tools to robustly and appropriately respond to victims of elder abuse, including persons with ADRD. For example, EJI currently hosts relevant resources on the law enforcement webpage, including: • Safe Return: Alzheimer's Disease Guide for Law Enforcement (Alzheimer's Association) http://www.alz.org/national/documents/SafeReturn_lawenforcement.pdf • A Booming Problem: Alzheimer's, Dementia, and Elder Abuse (COPS Office) http://cops.usdoj.gov/html/dispatch/05-2015/alzheimers_dementia_elder_abuse.asp • Approaching Alzheimer's: First Responder Training Program (Alzheimer's Association) http://www.alz.org/care/alzheimers-first-responder.asp • Communicating with Someone with Dementia (Alzheimer's Association) https://www.alz.org/help-support/caregiving/daily-care/communications In FY 2021, the EJI is collaborating with the FBI to support the development of curriculum for forensic interviewing with older adults. This is an advanced forensic interviewing certificate curriculum for established forensic interviewers with previous basic certification and extensive experience in forensic interviewing and or working with older adults and adults with ADRD. The advanced forensic interview certificate curriculum is designed to support forensic interviewers to gather information from alleged victims in the most reliable and legally defensible manner. From this in-depth curriculum, a supplemental curriculum for front line responders and another one for elder justice professionals also will be developed. This project builds upon a previous (December, 2017) EJI-hosted webinar on Forensic Interviewing With Older Adults, featuring aspects of dementia as part of this training that remains available for professionals to download. • https://www.justice.gov/elderjustice/video/forensic-interviewing-older-adults The EJI is collaborating with the University of Southern California to develop The Enhanced AIM Judicial Review Tool. This is a standardized framework and pragmatic tool based upon the Abuse Intervention Model (AIM) for judges, court officers, and investigators to better evaluate and assimilate evidence related to capacity and the risk for elder mistreatment, including aspects of ADRD.

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3.D.6	Work with communities to develop best practices for protecting people with AD/ADRD.	A guide to educate law enforcement and inform communities, families and caregivers about best practices for protecting persons with AD/ADRD and preventing them from wandering and becoming lost.	ACL		Ongoing	ACL, the NADRC and dementia grantees continue to make the provision of dementia-specific education of first responders a priority in their funded programs. The NADRC developed a guide for first responders entitled Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia. The guide helps community organizations collaborate with first responders to better serve people living with dementia, a need increasingly recognized by first responder agencies. This guide explains why this issue is gaining attention, provides strategies for building successful partnerships, and describes the types of programs that can benefit people living with dementia. Also included are resources such as training materials, sample policies, tip sheets and more.

In addition to the guide, ACL grantees developed a training session on the basics of dementia for First Responders which includes descriptions of dementia, the changes that accompany dementia (e.g., communication, behavior), and important safety and wandering issues related to dementia. Alzheimer's San Diego created a referral form that law enforcement can use. To refer an individual or family member to Alzheimer's San Diego for support or education. A complement to these resources are the 4-part training series of videos developed by Alzheimer's Orange County which present educational vignettes to address wandering, driving and encountering disoriented individuals on "house calls" involving actual first responders and actors portraying people living with dementia and reminders about how to handle the interactions and any follow-up.
• https://nadrc.acl.gov/node/155
• https://nadrc.acl.gov/node/196
• https://www.youtube.com/playlist?list=PLyUU5QfNKxwhm7NTgcmUGUsfKxs_qCb20

The EJI's Multidisciplinary Team Technical Assistance Center (MDT TAC) provides educational offerings and technical assistance to elder abuse MDTs on the topic of detecting and providing appropriately tailored elder abuse interventions for older adults with AD/ADRD.
• https://www.justice.gov/elderjustice/mdt-tac |

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
Strategy 3.E: Assess and Address the Housing Needs of People with Alzheimer's Disease and Related Dementias						
3.E.1	Evaluate the SASH program.	Analyze the SASH program model of coordinated health and supportive services within affordable housing settings.	ASPE		Completed	ASPE SASH reports • https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-sash-evaluation-findings-2010-2016 • https://aspe.hhs.gov/basic-report/support-and-services-home-sash-evaluation-highlights-evaluation-program-outcomes-2010-2016 The HUD Cityscape paper on SASH: The Impact of the Vermont SASH Program on Healthcare Expenditures • https://www.huduser.gov/portal/periodicals/cityscpe/vol20num2/ch1.pdf
3.E.2	Assess utilization of home health benefits.	Using data from Medicare Advantage plans to better evaluate utilization and benefits of home health care.	ASPE		Ongoing	ASPE is now working on research to better understand trends in home health care use in Medicare Advantage compared to traditional Medicare. • https://aspe.hhs.gov/basic-report/patterns-care-and-home-health-utilization-community-admitted-medicare-patients
3.E.3	Understand contributing factors to and policy implications of nursing facility closures.	Analyze nursing facility closures over the last decade.	ASPE		New	In fall 2020, ASPE began an evaluation of nursing facility closures over the last decade. Nursing facility closures can have negative effects on residents and affect access to care in this setting. Although a certain proportion of nursing facility closures is expected and may be considered an appropriate market response to poor performance or oversupply, stakeholders are concerned with recent news of increases in the number of closures and how that may limit access to necessary long-term care services in some circumstances. This study will explore the incidence rate of nursing facility closures per year over the last decade and describe factors that may be contributing to those closures. The study will contribute to HHS' general understanding of changes in the nursing facility industry and how recent closures may impact access for the aging population.
Goal 4: Enhance Public Awareness and Engagement						
Strategy 4.A: Educate the Public about Alzheimer's Disease and Related Dementias						
4.A.1	Enhance public outreach about AD/ADRD.	Update website and ADEAR site/publications and disseminate information through social media. Launched Podcast Series. Launched Communications Center.	ACL, NIH/NIA, CDC	Multiple cross-agency and funded partners	Updated	Through its grant and resource center programs, ACL continues to build awareness of AD/ADRD. All ACL grantees include awareness and outreach in their programs. Numerous grantee programs include dementia-friendly community activities in their projects, partnering with established AD/ADRD stakeholders, as well as training volunteer educators of community organizations including, but not limited to, faith-based organizations, business leaders and grass roots volunteer organizations like Rotary Clubs.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.A.1 (*continued*)		Launched Resources and Publications Center. Crafted Website Feature Stories from Journal Articles. Social Media Campaigns. Provided communication technical assistance to funded partners. Applied Digital First Best Practices to web and social media content.				ACL's NADRC website is an establish hub for resources to support community outreach and education efforts. The website offers a broad range of resources to support the development and implementation of community-based AD/ADRD education programs. • https://nadrc.acl.gov 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 AD/ADRD, participation in clinical trials, and caregiving is freely available. NIA promotes ADEAR's resources through outreach in the research and care communities and through media and advocacy organizations, via weekly e-alerts to more than 50,000 subscribers, and social media outreach to more than 10,000 followers. • http://www.Alzheimers.gov For its part, CDC's AD and Health Aging Program publishes web features, a series of podcasts, weekly newsletters (68,000 subscribers), and social media to increase awareness and engagement by the public and its stakeholders about AD/ADRD. Web features for 2019-2020 include: Web Features • Healthy Body, Healthy Brain https://www.cdc.gov/aging/publications/features/healthy-body-brain.html • Loneliness and Social Isolation in Older Adults https://www.cdc.gov/aging/publications/features/lonely-older-adults.html • Caring for Yourself When Caring for Another https://www.cdc.gov/aging/publications/features/caring-for-yourself.html • Minorities and Women Are at Greater Risk for AD https://www.cdc.gov/aging/publications/features/Alz-Greater-Risk.html Podcasts (Aging and Health Matters Series) • Healthy Body, Healthy Brain https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.A.1 (*continued*)						• Loneliness Puts Older Adults at Risk for Serious Medical Problems https://tools.cdc.gov/medialibrary/index.aspx#/media/id/407659 • What About the Caregivers? https://tools.cdc.gov/medialibrary/index.aspx#/media/id/406088 • The Importance of Physical Activity for Older Adults https://tools.cdc.gov/medialibrary/index.aspx#/media/id/405188 • AD--Genes Do Not Equal Destiny https://tools.cdc.gov/medialibrary/index.aspx#/media/id/402234 Also in 2019-2020, AD+HAP launched on its website a new Communication Center and Resources and Publications hub. CDC has participated in the Did You Know? feature offered by CDC's Center for State, Tribal, Local, and Territorial Support to promote prevention activities. Featured topics have included: brain health, memory loss, chronic conditions in relation to memory loss, and how dementia disproportionately effects minorities and women.
4.A.2	Facilitate translation of data and surveillance to inform the public.	Develop and disseminate scientific information to public health professionals in a concise and accurate manner.	CDC	Private partners	Updated	See 1.E.7 for information on resources developed using BRFSS data. • https://www.cdc.gov/aging/healthybrain/brfss-faq.htm • https://www.cdc.gov/brfss/index.html In 2019, CDC translated the national caregiving and SCD infographics in to Spanish and develop corresponding infographics for African American, AI/AN, Asian/Pacific Islander, Hispanic, Women, Men, Rural, LGBT, and Veterans. These infographics can be used to educate the public and aid in making decisions on how to allocate resources and funding. • https://www.cdc.gov/aging/data/index.htm • https://www.cdc.gov/aging/agingdata/index.html Additionally, CDC developed infographics co-branded with the Alzheimer's Association as well as IHS. These resources are marketed on their website, and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.A.2 (*continued*)						State of Aging and Health in America: Data Brief Series are topic-specific documents focusing on public health issues related to older adults developed by CDC and NACDD. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues. • https://www.cdc.gov/aging/publications/briefs.htm CDC also supported the Alzheimer's Association to develop a Needs Assessment Toolkit that serves as Guidance and Resources for state Public Health Agencies on Comprehensive Needs Assessments Related to AD/ADRD. This document aims to increase the use of information and insights to appropriately respond to the growing public health burden associated with AD/ADRD through comprehensive needs assessments. These are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans that are focused either exclusively on AD/ADRD, or more broadly on the incorporation of cognitive health and impairment into other state public health plans. Public health agencies have a high level of expertise related to developing and conducting needs assessments. This toolkit has been developed to help states leverage their expertise in conducting needs assessments to enhance their ability to gather and use information specifically related to AD/ADRD.
Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease and Related Dementias Awareness and Readiness across the Government						
4.B.1	Continue to convene federal partners.	Convene to share research findings, innovative or best practices, and information about new or upcoming initiatives.	ASPE	CDC, NIH/NIA, ACL, CMS, HRSA, AHRQ, IHS, SAMHSA, OASH, VA, NSF, DoD	Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.
4.B.2	Build upon lessons learned to improve the dementia-capability of state and local service systems.	Expand Dementia-Capability Toolkit to include educational materials on identifying persons with cognitive impairment, direct links to tools, and examples of best practices in other states.	ACL	CMS	Ongoing	HHS will improve the dementia-capability of state and community service systems through the ACL's ADPI and NADRC. ACL and NADRC have developed the Dementia Capability Assessment Tool designed to measure the dementia-capability of the LTSS in various organizations and measure improvement over time.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.B.2 (*continued*)						ADPI grantees, partners and other collaborators will work in peer-led groups on specific activities to make state and local-level improvements related to dementia-capability. The peer-led groups will develop practical tools to promote the adoption of dementia-capable practices at the state and local-levels. HHS will help states and communities meet the needs of people with AD/ADRD through an expanded Dementia Capability Toolkit and other, related resources. Additional materials will result from similar program activities. https://nadrc.acl.gov
4.B.3	Get Tribal input on AD/ADRD and support improved coordination between IHS, Tribal, and Urban Indian Health programs and the Tribal Aging Network.	Convene Tribal leaders. Improve coordination between IHS, Tribal, and Urban Indian Health programs and the Tribal Aging Network around 4 person-centered goals. IHS and ACL will adapt the VA approach to dementia warning signs and pilot-test it in clinical and community-based settings. IHS and ACL will partner with AD/ADRD advocacy organizations to link state and local chapters with Tribal Senior Centers and IHS, Tribal, and Urban Indian Health Programs.	IHS, ACL	ASPE, VA	Ongoing	HHS will solicit input from Tribal leaders on the impact of AD/ADRD on Indian Country during the annual Tribal Consultation process and through broader meetings and convenings. HHS will use these opportunities to convene leaders and solicit input on the needs related to recognition, diagnosis, and support for individuals with dementia and their families. Alzheimer's Association has started meetings with the United South and Eastern tribes and with the Northwest Portland Area Indian Health Board. There has been increased Tribal representation on the Alzheimer's Association/CDC HBI Road Map for Indian Country work.
4.B.4	Develop and update a public health Road Map for assisting state, Tribal, and local health departments in prioritizing actions	Convene experts, identify priorities, and develop a Road Map.	CDC		Ongoing	CDC supported the Alzheimer's Association to co-develop the third in a series of HBI Road Maps to advance cognitive health as an integral component of public health. This HBI State and Local Public Health Partnerships to Address Dementia. The 2018-2023 Road Map outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. 25 specific actions are proposed in 4 traditional domains of public health: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.B.4 (*continued*)						In collaboration with the Alzheimer's Association and numerous partners, the Road Map for Indian Country was released in 2019 and disseminated to multiple stakeholders and Tribal leaders. This Road Map for Indian Country has been designed specifically for public health systems serving AI/ANs and Native Hawaiians. • https://www.cdc.gov/aging/healthybrain/roadmap.htm • https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html • https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
4.B.5	Facilitate translation of findings into public health practice in Tribal communities.	Develop and update a Public Health Road Map for assisting Tribal entities in prioritizing actions. Develop materials to support implementation of the Public Health Road Map in Tribal Communities.	CDC	IHS, Alzheimer's Association, private partners	Updated Road Map released spring 2018	In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the Public Health Road Map for Tribal Communities, the HBI Road Map for Indian Country. The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion Road Map for Indian Country has been designed specifically for public health systems serving AI/AN adults. Additionally, there are several companion materials to support brain health in Tribal communities developed by CDC in partnership with ASTHO and Alzheimer's Association. CDC and Alzheimer's Association, in collaboration with IHS, also produced infographics sharing data from the 2015-2018 BRFSS describing caregiving and SCD among AI/AN adults. See 2.C.2 for information on CDC's partnership with NCUIH to develop culturally-appropriate resources on brain health. See 1.E.7 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.B.5 (*continued*)						State of Aging and Health in America: Data Brief Series, developed in collaboration with NACDD and CDC are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues. • https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html • https://www.cdc.gov/aging/data/index.htm • https://www.cdc.gov/aging/publications/briefs.htm
Strategy 4.C: Coordinate United States Efforts with Those of the Global Community						
4.C.1	Work with global partners to enhance collaboration.	Contribute to international dementia activities.	ASPE		Updated	The US participated in the WHO's GDO in 2019. • https://www.who.int/mental_health/neurology/dementia/Global_Observatory/en/

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.C.1 (*continued*)						The HCAP initiative is an innovative approach to assessing trends in cognitive function and aging in the US and worldwide. The primary aim of the HRS, funded by NIA and the SSA, is to collect and distribute multi-disciplinary data for research on aging. To provide the worldwide research community with new and richer data to study the prevalence, predictors, and outcomes of cognitive impairment and dementia. NIH first supported HCAP during in 2016 when investigators administered a supplemental in-home, 1-hour battery of cognitive tests to about 3,200 randomly selected HRS respondents age 65 and older, along with a 20-minute informant interview. The data from that 2016 assessment have been made publicly-available to the scientific community, and analyses are underway. HCAP 2020, a follow-up to the original, is now being planned. Researchers will readminister the same in-home cognitive assessment and seek an informant report from all surviving members of the original HCAP sample and from a new random sample of those age 65-68 in 2020. HCAP 2020 will provide extensive new data to better assess trajectories of cognitive decline. These data afford an unprecedented opportunity to more clearly describe trends in the incidence and prevalence of dementia around the world. HCAP is also being administered in other developed and developing countries, where HRS-like representative population surveys are conducted, including in China, England, India, Mexico, South Africa, and parts of the EU. In most of these studies, important biomarker data, including DNA for genotyping and future sequencing, is also being collected. • https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology • https://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.118334926.654419972.1601312536-181621991.1601312536

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
4.C.1 (*continued*)						NIA also supports an international team of researchers that has made more progress in explaining the genetic component of AD. Their analysis, involving data from more than 35,000 individuals with LOAD, has identified variants in 5 new genes that put people at greater risk of AD. It also points to molecular pathways involved in AD as possible avenues for prevention, and offers further confirmation of 20 other genes that had been implicated previously in AD. The results of this largest-ever genomic study of AD suggests key roles for genes involved in the processing of beta-amyloid peptides, which form plaques in the brain recognized as an important early indicator of AD. They also offer the first evidence for a genetic link to proteins that bind tau, the protein responsible for telltale tangles in the AD brain that track closely with a person's cognitive decline. The new findings are the latest from the IGAP consortium. The effort, spanning 4 consortia focused on AD in the US and Europe, was launched in 2011 with the aim of discovering and mapping all the genes that contribute to AD. • https://www.nih.gov/news-events/news-releases/data-sharing-uncovers-five-new-risk-genes-alzheimers-disease
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 and researchers.	ASPE	CMS, CDC, NIH/NIA, ACL, VA, IHS	Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.
5.A.2	Make needed improvements to data.	Develop questions to be fielded for data collection. Add to surveys.	ASPE	CDC/NCHS, NIH/NIA	Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.
5.A.3	Summarize data on cognitive impairment across states.	Report on BRFSS and NHANES data on cognitive decline and caregiving.	CDC		Updated	See 1.D.3 for full overview of work on BRFSS and NHANES. See 4.A.2 for full overview of the State of Aging and Health in America: Data Brief Series, developed by CDC in collaboration with NACDD. • https://www.cdc.gov/aging/agingdata/index.html • http://www.alz.org/publichealth/data-collection.asp • https://www.cdc.gov/aging/data/index.htm • https://www.cdc.gov/aging/healthybrain/surveillance.htm • https://www.cdc.gov/aging/data/index.htm • https://www.cdc.gov/aging/publications/briefs.htm • https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf • http://www.cdc.gov/nhanes • https://wwwn.cdc.gov/Nchs/Nhanes/2013-2014/CFQ_H.htm • https://wwwn.cdc.gov/Nchs/Nhanes/2011-2012/CFQ_G.htm

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
5.A.4	Develop and disseminate measures of awareness of AD/ADRD.	Release report on validated survey questions.	CDC		Updated Report expected late 2019	CDC examined the validity of subjective cognitive questions used in national surveys by comparing self-rated perceptions of cognitive functioning to functional measures. The report was released in 2019 in collaboration with NCHS. • https://www.cdc.gov/nchs/data/nhsr/nhsr126-508.pdf
5.A.5	Summarize existing data on people with AD/ADRD and their caregivers.	Develop and release data portal.	CDC	ASPE, NCHS, NIH/NIA, ACL	Updated	See 1.D.3 for full overview of work on BRFSS. • https://www.cdc.gov/aging/agingdata/index.html See 4.A.2 for full overview of the State of Aging and Health in America: Data Brief Series developed by CDC in collaboration with NACDD. • https://www.cdc.gov/aging/publications/briefs.htm See 1.E.7 for update on the Caregiving and SCD infographics. • https://www.cdc.gov/aging/data/index.htm CDC, NIA, and ACL provided new data benchmarks and goals related to AD/ADRD through Healthy People 2020 and Healthy People 2030. During the Healthy People 2020 close-out, more recent data was provided for DIA-1: Increase the proportion of adults aged 65 years and older with diagnosed AD/ADRD, or their caregiver, who are aware of the diagnosis and DIA-2: Reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed AD/ADRD. For Healthy People 2030, the dementia workgroup successfully retained DIA-1 and DIA-2 and added a third core objective DIA-3: Increase the proportion of adults with SCD who have discussed their confusion or memory loss with a health care professional. These 3 objectives each set new and ambitious targets to be achieved during the next decade to improve health and quality of life for people with dementia, including AD. • https://www.cdc.gov/aging/publications/healthy-people-2030/index.html
5.A.6	Provide analysis of BRFSS data on AD/ADRD and their caregivers in user-friendly formats.	Data analysis and material development.	CDC	NACDD	Updated	CDC partnered with NACDD to create a series of data briefs addressing topic-specific public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues. • https://www.cdc.gov/aging/publications/briefs.htm

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2019 and 2020
5.A.6 (*continued*)						See 1.D.3 for full overview of work on BRFSS, including information on the Cognitive Decline and Caregiver Optional Modules. • https://www.cdc.gov/aging/healthybrain/brfss-faq.htm • https://www.cdc.gov/aging/data/index.htm • https://www.cdc.gov/aging/agingdata/index.html • https://www.cdc.gov/brfss/index.html • https://www.cdc.gov/aging/healthybrain/surveillance.htm
Strategy 5.B: Monitor Progress on the National Plan						
5.B.1	Track National Plan progress.	Track progress on the Plan and incorporate measures into other efforts to monitor population health such as Healthy People 2020.	ASPE		Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.
5.B.2	Update the National Plan annually.	Release updated National Plan.	ASPE		Ongoing	This work will continue throughout the duration of the NAPA legislation and beyond.
5.B.3	Identify key indicators of progress on the National Plan.	Convene federal and non-federal partners.	ASPE		Ongoing	ASPE convened federal partners to identify key indicators of progress on the National Plan to Address AD. These indicators should be meaningful for the policy makers, program staff as well as the public and enhance our understanding of the impact of the activities described within the framework of the National Plan. Indicators may be available from federal program data or other sources. As a next step, ASPE will host a discussion of this work at a meeting of the Advisory Council on Alzheimer's Research, Care, and Services.

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.   Kawas CH, Kim RC, Sonnen JA, Bullain SS, Trieu T, Corrada MM. Multiple pathologies are common and related to dementia in the oldest-old: The 90+ Study. Neurology. 2015;85(6):535-542. doi:10.1212/WNL.000000000000183.

6.   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.

7.   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/.

8.   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.

9.   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.

10.   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.

11.   Favreault M, Urban Institute, ASPE Report, "Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief," February 2016. https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.

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.

13.   Up-to-date COVID mortality information available at: https://covidtracking.com/data/longtermcare.

14.   Brown EE, Kumar S, Rajji TK, Pollock BG, Mulsant BH. Anticipating and Mitigating the Impact of the COVID-19 Pandemic on Alzheimer's Disease and Related Dementias. Am J Geriatr Psychiatry. 2020;28(7):712-721. doi:10.1016/j.jagp.2020.04.010.

List of Acronyms Used

AAA	Area Agency on Aging
AAIC	Alzheimer's Association International Conference
ABCD	Addressing Challenging Behaviors in Dementia
ACL	HHS Administration for Community Living
ACP	Advance Care Planning
ACTC	Alzheimer's Clinical Trials Consortium
ACTC-DSN	Alzheimer's Clinical Trials Consortium-Down Syndrome Network
AD	Alzheimer's Disease
AD+HAP	Alzheimer's Disease and Healthy Aging Program
AD-PM	Alzheimer's Disease and Precision Medicine
AD-VANCE	Alzheimer's Disease Veteran-Centric Alliance Network for Health Care Excellence
ADC	Alzheimer's Disease Center
ADEAR	Alzheimer's Disease Education and Referral
ADI-SSS	Alzheimer's Disease Initiative-Specialized Supportive Services
ADL	Activity of Daily Living
ADNI	Alzheimer's Disease Neuroimaging Initiative
ADORE	Alzheimer's and Dementia Outreach, Recruitment, and Engagement Resources
ADPI	Alzheimer's Disease Programs Initiative
ADRC	Alzheimer's Disease Research Center
ADRD	Alzheimer's Disease and Related Dementias
ADSP	Alzheimer's Disease Sequencing Project
ADSSP	Alzheimer's Disease Supportive Services Program
AFTD	Association for Frontotemporal Degeneration
AHRQ	HHS Agency for Healthcare Research and Quality
AI/AN	American Indian/Alaska Native
AIDD	ACL Administration on Intellectual and Developmental Disabilities
AMP	Accelerating Medicines Partnerships
AMP-AD	Accelerating Medicines Partnerships-Alzheimer's Disease
AMP-PD	Accelerating Medicines Partnerships for Parkinson's Disease
AoA	ACL Administration on Aging
APS	Adult Protective Services
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
ASTHO	Association of State and Territorial Health Officials
AtG	Alternatives to Guardianship
AWV	Annual Wellness Visit
BRFSS	Behavioral Risk Factor Surveillance System
CADHC	Community Adult Day Health Care
CADRO	Common Alzheimer's Disease Research Ontology
CAP	Collaboration for Alzheimer's Prevention
CARES Act	Coronavirus Aid, Relief, and Economic Security Act
CBO	Community-Based Organization
CCBHC	Certified Community Behavioral Health Clinic
CCM	Chronic Care Management
CDC	HHS Centers for Disease Control and Prevention
CDMRP	Congressionally Directed Medical Research Program
CEU	Continuing Education Unit
CHIP	Children's Health Insurance Program
CLC	Community Living Center
CME	Continuing Medical Education
CMMI	CMS Center for Medicare and Medicaid Innovation

CMP	Civil Monetary Penalty
CMPRP	Civil Monetary Penalty Reinvestment Program
CMS	HHS Centers for Medicare & Medicaid Services
COVID-19	Novel Coronavirus
CSP	Cooperative Studies Program
CWOW	Center Without Walls
D-SNP	Dual Eligible Special Needs Plan
DNA	Deoxyribonucleic Acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DoL	U.S. Department of Labor
DYNASIM	Dynamic Simulation of Income Model
EES	Employee Education System
EHR	Electronic Health Record
EJI	DoJ Elder Justice Initiative
eLTSS	Electronic Long-Term Services and Supports
EU	European Union
FDA	HHS Food and Drug Administration
FEMA	Federal Emergency Management Agency
FHIR	Fast Healthcare Interoperability Resource
FID	Facility-initiated Involuntary Discharge
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Dementia
FY	Fiscal Year
GACA	Geriatrics Academic Career Award
GDO	Global Dementia Observatory
GRECC	Geriatric Research, Education, and Clinical Centers
GWEP	Geriatrics Workforce Enhancement Program
HBI	Healthy Brain Initiative
HBPC	Home-Based Primary Care
HCAP	Harmonized Cognitive Assessment Protocol
HCBS	Home and Community-Based Services
HCIA	Health Care Innovation Award
HHS	U.S. Department of Health and Human Services
HIT	Health Information Technology
HL7	Health Level 7
HRS	Health and Retirement Survey
HRSA	HHS 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
iCARE-AD/ADRD	Improving Care for People with Alzheimer's Disease and Related Dementias Using Technology
IDD	Intellectual and Developmental Disability
IGAP	International Genomics of Alzheimer's Project
IHS	HHS Indian Health Service
IMPACT	Imbedded Pragmatic Alzheimer's Disease and Related Dementias Clinical Trials
IMPACT-AD	Institute on Methods and Protocols for Advancement of Clinical Trials in AD/ADRD

InCASA	Innovations in Care and Support Award
INCLUDE	Investigation of Co-occurring Conditions across the Lifespan to Understand Down Syndrome
INFINITY	Intensive Versus Standard Ambulatory Blood Pressure Lowing to Prevent Functional Decline in the Elderly
JPND	Joint Programme -- Neurodegenerative Research
LBD	Lewy Body Dementia
LGBT	Lesbian, Gay, Bisexual, and Transgender
LOAD	Late-Onset Alzheimer's Disease
LTCO	Long-Term Care Ombudsman
LTSS	Long-Term Services and Supports
MCI	Mild Cognitive Impairment
MFH	Medical Foster Home
MIPS	Merit-based Incentives Payment System
MLTSS	Managed Long-Term Services and Supports
MOC	Maintenance of Certification
MoCA	Montreal Cognitive Assessment
MRI	Magnetic Resonance Imaging
MVP	Million Veteran Program
NACDD	National Association of Chronic Disease Directors
NADRC	National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer's Project Act
NASEM	National Academics of Science, Engineering and Medicine
NBHCAA	National Brain Health Center for African Americans
NCAPPS	National Center on Advancing Person-Centered Practices and Systems
NCEA	National Center on Elder Abuse
NCHS	NIH National Center for Health Statistics
NCUIH	National Council of Urban Indian Health
NHANES	National Health and Nutrition Examination Survey
NHATS	National Health and Aging Trends Survey
NIA	NIH National Institute on Aging
NIAGADS	National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site
NICHD	NIH National Institute of Child Health and Human Development
NIH	HHS National Institutes of Health
NIHB	National Indian Health Board
NIJ	DoJ National Institute of Justice
NIMHD	NIH National Institute on Minority Health and Disparities
NINDS	NIH National Institute of Neurological Disorders and Stroke
NLRC	National Legal Resource Center
NORC	National Ombudsman Resource Center
NOSI	Notices of Special Interest
NRC-SDM	National Resource Center for Supported Decision-Making
NTG	National Task Group on Intellectual Disabilities and Dementia Practices
NTG-EDSD	NTG Early Detection Screen for Dementia
OASH	HHS Office of the Assistant Secretary for Health
OMB	U.S. Office of Management and Budget
ONC	HHS Office of the National Coordinator for Health Information Technology
OWH	HHS Office on Women's Health
P.L.	Public Law

PAC	Post-Acute Care
PET	Positron Emission Tomography
PHCOE	Public Health Center of Excellence
PHE	Public Health Emergency
PPE	Personal Protective Equipment
PPS	Prospective Payment Systems
PRARP	Peer Reviewed Alzheimer's Research Program
PRC	Prevention Research Center
PREVENTABLE	Pragmatic Evaluation of Events and Benefits of Lipid-lowering in Older Adults
Project ECHO	Extension for Community Healthcare Outcomes project
PTSD	Post-Traumatic Stress Disorder
PWD	Persons with Disabilities
PwIDD-HBI	People with IDD Healthy Brain Initiative
QIO	Quality Improvement Organization
QUERI	Quality Enhancement Research Initiative
RADx	Rapid Acceleration of Diagnostics
REACH	Resources for Enhancing Alzheimer's Caregivers Health
REACH-VA	Resources for Enhancing Alzheimer's Caregivers Health-VA
RIC	Resources for Integrated Care
RITT	Rural Interdisciplinary Team Training
RPA	Research Partnership Award
SAMHSA	HHS Substance Abuse and Mental Health Services Administration
SASH	Support And Services as Home
SBIR	Small Business Innovation Research
SCD	Subjective Cognitive Decline
SDM	Supported Decision Making
SME	Subject Matter Expert
SSA	U.S. Social Security Administration
STAR-VA	Staff Training in Assisted Living Residence-VA
STTR	Small Business Technology Transfer
TBI	Traumatic Brain Injury
TREAT-AD	Target Enablement to Accelerate Therapy Development for Alzheimer's Disease
VA	U.S. Department of Veterans Affairs
VCID	Vascular Contributions to Cognitive Impairment and Dementia
VHA	VA Veterans Health Administration
WHO	World Health Organization