National Plan to Address Alzheimer's Disease: 2022 Update

U.S. Department of Health and Human Services

National Plan to Address Alzheimer's Disease: 2022 Update

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Introduction

National Alzheimer's Project Act

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

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

More than six million Americans are currently living with Alzheimer's disease (AD), and it is predicted that more than 13 million will be living with the disease by 2060.[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). In addition to the loss of connections between neurons, these brain plaques and tangles are the main pathological features of AD.[3] However, studies of brain tissue have found that people with dementia usually have a mixture of brain changes. They may have the hallmark plaques and tangles of AD mixed with variations typically linked to another related form of dementia, making precise diagnosis difficult.

In addition to AD, this National Plan addresses Alzheimer's disease-related dementias (ADRD) consistent with the approach Congress used in NAPA. ADRD include frontotemporal dementia (FTD), Lewy body dementia (LBD), vascular contributions to cognitive impairment and dementia (VCID), and mixed

[1] Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. "Population estimate of people with clinical Alzheimer's disease and mild cognitive impairment in the United States (2020-2060)." *Alzheimer's & Dementia*, 2021; 17(12): 1966-1975. doi:10.1002/alz.12362. https://pubmed.ncbi.nlm.nih.gov/34043283/.

[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. 2021; NIH Publication No. 11-6423. https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet.

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.[4] People with all forms of AD/ADRD 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, 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, many persons who survive with AD/ADRD are completely reliant on others for assistance with even the most basic ADLs, such as eating, dressing, and bathing.[5]

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 from 5.3% among adults ages 65-74 to 34.6% among adults aged 85 and older.[6] The causes of AD/ADRD are not completely understood, but researchers have discovered that these conditions usually develop from the combined effects of certain genetic, social, economic, educational, and environmental factors.[7,8,9,10] 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 or younger, often placing increased burden on their families and caregivers. The relative risk of dementia is higher in rural than urban areas, particularly among minority populations. Nationally, Black Americans are twice as likely and Hispanic or Latino (Hispanic) Americans are 1.5-times as likely to develop AD/ADRD compared to White Americans.[11,12]

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 as the population ages. The Bureau of the

[4] 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.

[5] National Institute on Aging. *What Is Dementia? Symptoms, Types, and Diagnosis*. https://www.nia.nih.gov/health/what-is-dementia.

[6] Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. "Population estimate of people with clinical Alzheimer's disease and mild cognitive impairment in the United States (2020-2060)." *Alzheimer's & Dementia*, 2021; 17(12): 1966-1975. doi:10.1002/alz.12362. https://pubmed.ncbi.nlm.nih.gov/34043283/.

[7] Barnes DE, Yaffe K. “The projected effect of risk factor reduction on Alzheimer’s disease prevalence.” *Lancet Neurol.*, 2011; 10(9): 819-828. doi:10.1016/S1474-4422(11)70072-2.

[8] Kunkle BW, Grenier-Boley B, Sims R, Bis JC, Damotte V, ..., Pericak-Vance MA. "Genetic meta-analysis of diagnosed Alzheimer's disease identifies new risk loci and implicates Aβ, tau, immunity and lipid processing." *Nat Genet*., 2019;51(3): 414-430. doi:10.1038/s41588-019-0358-2.

[9] Norton S, Matthews FE, Barnes DE, Yaffe K, Brayne C. "Potential for primary prevention of Alzheimer’s disease: An analysis of population-based data." *Lancet Neurol*., 2014; 13(8):788-794. doi:10.1016/S1474-4422(14)70136-X.

[10] Yaffe K, Falvey C, Harris TB, Newman A, Satterfield S, Koster A, Ayonayon H, Simonsick E. "Effect of socioeconomic disparities on incidence of dementia among biracial older adults: Prospective study." *BMJ*, 2013; 347. doi:org/10.1136/bmj.f7051.

[11] Rajan K, Weuve J, Barnes L, Wilson R, Evans D. “Prevalence and incidence of clinically diagnosed Alzheimer's disease dementia from 1994 to 2012 in a population study.” *Alzheimer's & Dementia*, 2019; 15(1): 1-7. doi:10.1016/j.jalz.2018.07.216.

[12] Samper-Ternent R, Kuo Y, Ray L, Ottenbacher K, Markides K, Al Snih S. "Prevalence of health conditions and predictors of mortality in oldest old Mexican Americans and non-Hispanic Whites." *Journal of the American Medical Directors Association*, 2012; 13(3): 254-259. doi:10.1016/j.jamda.2010.07.010.

Census estimates that the number of people aged 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, often family members and friends, provide the majority of care for people with AD/ADRD in the community. Unpaid caregivers frequently 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.[13]

Dementia care costs are significant and often a burden to families and others providing unpaid care. Researchers estimated that the total value of health, long-term care, and caregiving for a person with probable dementia in the last 5 years of life was $287,000 (in 2020 dollars). These costs are significantly higher than care for a person with heart disease ($175,000) or cancer ($173,000).[14] 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.[15] Similarly, estimates from national data show that nearly seven out of ten residents in assisted living residences have some form of cognitive impairment.[16] 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 home and community-based services (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 long-term services and supports (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.[17]

[13] 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.

[14] Kelley AS, McGarry K, Gorges R, Skinner JS. "The burden of health care costs for patients with dementia in the last 5 years of life." *Annals of Internal Medicine*, 2015; 163(10): 729-736. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4809412/.

[15] Magaziner, J, German P, Zimmerman SI, Hebel JR, Burton L, Gruber-Baldini AL, May C, Kittner S. "The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older: diagnosis by expert panel." *Gerontologist*, 2000; 40(6): 663-72. doi:10.1093/geront/40.6.663.

[16] Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, Covinsky KE. "Patient and caregiver characteristics and nursing home placement in patients with dementia." *JAMA*, 2002; 287(16): 2090-2097. doi:10.1001/jama.287.16.2090.

[17] Favreault M. Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. 2016. https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.

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 person 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.[18,19]

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, their risk factors, and their impacts, as well as opportunities for improvement. The National 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 National Plan, HHS and its partners sought to leverage these resources and activities, improve coordination,

[18] Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, Covinsky KE. "Patient and caregiver characteristics and nursing home placement in patients with dementia." *JAMA*, 2002; 287(16): 2090-2097. doi:10.1001/jama.287.16.2090.

[19] 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.

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. 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 challenges 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 National 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 continue to take transformative action needed to address these diseases. With ongoing input from 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 six goals 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.
6. Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer’s Disease and Related Dementias.

2022 Update

May 2022 marked the 10th Anniversary of the first National Plan. HHS commemorated this Anniversary through several publications and presentations highlighting HHS agencies’ accomplishments in addressing AD/ADRD. The Administration for Community Living (ACL) hosted a National Alzheimer’s and Dementia Resource Webinar on Wisconsin’s Dementia Care Specialist Program. The National Institute on Aging (NIA) developed the Progress and Potential: Alzheimer’s and Related Dementias Research video series, which highlights some of the major scientific advances that have occurred in AD/ADRD research in the past decade and the potential for greater progress in the future.

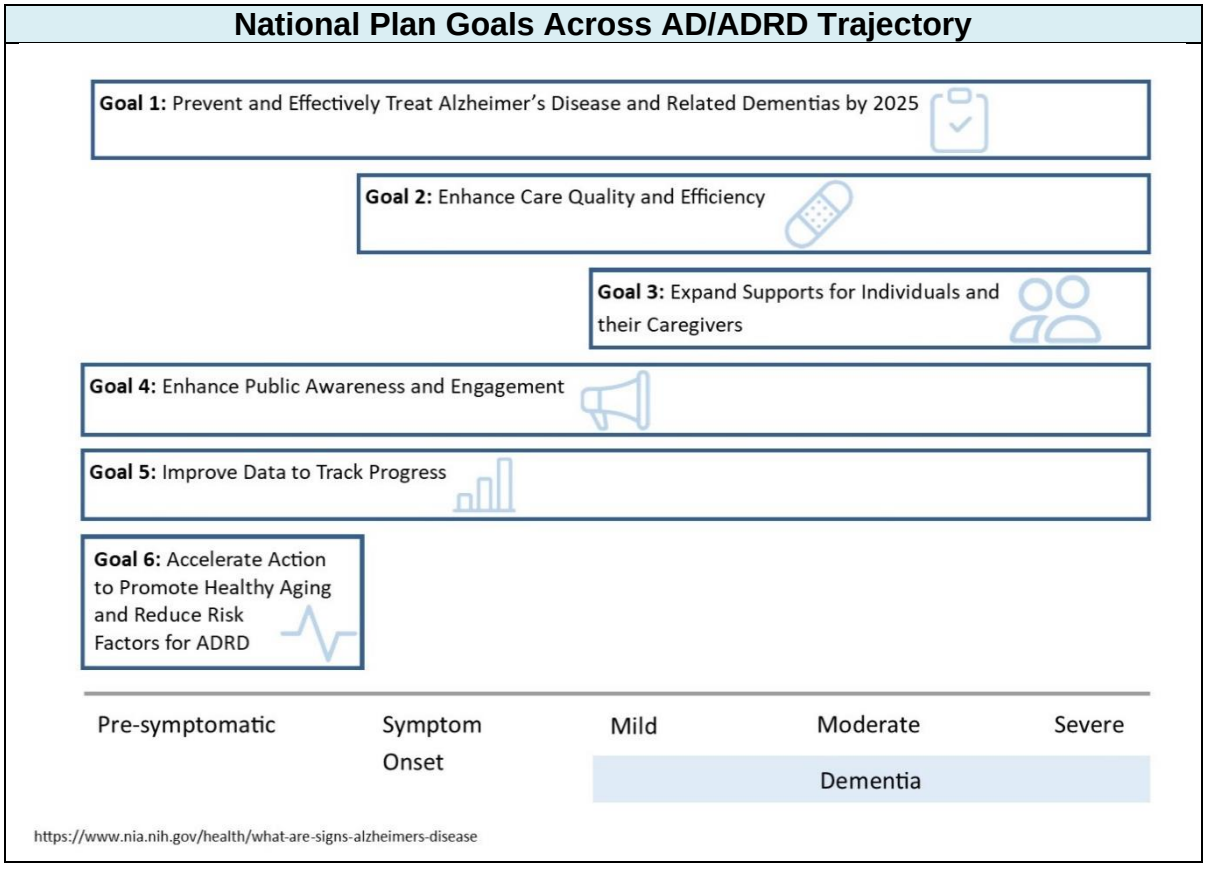
The Anniversary was also an opportunity to set and focus on two key priorities for the National Plan moving forward: addressing disparities in AD/ADRD and building partnerships with states, communities, and tribes. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) published an issue brief: *Federal Efforts to Address Racial and Ethnic Disparities in AD/ADRD*. The Indian Health Service (IHS) established the Alzheimer’s Grant Program, launching a set of education and training efforts aimed at increasing skills and capacity in geriatrics, including for persons living with dementia and their caregivers, in IHS, Tribal, and Urban Indian Health (UIH) primary care. The IHS also launched the Indian Health Geriatric Scholars pilot. The pilot will provide primary care clinicians at IHS, Tribal, and UIH

programs with an individual intensive learning track for professional continuing education. Additionally ACL, through their Office of American Indian, Alaska Native and Native Hawaiian Programs began working with a variety of culturally-competent AD/ADRD experts to develop and make available a broad range of educational curricula and tools to support increasing the dementia capability of Tribal communities across the nation. To better engage states and learn from their successes in addressing the needs of people with AD/ADRD, HHS sponsored a state policy roundtable to hear from state leaders about their work to address AD/ADRD.

In 2023 and beyond, HHS and its partners will continue to focus on addressing inequities among health and well-being of people with AD/ADRD and their families and caregivers. Expanding and building upon existing federal efforts to address disparities, including but not limited to racial and ethnic disparities, is a necessity in achieving equity. Building partnerships with states, communities, and tribes will also help the National Plan better address disparities, as it will be informed by best practices developed with direct input from community stakeholders. These partnerships will enable the National Plan to elevate and incorporate state, community, and Tribal interventions across the spectrum of AD/ADRD-related needs and challenges and transform it from a federally-focused effort to a truly national one.

For more information, see:

- https://www.youtube.com/playlist?list=PLmk21KJuZUM5en04l9gF08T74EMmFSkY5
- https://aspe.hhs.gov/reports/federal-efforts-address-adrd-disparities



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 additional prevention and treatment modalities by 2025. Ongoing research and clinical inquiry can inform our ability to prevent AD/ADRD, minimize its symptoms, and delay its progression. Under this goal, HHS will continue to 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 preventing AD/ADRD and minimizing it as a health burden by 2025. During the course of this work, National Institutes of Health (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

Lead Agencies: NIH, NIA
Partners: national and international experts, public and private stakeholders, academia, industry, professional and advocacy groups

In April 2021, NIA hosted the fourth *Alzheimer's Disease Research Summit*, with previous summits occurring in 2012, 2015, and 2018. The summits bring together a multi-stakeholder community, including government, industry, academia, private foundation, and advocacy groups, to identify research priorities and further translate AD/ADRD research findings into practice. The goal is to accelerate the development of effective, disease-modifying, and palliative therapies for the cognitive as well as neuropsychiatric symptoms (NPS) of AD/ADRD. The 2021 Summit built on the foundation laid through the work of the previous summit participants. Participants provided individual input that showcased progress to date and identified further gaps and opportunities toward the goal of precision medicine for AD/ADRD treatment and prevention. NIH is committed to regularly updating its research priorities and plans are underway for the next AD Research Summit in 2024.

For more information, see:

- https://www.nia.nih.gov/2021-alzheimers-summit
- https://www.nia.nih.gov/research/milestones

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

Lead Agency: NIA

National research summits (including the *Alzheimer's Disease Research Summit*, *Alzheimer's Disease-Related Dementias (ADRD) Summit*, and *National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers)* are held yearly on a rotating basis to gather scientific input and identify gaps and opportunities. This information factors 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, which includes success criteria and specific implementation activities to track progress, 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. The milestone database was last updated in July 2022.

In addition to NIH Summits, NIH has also gathered important input on research priorities through activities with the National Academies of Science, Engineering, and Medicine (NASEM). For example, NASEM released a decadal survey report titled *Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Science* in August 2021. It was sponsored primarily by NIA with support from NIH's Office of Behavioral and Social Sciences Research and the Department of Veterans Affairs (VA), ASPE, AARP, Alzheimer's Association, American Psychological Association, JPB Foundation, and John A. Hartford Foundation. The NASEM-led decadal process included several public workshops and provided opportunities for input from experts, researchers, advocacy organizations, and persons living with dementia and care partners. The report highlights behavioral and social science research opportunities on AD/ADRD for the next 10 years. This report offers a blueprint for the next decade of behavioral and social science research to reduce the negative impact of dementia for America's diverse population. Reducing the impact calls for research that addresses the causes and solutions for disparities in developing dementia and receiving adequate treatment and support. It calls for research that sets goals meaningful not just for scientists, but for people living with dementia and those who support them.

Additionally, in June 2021, NASEM held an NIA-sponsored virtual workshop, "Behavioral and Social Research and Clinical Practice Implications of Biomarkers and Other Preclinical Diagnostics of Alzheimer's Disease and AD-Related Dementias". The primary objective of the workshop was to engage in meaningful discussions about the implications of biomarkers and other preclinical diagnostics of AD/ADRD, and to generate ideas for future research that might be of interest to the NIA.

For more information, see:

- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones
- https://www.nationalacademies.org/our-work/decadal-survey-of-behavioral-and-social-science-research-on-alzheimers-disease-and-alzheimers-disease-related-dementias
- https://www.nia.nih.gov/2020-dementia-care-summit
- https://www.nia.nih.gov/2021-alzheimers-summit
- https://www.nia.nih.gov/research/milestones
- https://www.nia.nih.gov/sites/default/files/2022-06/2021-06-28_virtual_workshop_implications_bsr_preclinical_markers_adrd.pdf
- https://www.ninds.nih.gov/news-events/events/adrd-summit-2022

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

Lead Agency: ASPE
Partners: NAPA Advisory Council, NIH, NIA

HHS and its federal partners use the diverse input received through the three research summits on AD/ADRD 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.

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

Lead Agency: ASPE
Partners: NAPA Advisory Council, NIH, NIA

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. The Research Subcommittee of the Advisory Council 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.

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

Lead Agencies: NIA, NINDS

Since the advent of the National Plan, NIH's planning process for research on AD/ADRD has expanded in inclusion and scope, to include several NIH Institutes and Centers and stakeholders across the scientific and care communities. Gathering input from the broader community is critical to updating research recommendations, ensuring prioritization is based on important scientific questions, and identifying 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 the implementation research milestones, which set forth activities through FY 2025 to address the goals of the National Plan. The latest of these updates took place after the 2020 *Dementia Care and Caregiving Research Summit*, and the 2021 *Alzheimer's Disease Research Summit*. Updates are in progress following the ADRD summit in March 2022.

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

Lead Agency: NINDS
Partners: academia, industry, professional and advocacy groups

The National Institute of Neurological Disorders and Stroke (NINDS) convened the most recent *Alzheimer's Disease-Related Dementias (ADRD) Summit* on March 22-23, 2022. This was the fourth such summit, with previous summits occurring in 2013, 2016, and 2019. The ADRD summits complement the Alzheimer's Disease Research and AD/ADRD Care and Caregiving Summits and are a central piece of NIH's sustained efforts to engage a broad array of stakeholders in setting national ADRD research priorities. The 2022 ADRD Summit addressed a range of topics including FTD, LBD, VCID, dementia related to traumatic brain injury (TBI), and multiple etiology dementias (including TDP-43 in common dementias). Broad cross-cutting areas such as health equity and the impact of COVID-19 on AD/ADRD risk were also discussed. Research recommendations that reflect critical scientific priorities for ADRD research will be presented to the NINDS Council for approval and will become new research milestones in late 2022.

For more information, see:

- https://www.ninds.nih.gov/news-events/events/adrd-summit-2022

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

Lead Agencies: ASPE, NIH
Partners: NAPA Advisory Council, academia, industry, professional and advocacy groups

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 held as a Virtual Summit Series in 2020.

The 2020 *Dementia Care and Caregiving Summit* brought together individuals representing a variety of disciplines and backgrounds, including researchers as well as those living with dementia, care partners, providers, and advocates to identify evidence-based programs, strategies, approaches, and other research that can be used to improve the care, services, and support of persons living with dementia and their caregivers. Released in December 2020, the final report summarizes research gaps and opportunities for propelling advances in policy, practice, and care. These include the need for research on the economic impact of care on individuals, families, health systems, and society; and the need for innovation in how medical care and LTSS for persons with dementia are organized, financed, and delivered. There is strong evidence of profound disparities in dementia care among subpopulations most affected by AD/ADRD, and new research is needed to explore effects on health and receipt of care in subpopulations that are less well understood (e.g., minoritized populations and those who live alone with dementia).

For more information, see:

- https://twitter.com/search?q=%23DementiaCareSummit&src=typeahead_click&f=live
- 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://www.nia.nih.gov/sites/default/files/2021-01/DementiaCareSummitReport.pdf

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(ONGOING) Action 1.A.8: Regularly review the Congressionally Directed Medical Research Program's Peer Reviewed Alzheimer's Research Program Strategic Plan

Lead Agency: DoD

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 CDMRP 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 released 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

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

HHS and its federal partners will continue to expand clinical trials on pharmacologic and non-pharmacologic interventions, across a diversity of targets, to prevent AD/ADRD and manage and treat its symptoms. The Federal Government is working proactively to address the challenge of enrolling people in clinical trials who are representative of the country's diverse population, including racial and ethnic groups that are at higher risk for AD/ADRD, through continued development of new partnerships and outreach strategies. 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

Lead Agencies: NIA, NINDS
Partners: potential research partners in the public and private sectors

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 continue to refine and develop new tools to improve the identification and validation of 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, the involvement of metabolic and cerebrovascular pathways, the regulation of cell-type-specific proteome dynamics, the characterization of the preclinical/prodromal phase of alpha-synucleinopathies, the etiology of infectious pathogens in AD/ADRD, and the selective cell and network vulnerability and impact of brain aging in neurodegenerative diseases. For example, in 2022, NIA released a FOA to stimulate research to define and characterize neural cell populations (e.g., neurons and glia), neural activity and circuits, structural and functional networks, and brain regions that are vulnerable (or resistant) in brain aging and AD and the mechanisms underlying such selective vulnerability (PAR-21-040). Also in 2022, NINDS is funding new research into the VCID by supporting studies into the role of astrocytes in neurovascular degeneration (PAR-22-037) and encouraging the development of new technologies that can assess neurovascular changes at the molecular and cellular level (PAR-22-026). This broader view of the basic biology of AD/ADRD could lead to potential breakthroughs.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-046.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-051.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-052.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-19-007.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-016.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-034.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-037.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-040.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-041.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-023.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-026.html

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-029.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-037.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-059.html

A key part of NIH's strategy for developing new treatments for AD/ADRD is to bolster the translation of basic research findings into discovery and development of new drugs and devices for disease diagnosis, prevention, and treatment. 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, few drugs or devices are found to be both safe and effective and approved by the Food and Drug Administration (FDA). NIH continues to support a pipeline of funding opportunities aimed at discovering and developing new and diverse candidate devices and drugs for the diagnosis, prevention, and treatment of AD/ADRD. NIH makes data-informed decisions about possible candidate targets, following scientific progress closely and changing direction, when necessary, based on new evidence. In addition, 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. NIA and NINDS also released targeted FOAs designed to promote a diverse AD/ADRD research workforce that have the skillsets related to data science and drug discovery. These opportunities support investigators at three different key career stages: predoctoral, postdoctoral, and advanced postdoctoral.

For more information, see:

- 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/pa-files/PAR-20-110.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-20-122.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-217.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-218.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-220.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-022.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, 13 have now matured through the preclinical development process and are currently being tested in humans in Phase 1 and Phase 2 clinical trials. These 13 new drug candidates target multiple aspects of the disease process including neuroinflammation, proteostasis (e.g., abnormal protein folding), neurogenesis, metabolic and vascular dysfunction, etc.

Established in 2019, the TaRget Enablement to Accelerate Therapy development for Alzheimer's Disease (TREAT-AD) Translational Centers are a $73 million enterprise focused on diversifying and accelerating therapy development for AD/ADRD through the development of open-source tools, reagents, and methods for robust validation of candidate targets delivered by the Accelerating Medicines Partnership® Program for Alzheimer's Disease (AMP®-AD) program 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. In August 2021, the NIA SBIR team published a paper describing the impact of NIA's $280 million investment in this research over the past 11 years. During this timeframe, NIA has supported more than 600 grants to more than 230 small businesses in 37 states. For example, one NIA SBIR grant supported the development of the first blood test (PrecivityAD) that can help detect the presence of amyloid plaques in the brain, a hallmark of AD.

For more information, see:

- https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12392
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-025.html
- https://precivityad.com/news/alzheimers-breakthrough
- https://www.nia.nih.gov/news/nih-small-business-funding-boosts-alzheimers-science-advances

NIH's AMP-AD and AMP Program for Parkinson's Disease (AMP-PD) programs have transformed the way new targets and biomarkers are discovered by supporting large-scale team-science and rapid and broad sharing of data and knowledge. NIH recently announced the next stage of the AMP-AD program (AMP-AD 2.0). During the first phase, the AMP-AD program's open science, big data approach enabled research teams to identify and make publicly available more than 500 unique candidate targets for this complex disease. In the second phase, NIH is leading research efforts to enable a precision medicine approach to discovery of novel therapeutic targets and biomarkers. AMP-AD 2.0 will also focus on generating data from diverse cohorts, specifically Black and Latino cohorts who are disproportionately affected by the disease. All data and analytical tools will be made available to the wider research community through a centralized data infrastructure, the AD Knowledge Portal. The AD Knowledge Portal also serves as the central repository for a series of NIH-supported open science target discovery consortia, such as Molecular Mechanisms of the Vascular Etiology of Alzheimer's Disease, Resilience-AD, and Psych-AD.

For more information, see:

- https://www.nia.nih.gov/news/nih-invests-next-iteration-public-private-partnership-advance-precision-medicine-research
- https://www.nia.nih.gov/research/amp-ad
- https://www.nia.nih.gov/research/blog/2020/11/open-science-delivers-wealth-ad-adrd-research-data-portal-near-you
- https://www.nia.nih.gov/research/dn/alzheimers-disease-sequencing-project-study-design
- https://www.nih.gov/research-training/accelerating-medicines-partnership-amp
- https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Accelerating-Medicines-Partnership-Parkinsons-Disease-AMP-PD

NIA recently funded six new projects through its Alzheimer's Drug Development Program. These projects are focused on developing new drug candidates that target different biological process, such as brain inflammation, lipid metabolism, metabolic and hormonal dysregulation among others. Each project aims to submit an Investigational New Drug Application to FDA to test promising new therapeutics in humans.

For more information, see:

- https://grants.nih.gov/grants/guide/pa-files/par-18-820.html

In 2020, NIH broke ground on its Bethesda, Maryland, campus to construct a new intramural research facility devoted to AD/ADRD research, the Roy Blunt Center for Alzheimer's Disease and Related Dementias Research, which houses the NIH Center for Alzheimer's and Related Dementias (CARD). CARD is a collaborative initiative designed to combine the power of NIH intramural science with the work of researchers around the globe to push boldly ahead in basic, translational, and clinical AD/ADRD research. The dedicated facility opened its doors in 2022 and CARD researchers are now building multi-disciplinary collaborations among scientists on the NIH campus and in academia and industry. More than half of CARD staff will be comprised of visiting investigators who will rotate into CARD with new perspectives and ideas to complement the deep AD/ADRD expertise held by permanent CARD staff. In addition, CARD offers multiple opportunities for early career investigators to hone skills needed for the translation of discoveries into therapies through unique opportunities such as the Alzheimer and Related Dementias Independent Scholars Program.

For more information, see:

- https://card.nih.gov/
- https://card.nih.gov/job-training-opportunities/alzheimers-dementias-scholars-program

NIH supports the Model Organism Development and Evaluation for Late-Onset Alzheimer's Disease (MODEL-AD) Translational Centers to develop and characterize new mouse models for late-onset AD (LOAD), essential tools for basic research and therapy development. To date, MODEL-AD research teams have created more than 60 genetically modified mouse models. These models are available to the research community through the Jackson Laboratory Center for Alzheimer's and Dementia Research's Mouse Model Resource; all the data, protocols, and other resources are available through the AD Knowledge Portal and the MODEL-AD explorer.

NINDS also supports several large grants to develop and validate advanced mammalian models for FTD, VCID, LBD, and mixed dementias/neurodegeneration.

For more information, see:

- https://adknowledgeportal.synapse.org/Explore/Experimental%20Tools
- https://modeladexplorer.org
- https://reporter.nih.gov/search/WqMML-IIKk6bM4TRVLbtlg/projects?shared=true
- https://www.model-ad.org/

The MODEL-AD centers and other NIH open science programs such as AMP-AD consortia and the TREAT-AD centers have transformed the way that scientists collaborate and share their data and knowledge to discover new biological mechanisms of disease, and find new drug candidates for testing.

For more information, see:

- https://www.model-ad.org/
- https://www.nia.nih.gov/news/nih-funded-translational-research-centers-speed-diversify-alzheimers-drug-discovery
- https://www.nia.nih.gov/research/amp-ad
- https://www.nia.nih.gov/research/blog/2020/11/open-science-delivers-wealth-ad-adrd-research-data-portal-near-you

One way that NIH works to find effective ways to treat dementia is by considering drugs that FDA has already deemed safe for people with other conditions. The NIA Intramural Research Program has recently launched the Drug Repurposing for Effective Alzheimer's Medicines (DREAM) study. DREAM is a collaboration with researchers at Harvard Medical School, Rutgers University, and Johns Hopkins University School of Medicine to repurpose FDA-approved drugs for treatment of dementia.

NIA also funds drug repurposing research at its grantee institutions. NIH released a funding initiative in 2020 called Translational Bioinformatics Approaches to Advance Drug Repositioning and Combination Therapy Development for Alzheimer's Disease, which aims to leverage the power of big data and open science in advancing drug repurposing and combination therapy development. Through this initiative, NIA has funded eight projects applying computational approaches to identify drug repositioning candidates for AD/ADRD.

For more information, see:

- https://grants.nih.gov/grants/guide/pa-files/PAR-20-156.html
- https://pubmed.ncbi.nlm.nih.gov/33304987/
- https://reporter.nih.gov/search/Cs_VZiGXQ0eAYG4dF94MNA/projects
- https://www.nia.nih.gov/news/nia-study-identifies-fda-approved-drugs-may-also-be-helpful-dementia

NIA established the Alzheimer's Disease Preclinical Efficacy Database (AlzPED) to improve the rigor and reproducibility of preclinical testing studies of candidate therapeutics for AD/ADRD by making preclinical animal data publicly available and searchable in a knowledgebase. AlzPED is a partnership among NIA, NIH Library, Alzheimer's Association, Alzheimer's Drug Discovery Foundation, and Sage Bionetworks, hosting over 1,200 studies on preclinical testing of candidate therapeutics for AD/ADRD. AlzPED also provides a platform for sharing studies with negative findings.

For more information, see:

- https://alzped.nia.nih.gov/

The AD Knowledge Portal, an informatics data-sharing platform that began as the data repository for the AMP-AD Target Discovery Program, and the portal-linked, open-source platform Agora have enabled access to a vast amount of high-quality molecular data, analytical results, and candidate targets generated by the AMP-AD program research teams. The AD Knowledge Portal now includes data and resources from numerous NIA-supported programs and is open for data contributions from the greater research community.

For more information, see:

- https://adknowledgeportal.synapse.org/

NIA's Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research Program is designed to encourage a next generation of scientists to pursue research and academic careers in neuroscience, AD/ADRD, and healthy brain aging. NIA seeks to turn fresh ideas from scientists in other fields into pilot studies for innovative AD/ADRD research programs that leverage and build upon their existing expertise and to build a more robust pipeline of committed AD/ADRD researchers. As of July 2022, 87 early career researchers have received funding through this program.

For more information, see:

- https://grants.nih.gov/grants/guide/pa-files/PAS-19-391.html
- https://grants.nih.gov/grants/guide/pa-files/PAS-19-392.html
- https://grants.nih.gov/grants/guide/pa-files/PAS-19-393.html
- https://reporter.nih.gov/search/NLkaHTHIS0CqS2B125xnvg/projects

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

Lead Agencies: NIA, NINDS
Partners: research partners in the public and private sectors

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. This project involves more than 350 international investigators at 62 institutions. Data come from more than 60 cohorts of research participants. The Genome Center for Alzheimer's Disease quality control checks and harmonizes all the genetic data so that when a variant in the genome is uncovered, it can be compared against the data from thousands of other genomes. 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, and in 2021 the Follow-Up Study 2.0. Together, these initiatives aim to pursue rare variants in a range of different populations (e.g., Black, Hispanic, American Indian/Alaska Native [AI/AN], Asian). Teams are presently working to recruit new cohorts of ethnically diverse participants.

In keeping with the high priority that the AD/ADRD genetics community places on diversity, the ADSP plans to have more than 100,000 ethnically diverse study participants by 2023. An important overarching goal of the ADSP Follow-Up Study is to genetically define subgroups of subjects that carry specific sets of genes and match them with biomarkers, functional genomics, and clinical data. This will define subtypes of the disease. Defining subtypes will allow better selection of subjects for clinical trials because outcomes of drug therapies can be better targeted toward groups of individuals who have similar characteristics. It is particularly important to define ethnic diversity in terms of disease risk because ethnic groups vary widely in the degree of risk at particular locations in the genome and it is likely the clinical trials will need to be designed differently depending upon the ethnicity of the study population.

The 2021 Phenotypic Data Harmonization Initiative is harmonizing clinical data from all of the ethnic cohorts in the ADSP. These data will become a long-lived "legacy" dataset that will be perpetually curated. A network of researchers with expertise in genetics, epidemiology, and clinical specialties are working with the ADSP and with study cohort leads on data harmonization efforts to optimize the ability to identify well-targeted therapeutic approaches for AD/ADRD. The National Alzheimer's Coordinating Center (NACC) shares phenotypic and related clinical data with the ADSP and is strongly supporting this initiative.

The ADSP also recently launched a Machine Learning/Artificial Intelligence Initiative. The amount of genetic data that now is available is massive and it has been extraordinarily difficult to analyze using classical methods because the data are so complex. This initiative supports the development of fast and efficient Machine Learning/Artificial Intelligence approaches to identify the genetics that increase risk of or protection against AD/ADRD. The emphasis is on the development and sharing of transformative Machine Learning/Artificial Intelligence-based systems, emerging tools, and modern technologies for the analysis of genetic data.

In 2021, the ADSP also launched a Functional Genomics Consortium. Functional interpretation of genetic variations has been challenging historically and remains a persistent bottleneck in genetic studies of complex diseases. This hinders the discovery of genetic-based targets for therapeutics. To connect genetic variants to downstream effectors and functions, a number of issues will be addressed by this initiative, including the need to: (1) pinpoint causal variants that affect disease susceptibility and/or progression; (2) characterize the molecular and biochemical effect of these variants and identify the target genes on which these variants act and the cell-types and states in which these variants operate; (3) determine links to heterogeneous cellular and pathologic mechanisms; and (4) identify genetic drivers underlying AD endophenotypes that are clinically

relevant but difficult to ascertain. Investigators from the AMP-AD program and ADSP Consortia are working together to find intersections between the gene clusters that the ADSP has identified and the functional networks that the AMP-AD program team has reported.

NIAGADS now hosts 89 human genetics datasets with 144,242 samples and has a genomics database for cross-referencing and visualizing known genomic variants. All data generated by the ADSP are deposited into NIAGADS. In 2022, NIAGADS aims to release data generated under the initiative to support analysis on approximately 37,000 whole-genomes to find novel genetic variants that modulate AD/ADRD risk. 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.

The National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD) is an NIA-supported resource to help scientists accelerate and streamline their efforts. NCRAD serves AD/ADRD scientists by banking a wide range of biospecimens, recently including pluripotent stem cells. Through a collaboration with NIAGADS, NCRAD supports state-of-the-art genome and genotyping arrays for samples in several new studies, including the 90+ Study, a longitudinal study of aging and cognition among participants over age 90, and the Amyloid Neuroimaging and Genetics Initiative, an add-on for participants in the Imaging Dementia-Evidence for Amyloid Scanning Study.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-021.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-234.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-269.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-19-288.html
- https://grants.nih.gov/grants/guide/pa-files/par-20-099.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-20-110.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-212.html
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-21-005.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-006.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-001.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-021.html
- https://www.nia.nih.gov/research/resource/national-centralized-repository-alzheimers-disease-and-related-dementias-ncrad
- 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 70 regions of the genome that are associated with the disease. Of these, variants in more than 23 individual genes have been linked to increased risk of 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/notice-files/NOT-AG-18-001.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-046.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

NIA and NINDS also fund projects to advance further discovery for genetic factors and molecular pathways involved in AD/ADRD, such as LBD. Intramural and extramural researchers supported

by NIA and NINDS have now published several papers on the genetic underpinnings of LBD. In 2021, they identified two new LBD-associated genes (BIN1 and TMEM175) and confirmed the disease association for three other genes that have previously been identified (SNCA, APOE, and GBA). Combined with work from other laboratories, genetic studies have established that LBD shares risk profiles and pathways with AD and Parkinson's disease, but that it can also have its own unique genetic risk profile. One example of shared risk between AD and LBD is illustrated by a 2022 study from the NINDS-funded LBD Center Without Walls on the role of the APOE4 gene, most commonly associated with AD, in patients with mixed AD and LBD pathologies. They found that patients with LBD (e.g., clumps of abnormal alpha-synuclein) also had increased AD-related pathologies and that APOE4 made these changes worse.

For more information, see:

- https://pubmed.ncbi.nlm.nih.gov/33589841/
- https://pubmed.ncbi.nlm.nih.gov/35471463/
- https://www.mayo.edu/research/centers-programs/discovery-translation-labs-brain-program/lewy-body-dementia-center-without-walls

While it is known that vascular damage in the brain occurs in over half of AD/ADRD cases and is very common in other forms of dementia, researchers are still working to identify the precise vascular risk profiles that may predict cognitive decline and dementia. To address this research gap, in 2022 NINDS made administrative supplements available to existing large cohort clinical studies that have collected or are collecting MRI images of VCID-related vascular damage and have the ability to perform in-depth, post-mortem neuropathology. With supplemental funding, these studies will examine in detail the extent to which vascular imaging findings during life relate to post-mortem pathology of AD/ADRD.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-22-001.html

The VA continues to support projects that curate and develop AD phenotypes using VA clinical data. These projects will produce pilot data for VA's collaboration with the NIA on their Phenotypic Data Harmonization Initiative. In addition, there has been continued support for research projects that utilize veterans data in the Million Veteran Program cohort to study the genetic risk factors for AD/ADRD. Examining genetic risk for dementia in previously understudied veterans of African and Hispanic ancestries is the focus of some of the VA-supported efforts.

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

Lead Agency: NIA
Partners: ACL, FDA, VA, CDC, HRSA

Starting in 2016, NIA led an effort to develop comprehensive goals and strategies to enhance recruitment into clinical research, particularly focusing on underrepresented communities, with facilitation by the Alzheimer's Association and in close collaboration with experts from government, private, and academic sectors. 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.

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 supports the National Strategy and represents some of the materials and activities that Alzheimer's Disease Research Centers (ADRCs), Alzheimer's Clinical Trials Consortium (ACTC), 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. The repository has evolved as researchers have nominated their resources for NIA's consideration. Newly added resources include a brain donation Question & Answer web page, an infographic on the difference between clinical trials and observational studies, tools to reduce disparities in research participation among Asian Americans and Pacific Islanders (AAPI), an activity book for individuals experiencing memory loss, a Spanish language website with information on memory problems and dementia, a series of videos on the implications of systemic racism in clinical research, and numerous scientific research articles.

NIA recently released a web-based communication tool, called Outreach Pro, 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. More information about Outreach Pro is included under Action 1.B.4.

For more information, see:

- https://outreachpro.nia.nih.gov
- https://www.nia.nih.gov/news/nih-unveils-new-online-tool-improve-alzheimers-clinical-trials-recruitment
- https://www.nia.nih.gov/research/adore

NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through Alzheimers.gov and its Alzheimer's Disease Education and Referral (ADEAR) website portal; clinical trials listing and monthly e-alert to more than 29,000 subscribers; social media; infographics; presentations; promotion of ADORE materials; and collaboration with other federal agencies and advocacy organizations to encourage research participation among older adults, including through a Focus on Aging interagency webinar series. All materials are drafted in plain language formats for ease of communications.

For more information, see:

- https://www.alzheimers.gov/clinical-trials
- https://www.nia.nih.gov/health/about-adear-center

A key factor for improving enrollment is to help researchers monitor actual recruitment against planned milestones. To achieve the ability to track, report, and manage enrollment data, NIA has recently launched the Clinical Research Operations and Management System (CROMS) to provide NIA staff and grantees with real-time tracking, reporting, and management of clinical research enrollment data, study documents, and activities. Through CROMS, NIA now tracks, manages, and reports on enrollment data and activities made possible via the NIA-funded clinical research portfolio. CROMS will provide critical and real-time information to ensure that NIA-supported clinical studies are making appropriate progress toward reaching their inclusion recruitment goals related to multiple underrepresented groups.

For more information, see:

- https://www.nia.nih.gov/research/grants-funding/nias-clinical-research-operations-management-system-croms

NIA-funded AD/ADRD infrastructure -- such as the ACTC, the ADRCs, and the NIA IMbedded Pragmatic Alzheimer's disease and AD-Related Dementias Clinical Trials (IMPACT) Collaboratory -- also provides centralized resources and shared expertise to researchers nationwide to support recruitment into AD/ADRD clinical research.

For more information, see:

- https://impactcollaboratory.org/
- https://www.actcinfo.org/
- https://www.nia.nih.gov/health/alzheimers-disease-research-centers

As part of an ongoing collaboration between the VA Office of Research and Development and NIA launched in 2021. NIA provided supplemental funds to five VA sites to increase the recruitment of veterans into NIA-funded studies and this collaboration has thus far resulted in successfully recruiting more than 60 veterans for AD/ADRD research. As part of the program, the VA and NIA are partnering with the NIA-funded ADRCs to increase veteran participation in research. Strategic priorities for the pilot include recruiting veterans, especially from diverse populations, and investigating unique risk factors for this population. Research coordinators at each participating ADRC have worked directly with the VA and NIA staff to identify and address challenges, develop pragmatic solutions, and share best practices and materials to increase veteran outreach and sustain enrollment.

For more information, see:

- https://www.nia.nih.gov/news/nia-va-effort-increases-recruitment-veterans-alzheimers-research
- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/recruitment-and-educational

Since 2020, the VA has been 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 statins can prevent dementia and disabilities 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.

In 2019, the Health Resources and Services Administration's (HRSA's) 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. This training continues into the fourth year of funding (FY 2022).

For more information, see:

- https://www.hrsa.gov/grants/find-funding/HRSA-19-008

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

Lead Agencies: NIA, NIMHD
Partner: ACL

See Action 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research and efforts to increase enrollment in clinical trials and other clinical research through community, national, and international outreach. This strategy includes approaches to specifically 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://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-212.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
- https://www.nia.nih.gov/research/recruitment-strategy
- https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf

As noted in Action 1.B.3, NIA recently released a web-based communication tool, called Outreach Pro, 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. Before launching Outreach Pro in Summer 2021, NIA conducted a series of focus groups, surveys, and stakeholder interviews to tailor recruitment materials for clinical studies to reach underrepresented populations more effectively. Using the findings from this research, NIA has developed a set of materials and messaging, including videos and other multi-media, print ads, posters, and social media, tailored to diverse populations, including Black and Hispanic, in both English and Spanish, and Chinese Americans, Indian Americans, and Filipino Americans in both English and their respective languages. NIA is currently using a similar approach to develop materials for AI/AN. Materials developed are made available to the public in both ADORE and Outreach Pro. NIA has also recently launched a Spanish version of the Alzheimers.gov website.

For more information, see:

- https://outreachpro.nia.nih.gov/
- https://www.alzheimers.gov/es
- https://www.nia.nih.gov/news/alzheimers-gov-website-now-available-spanish

The NIA-supported ACTC aims to develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations, and to establish a new Minority Outreach and Recruitment Team. This network has 35 member sites in the United States and has participating sites in the United States and abroad. The ACTC is developing and implementing best practices and latest methods for the conduct of AD/ADRD trials, including strategies for improving inclusion and retention of clinical trial participants from diverse populations.

For more information, see:

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

NIA also supports 33 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 ADRC has its own area of emphasis, these 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 developed a Hispanic interest group that includes a Listserv for Hispanic researchers, those with an interest in research with Hispanic participants, and issues specific to Spanish language assessment. This group is helping to ensure that materials are available in Spanish, thereby addressing the needs of Spanish speaking participants, and to assure 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 further incentivize innovative ideas and opportunities in AD/ADRD research, NIA has funded four exploratory ADRCs. These new centers will broaden current ADRC research initiatives with

underrepresented populations such as Black Americans, Native Americans, and those in rural communities -- all of which have different risk factors for developing these devastating diseases.

NIA recently funded Foundations of Representative Engagement, Valid, and Effective Recruitment in Alzheimer's Research. Through this project, researchers are developing and implementing novel methods for recruitment, engagement, and retention of minorities into AD/ADRD studies through community engagement and the ADRCs. The research team is also developing recruitment, engagement, and retention metrics and interventions and establishing communications frameworks to improve literacy for both the general public and research communities.

For more information, see:

- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6249084/
- https://www.nia.nih.gov/research/adc
- https://www.nia.nih.gov/news/nih-expands-nations-alzheimers-and-related-dementias-research-capacity
- https://reporter.nih.gov/search/ixuI3REUAEeJqoU8Xa4hOA/project-details/10094911#description

In April 2021, NIA hosted a virtual meeting to discuss the practice-based research networks (PBRNs) to address AD/ADRD clinical trial recruitment and retention disparities within under-served populations. PBRNs are networks of health care clinicians and practices working together to answer community-based health care questions, to translate research findings into practice, and to directly engage diverse and under-served communities. NIA is investigating the possibility of developing a PBRN as a long-term solution to create sustainable and mutually beneficial relationships with under-served communities to address the systemic barriers that reduce their potential to participate in AD/ADRD and aging clinical research studies. Since the meeting, NIA has been working to organize an external group of researchers and community organizations to offer input, feedback, and recommendations on how to develop a successful AD/ADRD PBRN. NIA also issued a Request for Information (RFI) in March 2022 to seek input on the Capacity and Support Needed to Increase Community-based Research Networks Participation in AD/ADRD Clinical Trials (NOT-AG-22-018). This RFI sought pragmatic insights and recommendations on the challenges and potential opportunities to build capacity for these networks and engage a wider, more diverse group of participants in AD/ADRD clinical trials. Respondents to the RFI discussed challenges associated with developing sustainable community partnerships and increasing NIA's research presence in communities. They also offered ideas to build, increase, and sustain community engagement with current or future AD/ADRD clinical trials.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-22-018.html
- https://impactcollaboratory.org/event/nia-virtual-meeting-development-of-an-nia-practice-based-research-network-to-conduct-ad-adrd-clinical-research/
- https://videocast.nih.gov/watch=41795

An administrative supplement to the Health and Retirement Study (HRS) has allowed an increased enrollment of minoritized populations to help to meet this overarching goal. Approximately 6,700 Black Americans and 5,400 Hispanic Americans are being recruited and added to the prospective longitudinal cohort study. The National Health and Aging Trends Study (NHATS), which samples Medicare beneficiaries, and its sister study, the National Study of Caregiving (NSOC), has oversampled Black participants since 2011. A recent administrative supplement to NHATS/NSOC will enable the study to enroll an additional 2,000 Hispanic individuals and approximately 700 additional Hispanic care partners. The Hispanic add-on sample will allow researchers to study AD care needs and caregiving to older Hispanic adults, contrasting them with experiences of non-Hispanic groups with AD and their caregivers and with Hispanic older adults needing care for other reasons.

NIA also has released several FOAs to fund grants that target gaps in methods and outcomes regarding participant recruitment and retention and spur educational activities that expand and diversify the AD/ADRD clinical trial workforce. Some of these efforts are in coordination with other NIH Institutes and Centers through the NIH-wide UNITE initiative.

For more information, see:

- https://www.nia.nih.gov/research/blog/2021/09/unyielding-commitments-research-workforce-diversity
- https://www.nih.gov/ending-structural-racism/unite

National Institute on Minority Health and Health Disparities (NIMHD) supports the Center for American Indian and Alaska Native Health Disparities project, which provides administrative core research support for responding to the increasing incidence of cognitive impairment, dementia, and AD/ADRD among AI/AN people, and the burden this poses for individuals, caregivers, their communities, and relevant systems of care. Additionally, the NIMHD-funded Effects of Hospital-Community-Public Health Integration on Racial and Ethnic Disparities in Mental Health study will generate evidence on how to expand health information technology (HIT) infrastructure in rural areas to promote health care quality for racialized rural patients with AD/ADRD and risk factors associated with these conditions. NIMHD-funded researchers are also conducting a cluster, randomized controlled trial to evaluate the appropriateness of an intervention that uses a game format for patients with mild cognitive impairment (MCI) and are at risk for AD/ADRD. Participants in the trial include individuals from diverse communities who are underrepresented in clinical trials.

For more information, see:

- https://reporter.nih.gov/search/s8LxXf2FJU-24nxeEUSgpw/project-details/10164617
- https://reporter.nih.gov/search/s8LxXf2FJU-24nxeEUSgpw/project-details/10498316
- https://reporter.nih.gov/search/s8LxXf2FJU-24nxeEUSgpw/project-details/10498912

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

Lead Agency: NIA
Partner: VA

As of March 2022, NIH supports approximately 200 pharmacological (drug) and non-pharmacological (non-drug; lifestyle) interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD. This includes approximately 70 NIH-supported drug trials for AD/ADRD, the majority of which are in early-phase development (Phase 1 or 2 trials) with several late-phase (Phase 3) trials also in progress. These interventions are testing a range of diverse drug targets, including but not limited to amyloid, cell metabolism, inflammation, tau, and vasculature. Each of these trials are designed to accelerate progress towards effective prevention and treatment strategies.

The ACTC, a next-generation clinical trials infrastructure designed to harness best practices and latest methods for AD/ADRD trials, includes 35 member sites across the United States along with numerous participating sites in the United States and other countries. ACTC trials are supported by a funding opportunity for Phases Ib-III of pharmacological and non-pharmacological interventions in individuals across the AD/ADRD spectrum from presymptomatic to more severe stages of disease. A key area of focus for ACTC has been to improve diversity in recruitment and in the clinical trial workforce. The ACTC Minority Outreach and Recruitment Team is developing central and local partnerships with diverse communities to enhance representation of these underrepresented groups in AD/ADRD trials. The ACTC Inclusion and Diversity Committee has been conducting mentorship activities for ACTC early career investigators and trial study staff. Additionally, the ACTC Patient Advisory Board has been constituted with a focus on inclusion of

individuals from underrepresented populations as well as from across the disease spectrum. Furthermore, ACTC supports the Institute on Methods and Protocols for Advancement of Clinical Trials in AD/ADRD (IMPACT-AD), a comprehensive training program that aims to educate and promote diversity among research professionals and future principal investigators in the field of AD/ADRD research. Sharing of data and biosamples is another key element of the ACTC, and it is part of NIA's enabling infrastructure for data-driven and predictive therapy development. All design, methods, procedures, etc. developed will be shared with the larger research community as will trial data and biosamples per NIA requirements noted earlier.

For more information, see:

- https://grants.nih.gov/grants/guide/pa-files/PAR-20-309.html
- https://impact-ad.org/about/
- https://www.actcinfo.org/
- 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

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://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
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-016.html

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(**ONGOING**) Action 1.B.6: Expand research focused on needs related to the intersection of Down syndrome and Alzheimer's disease and related dementias

Lead Agency: NIH

In FY 2018, appropriations provided by Congress allowed NIH 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 2021, Congress appropriated an additional $65 million to expand INCLUDE.

In FY 2018, NIH spent almost $23 million to jump-start INCLUDE via administrative supplements, including one focused on creating an AD/ADRD clinical trial network for adults with Down syndrome. This network, the ACTC-Down Syndrome Network aims to utilize the existing depth and breadth of expertise across its ACTC infrastructure to conduct AD/ADRD 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/ADRD in adults with Down syndrome. The project received additional funding in FY 2021 to continue and expand this work. In FY 2021, through the INCLUDE project, several other research projects focused on AD/ADRD in Down syndrome -- including a study utilizing a new chimeric mouse model of AD in Down Syndrome and project investigating a precision medicine approach for use of anti-inflammatories in future Down Syndrome trials -- are currently funded.

For more information, see:

- https://clinicaltrials.gov/ct2/show/NCT04165109

- https://reporter.nih.gov/project-details/9749625
- https://reporter.nih.gov/project-details/9893363
- https://www.nih.gov/include-project
- https://www.nih.gov/include-project/funding

The Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS) is a multi-disciplinary, multi-site longitudinal study examining biomarkers of AD in a large cohort of adults with Down syndrome ages 25 and above. ABC-DS was initiated in 2015 by NIA and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) with the funding of two groups of research collaborators -- Neurodegeneration in Aging Down Syndrome and Alzheimer's Disease in Down Syndrome. In September 2020, the continuation of ABC-DS was funded by NIA, NICHD and the Trans-NIH INCLUDE Project. ABC-DS researchers will follow the cohort of people with Down syndrome to conduct three projects. The next iteration of ABC-DS includes an emphasis on increasing the diversity of individuals in the cohort of adults with Down syndrome. The Alzheimer's Disease/Down Syndrome Outreach, Recruitment, and Engagement Core will rapidly disseminate information to Down syndrome communities and engage underrepresented racial and ethnic groups.

A recent analysis of data from ABC-DS suggests that people with Down syndrome show similar changes in metabolic processes as people with late-stage AD. The same pattern of metabolic changes occurs for people with Down syndrome who go on to develop AD and people with late-stage AD. The findings suggest that measures of of metabolites may have potential as blood-based biomarker tests.

In 2020, NACC developed a Down syndrome-specific clinical and cognitive assessment module, implemented for use in research that is harmonized with some of the ABC-DS clinical and neuropsychological measures and available for use by ADRCs and Intellectual and Developmental Disabilities Research Centers for research purposes. Data and biosamples generated from the participants who are being evaluated with the module will also be available for broader sharing.

For more information, see:

- https://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx
- https://naccdata.org/data-collection/forms-documentation/ds-3
- https://www.nia.nih.gov/news/people-down-syndrome-and-alzheimers-show-similar-changes-metabolic-processes-people-late-stage
- https://www.nia.nih.gov/research/abc-ds
- https://www.nia.nih.gov/research/blog/2021/06/teaming-expand-alzheimers-and-down-syndrome-research
- https://www.nichd.nih.gov/research/supported/eksiddrc

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.7: Issue a joint Department of Veterans Affairs/National Institute on Aging career development award for clinician-scientists in the area of dementia research

Lead Agencies: NIH, NIA

Since 2021, the VA has funded several research studies in response to the early career physician-scientist mentored research in AD/ADRD funding announcement. This program has been approved for another three years. Eligibility for this program has been expanded to also include clinical psychologists.

(UPDATED) Action 1.B.8: Research the impacts of COVID-19 and Post-COVID Conditions on risk of AD/ADRD, cognition, and brain health

Lead Agencies: NIH, NIA

NIH is looking closely at the long-term effects of COVID-19 infection (also known as Long COVID) through the recently launched Researching COVID to Enhance Recovery (RECOVER) Initiative. The RECOVER Initiative has multiple scientific aims, including to understand the full clinical spectrum of Long COVID, and to define distinct subtypes of Long COVID. It will also investigate how COVID-19 affects cognition, cognitive decline, and dementia. Thousands of diverse participants across the lifespan will take part in the national, patient-centered study.

For more information, see:

- https://recovercovid.org/about
- https://www.nih.gov/news-events/news-releases/nih-builds-large-nationwide-study-population-tens-thousands-support-research-long-term-effects-covid-19

NIA has been a key contributor in NIH efforts to support research on the social, behavioral, and economic impacts of COVID-19, particularly in vulnerable populations, including individuals with cognitive impairment or dementia.

NIA issued its own Notices of Special Interest (NOSI) to stimulate much-needed research on aging and COVID-19. NIA has supported several administrative supplements and revision applications on COVID-19 related topics include neuroscience and AD/ADRD; aging biology; social, behavioral, and economic research; dementia care and caregiving; and geriatrics and gerontology.

In addition, NIA issued a funding opportunity for COVID-19 clinical trial implementation projects on aging-related topics in at-risk older adult populations, including those with cognitive impairment and AD/ADRD. In 2021, NIA also issued a NOSI to stimulate research on neurological and neurocognitive sequelae originating from SARS-CoV-2 infection in aging and age-related neurodegeneration. NINDS issued a funding opportunity titled, Impact of COVID-19 on Dementia Risk, Progression and Outcomes in AD/ADRD Populations (NOT-NS-21-037) to solicit research on the effect of COVID-19 exposure on subjects who have, or are at risk for, developing AD/ADRD.

NIA is also co-sponsoring a variety of other COVID-targeted funding opportunities, such as those specific to the Rapid Acceleration of Diagnostics 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 Public Health Emergency (PHE), including those who work in the field of AD/ADRD. This support encompasses ongoing communications on COVID-related issues (e.g., multiple 2021 web updates), outreach on federal COVID-19 resources for older adults, and flexibilities for grant applicants whose research has been affected by the pandemic.

NIA also collaborated with the Centers for Disease Control and Prevention (CDC) via an interdepartmental agreement, which supported the NIA IMPACT Collaboratory Long-Term Care Data Cooperative (an NIA grant) to monitor COVID-19 vaccine-related adverse events among vulnerable nursing home residents,

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-022.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-033.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-016.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-21-037.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-20-234.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-213.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-035.html
- https://www.nia.nih.gov/health/government-covid-19-resources-older-adults
- 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/research/grants-funding/nia-covid-19-response
- https://www.nia.nih.gov/research/dbsr/social-behavioral-and-economic-sbe-research-covid-19-vulnerable-and-health-disparity
- https://www.nih.gov/research-training/medical-research-initiatives/radx/funding#radx-up

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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

Lead Agencies: NIA, NINDS
Partners: ADNI partners, AMP partners

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 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 once 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 18th 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. ADNI has also accumulated a great deal of clinical, neuroimaging, cognitive, biofluid biomarker and genetic data, and biofluid samples available to researchers, resulting in more than 3,500 publications.

For more information, see:

- http://adni.loni.usc.edu/

The AMP-AD program, as noted above, is an NIH-led precompetitive public-private partnership to identify and validate the most promising biological targets of AD to advance diagnostic and drug development. The first phase, the AMP-AD program 1.0, consisted of two components: The Biomarkers Project and the Target Discovery and Preclinical Validation Project. The Biomarkers Project incorporated tau PET imaging into two NIH-funded prevention trials (A4 Trial and Dominantly Inherited Alzheimer Network Trial Unit [DIAN-TU]).

Data-sharing under the AMP-AD program includes making the screening data and biosamples available after enrollment completion and making post-randomization data and biosamples available as soon as possible after completion without compromising trial integrity. The Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) trial has achieved the first milestone by making the pre-screening data and biosamples available (via the Laboratory of Neuroimaging). This is the first registration trial to ever do so, and since the data was made available there have been over 600 data requests and nine publications using the A4 screening data.

For more information, see:

- https://www.nia.nih.gov/research/amp-ad

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. Since Fall 2020, physicians in clinical practice have been able to order a blood test for amyloid protein, a hallmark sign of AD, for an individual who is not participating in a study. In February 2022, this blood test was found to effectively predict the presence of beta-amyloid in the brain; and the test became even more accurate when the research team took into account the version of APOE (a gene linked to AD risk) that each person had. Several other blood tests are in development. In addition, advances were made in brain imaging, most notably the FDA-approval of the first PET scan product to detect tau tangles in the brain, another hallmark sign of AD/ADRD. 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 AD, or a combined decline in memory and walking speed as a sign of dementia.

For more information, see:

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html
- https://www.nia.nih.gov/news/blood-test-can-predict-presence-beta-amyloid-brain-new-study-finds
- https://www.nia.nih.gov/news/blood-test-method-may-predict-amyloid-deposits-brain-potentially-indicating-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/nia-small-business-funding-seeks-find-blood-based-diagnostic-alzheimers-disease

To meet the pressing need to better understand the prevalence, progression, and clinical impact of AD/ADRD among Mexican Americans, NIH awarded additional funding in 2020 for more PET

scan and other biomarker measures to the ongoing Health and Aging Brain Among Latino Elders (HABLE) study. The additional funding will support the Health and Aging Brain Among Latino Elders-Amyloid, Tau, and Neurodegeneration (HABLE-AT(N)) study, which enables researchers to collect amyloid and tau PET imaging and other biomarker measures. The goal is to better understand health disparities of brain aging and AD/ADRD between Mexican Americans and non-Hispanic Whites. An additional benefit of HABLE and HABLE-AT(N) will be the ability to better classify/categorize participants into groups by type of dementia and stage of the disease. This will help facilitate potential enrollment in future studies and the tailoring of therapies as they become available.

For more information, see:

- https://www.nia.nih.gov/news/nih-augments-large-scale-study-alzheimers-disease-biomarkers

At Columbia University, investigators recruit students from underrepresented groups to conduct research projects with neuroimaging data for their NIA-funded Summer of Translational Aging Research for Undergraduates. The trainees are helping to develop brain images as biomarkers of dementia through NIA's Advancing Diversity in Aging Research Through Undergraduate Education program.

For more information, see:

- https://grants.nih.gov/grants/guide/pa-files/PAR-17-290.html
- https://www.columbianeurology.org/education-and-training/summer-translational-aging-research-undergraduates-star-u

To enable better patient stratification, diagnosis, and tracking of disease progression in ADRD (e.g., LBD, FTD, VCID) and dementias with mixed etiologies, NINDS continues to release funding opportunities to support the development of biomarkers, including imaging agents. In 2022, NINDS reissued a call for applications to study the structural biology of AD/ADRD-related misfolded or dysfunctional proteins (PAR-22-208). Additionally in 2022, NINDS released a funding announcement (RFA-NS-22-06) to invite studies that will expand the use of existing ADRD data resources to drive, via computational modeling, new discoveries that can lead to better understanding of mechanisms, clinical risk assessment and outcomes, and to identify novel candidate biomarkers for ADRD.

To further our understanding of potential biomarkers for LBD, NINDS is supporting several projects and programs. The NINDS-supported Parkinson's Disease Biomarkers Program (PDBP) is dedicated to identifying and developing biomarkers for both Parkinson's disease and LBD and enabling broad sharing of clinical data and biospecimens across the research community. At this time, investigators at 14 institutions are conducting biomarker research in LBD and contributing longitudinal, standardized clinical and biospecimen data from brain tissue to the PDBP Data Management Resource and the BioSEND brain tissue biorepository for sharing with the scientific community. More than 300 LBD subjects have been enrolled and continue to be followed as part of this effort. With the 2022 renewal of the Biomarkers for the Lewy Body Dementias Initiative (RFA-NS-22-001), NINDS is expanding the number of institutions and breadth of current LBD biomarker discovery research. Additionally, the AMP-PD initiative, which is a public-private partnership conducting deep molecular characterization and longitudinal clinical profiling of Parkinson's disease and LBD, includes data and samples from patients with LBD.

For more information, see:

- https://biosend.org/
- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-18-082.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-21-001.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/pa-files/PAR-22-208.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
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-001.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-006.html
- https://pdbp.ninds.nih.gov/lewy-body-data

In 2021-2022, NINDS renewed MarkVCID, which is a consortium of nine research sites and a coordinating center to clinically validate biomarkers developed during the first five years of this program for the small vessel diseases of the brain that result in VCID. In 2021, the consortium published its first promising results of several different biomarker protocols that are designed to be used in clinical research and eventually in clinical practice to help detect VCID in patients. Over the course of Phase 1, MarkVCID researchers winnowed down 47 candidate biomarkers to a final five that have moved on to Phase 2 to be validated in large-scale, multi-site clinical trials. These protocols are fully standardized and include neuroimaging measures, fluid-based biomarkers, and cognitive testing and other clinical measures. Larger, racially and ethnically diverse populations will be studied in Phase 2. It is expected that MarkVCID will determine the respective effectiveness of these respective biomarkers in Hispanic, Black/African American, and White populations and become a gold standard for rigorous biomarker assessment.

For more information, see:

- https://markvcid.partners.org/
- https://pubmed.ncbi.nlm.nih.gov/33480157
- https://pubmed.ncbi.nlm.nih.gov/33480172

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

Lead Agencies: NIA, NINDS
Partners: FDA

The NIA IMPACT Healthcare Collaboratory received COVID-19 supplements to establish partnerships with the nursing home industry to establish and develop data-sharing infrastructure and reporting systems to monitor the effects of the COVID-19 vaccines administered to frail older adults, on whom the vaccines were not widely tested prior to approval for use under emergency. Use of Electronic Health Record (EHR) data from this initiative provided near real-time insight on vulnerable populations in nursing homes, which was used by the CDC Advisory Committee on Immunization Practices to monitor adverse events of COVID-19 vaccination among vulnerable older adults. In the near future, the nursing home EHR data will be linked with the Centers for Medicare & Medicaid Services (CMS) claims data, which can be used to improve our national response to the pandemic and public health outcomes for older adults in addition to facilitating pragmatic trials.

For more information, see:

- https://impactcollaboratory.org/building-infrastructure/
- https://www.nia.nih.gov/research/dbsr/nia-impact-collaboratory

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 A4 study, and

the DIAN-TU. Collaborative efforts like CAP provide an effective platform for implementation of AD/ADRD research standards and advancing AD/ADRD 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/

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/

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

Lead Agency: NIA

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 2021, 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 ten countries have joined the IADRP effort.

In 2018, the IADRP database was relaunched with several changes to the Common Alzheimer's Disease Research Ontology, 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

NIH is committed to data-sharing as a way to synergize research and facilitate collaborative science while ensuring appropriate protections for research involving human data and oversight of research conduct, data quality, data management, data-sharing and data use. A collaborative approach among the major cohorts could expedite epidemiological discovery by assembling multi-level data collected across the lifespan and by providing a framework for multi-disciplinary research. NIH's aging and AD/ADRD cohorts have been central to this mission, providing pivotal information on healthy aging and factors related to risk of and protection for AD/ADRD. A comprehensive, and publicly accessible inventory of cohorts is fundamental to facilitate

collaborative scientific efforts, sharing of data and cost-effective assembly and utilization of resources. In return, this will assist the research community in the planning of new studies and will enable NIA in maximizing the returns on investments. NIA is working with the NIH Center for Information Technology to pilot-test the creation of a database for cohorts supported by NIA. The objectives of this project are to create a user-friendly cohort database of NIA's longitudinal studies which will:

- Increase transparency and scientific quality and collaboration through public access to the aging and AD/ADRD cohort's descriptive information.
- Assist the research community in identifying and accessing population resources for research in aging and AD/ADRD.
- Improve the return on investment in the cohorts' infrastructure for researchers and NIA.
- Promote collaborative research projects for topics not easily addressed by a single study.

The NIH recognizes that the sharing of scientific data expedites the translation of research results into knowledge, products, and procedures to improve human health. Accordingly, the NIH will implement a new Data Management and Sharing Policy, effective January 25, 2023, that requires researchers to prospectively plan for how scientific data will be preserved and shared through submission of a Data Management and Sharing Plan.

For more information, see:

- https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-and-sharing-policy/data-management-and-sharing-policy-overview#after

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

Lead Agency: NIA

NIA participates in the Alzheimer's Disease Funders' meeting held annually during the 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 ten countries and is publicly available for use.

For more information, see:

- https://iadrp.nia.nih.gov

The NIA-supported Harmonized Cognitive Assessment Protocol (HCAP) project, implemented in the HRS and similar sister studies in other countries, 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, is to collect and distribute longitudinal multi-disciplinary data on a nationally representative sample of over 20,000 Americans over the age of 50 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 this field period, 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. Many of the HCAP participants also participated in the HRS venous blood study, which is projected to yield plasma AD biomarkers when there is consensus on the best protocol for their analysis. Genotype information are already available for those HCAP (and HRS) participants who consented to being genotyped. 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. It is now projected to be back in the field as soon as the necessary home visits to the HCAP respondents are deemed to be safe. To further facilitate health disparities research, the HRS is

recruiting 2,000 additional racial and ethnic minority respondents. By continuing to diversify this cohort, researchers using HRS data will be able to design studies that provide insights into potential racial/ethnic differences in the incidence, prevalence, and impact of AD/ADRD.

For more information, see:

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-012.html
- https://hrs.isr.umich.edu/welcome-health-and-retirement-study
- https://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.202519186.2017360935.1670277481-1021185182.1670277481
- https://reporter.nih.gov/project-details/10003934
- https://reporter.nih.gov/project-details/10017122
- https://reporter.nih.gov/project-details/9618704
- https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology
- https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/

The HCAP has been administered in a diverse range of countries, where HRS-like representative population surveys are conducted, including China, England, India, Mexico, South Africa, and Chile. It will also be conducted in parts of the European Union, Ireland, Northern Ireland, Dominican Republic, and Lebanon. To date, the data from England, India, South Africa, China, and Mexico have been publicly released.

For more information, see:

- https://charls.pku.edu.cn/en/index.htm
- https://haalsi.org/projects-cores
- https://hcap.isr.umich.edu/
- https://lasi-dad.org/
- https://www.elsa-project.ac.uk/
- http://www.mhasweb.org/Data.aspx

In 2019, NIA funded a research network to facilitate collaboration among longitudinal studies of aging around the world to harmonize methods and content. The ultimate goal of the HCAP Network is to develop international data resources for the study of AD/ADRD that will expand research opportunities to exploit cross-country variation in key life-course factors that likely affect cognitive function and the risk for AD/ADRD, such as educational attainment, wealth, retirement policies, diet, and the prevalence and treatment of cardiovascular risk factors. Currently, 11 studies representing countries from all over the world participate in Network activities.

For more information, see:

- https://hcap.isr.umich.edu/

The rationale for NIA's support to global AD/ADRD research and training is compelling. The wide variety of diets, health-related behaviors, and environmental exposures, as well as genetic variation within low and middle income countries (LMICs) and their respective populations can provide valuable insight on factors that contribute or protect against AD/ADRD. Research in LMICs will not only help to mitigate AD/ADRD in the developing world but will also increase our knowledge of the complexity and heterogeneity of this disease in the global context. Data from these studies may be extrapolated to United States populations that share similar sociodemographic backgrounds to LMIC populations (e.g., race/ethnicity, low-resource, rural, etc.). To this end, NIA collaborates with the NIH's Fogarty International Center (FIC) to support global research for AD/ADRD in LMICs. NIA is currently collaborating with FIC on the Global Environmental and Occupational Health (GEOHealth) Program with the aim to support research on environmental and occupational health threats in relation to AD/ADRD. Each NIA GEOHealth hub is supported by two coordinated, linked awards: (1) a cooperative research award to an

institution in a developing nation; and (2) a training award to a United States institution with substantial NIH involvement to coordinate research training. Over the past 20 years, NIA has also worked with FIC on the Global Brain and Nervous System Disorders Research Across the Lifespan Initiative, which supports investigator-initiated and exploratory research on brain and other nervous system function and disorders throughout life in LMICs. These supported grants represent strong collaborations between United States investigators and their LMIC partners. NIA is currently supporting six grants under this initiative. NIA is working to support the development of early-stage investigators who have begun to establish research programs and who will be ready to assume leadership roles in their field of expertise and will be poised to change theory, practice, and health outcomes related to the health of older individuals in LMICs through partnership in the Emerging Global Leader Award (K43) and Institutional Training Program (D43). The Emerging Global Leader Award will provide LMIC early-stage investigators the opportunity for joint mentorship by a United States and LMIC established researcher while the Institutional Training Award will support collaborative research training between institutions in the United States and LMICs for research on chronic, non-communicable diseases including AD/ADRD. NIA is also supporting the development of institutional training programs by LMIC institutions through the Chronic, Noncommunicable Diseases and Disorders Across the Lifespan: Fogarty International Research Training Award (NCD-LIFESPAN). NCD-LIFESPAN is expected to strengthen the research capacity of the awarded institution's country by training a cadre of scientists to contribute to important advances in clinical practice and public health policies. NIA also participates in the Global Alliance for Chronic Diseases (GACD) Implementation Research to Reduce NCD Burden in LMICs program. GACD is a larger global initiative in which NIH, including NIA, participates. Through this initiative, NIA will support implementation research addressing risk factors associated with non-communicable diseases in LMICs.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-027.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-835.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-836.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-18-901.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-230.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-TW-21-001.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-TW-21-002.html
- https://www.fic.nih.gov/Programs/Pages/brain-disorders.aspx
- https://www.nia.nih.gov/research/blog/2021/04/addressing-global-challenges-aging-and-dementia

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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 quickly and accurately to the general public, medical practitioners, the MedTech and pharmaceutical industries, and public health systems.

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

Lead Agency: NIA
Partners: FDA, ACL, CDC, partner organizations

NIA continues to expand its efforts to educate clinicians about recent research findings, clinical practice tools for assessment, diagnosis and management of cognitive impairment, training

materials, and a patient checklist handout in English and Spanish, and other resources available online in a mini-portal of resources for professionals.

NIA also continues to promote research findings through press releases, research highlights, and feature articles.

In 2020, NIA and partner federal agencies led efforts to update and enhance the Alzheimers.gov website. NIA launched this new portal to Federal Government AD/ADRD information and resources in February 2021. The site features:

- Information about AD/ADRD.
- Tips and resources for caregivers and people living with dementia.
- Updates on Federal Government activities to address AD/ADRD.
- How to take part in clinical research and how to find studies.
- Resources for health care providers, community and public health workers, and researchers.

NIA launched a Spanish version of the site in October 2021.

For more information, see:

- https://www.alzheimers.gov/
- https://www.alzheimers.gov/eshttps://www.nia.nih.gov/news/press-releases
- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals
- https://www.nia.nih.gov/news/featured-research

In June 2022, the Building Our Largest Dementia (BOLD) Infrastructure Public Health Center of Excellence (PHCOE) for Dementia Caregiving, funded by the CDC, convened the national meeting *Public Health Opportunities and Challenges of Dementia Caregiving* in Minneapolis, Minnesota. This meeting brought together over 400 public health professionals and partners to explore dementia caregiving through the public health lens and discuss opportunities for collaboration across sectors that can advance the national agenda for supporting family caregivers of people living with dementia. Sessions included best practices, testimony from those with dementia and their caregivers, and opportunities to share successes and challenges amongst participants.

For more information, see:

- https://bolddementiacaregiving.org/dementia-caregiving-as-a-public-health-priority-national-conference/

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

Lead Agency: NIA
Partners: ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations

NIA's 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. In addition, the ADEAR Center responds to public inquiries for information on AD/ADRD through its information and referral line.

In FY 2019, one GWEP grant recipient (University of Southern California) partnered with three Alzheimer's Disease Centers (ADCs) and continues to do so. The remaining 47 GWEP grant recipients that are currently funded 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
- https://www.nia.nih.gov/health/about-adear-center

(ONGOING) Action 1.E.3: Facilitate translation of findings into public health practice

Lead Agency: CDC
Partners: private partners

CDC provided funds to the Alzheimer's Association through a cooperative agreement to co-develop the third in a series of Healthy Brain Initiative (HBI) Road Maps to advance cognitive health as an integral component of public health. This *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.

In 2022, the Alzheimer's Disease Team collected information from 23 BOLD program awardees on the status of their efforts to implement Road Map Activities. Preliminary analyses of this data indicated that:

- Every one of the 25 Road Map actions has been taken up by at least one of the 23 BOLD Program awardees. Actions are either being implemented in programmatic activities or in the process of being added to jurisdiction strategic plans.
- Road Map activities are fairly evenly balanced across the four traditional domains of public health.
- As expected, the largest number of awardees are engaged with the required actions P-1 and M-3.
- The next most actively engaged actions are E-1 and W-3.
- With respect to prevention focus areas, BOLD awardees are working on Road Map actions in the risk reduction area most frequently by a substantial margin, followed by early detection and diagnosis.

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, using data for action and the education of health professionals. The associated Road Map planning tool was developed to guide state and local public health professionals through quick steps in selecting Road Map actions 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/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/publications/podcasts.htm

In late FY 2020, CDC made the first awards for the BOLD Infrastructure for Alzheimer's Act to three BOLD Public Health Centers of Excellence (PHCOEs) and 16 BOLD Public Health Programs awards. Recipients to establish the three PHCOEs are: “Dementia Caregiving at the University of Minnesota”; “Dementia Risk Reduction at the Alzheimer’s Association”; and “Early Detection of Dementia at the New York University School of Medicine.”

States awarded at the Enhanced Level for BOLD Public Health Programs include Georgia, Minnesota, Rhode Island, Virginia, and Wisconsin. The Enhanced recipients are working on implementing their state AD/ADRD plan. 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 (NPAIHB). The Core recipients are building their coalitions and starting the process of developing a jurisdictional AD/ADRD plan.

CDC awarded the second round of recipients of the BOLD Public Health Programs awards in late FY 2021. These were awarded at the Core Level to Arkansas, City of Boston, Connecticut, Idaho, Louisiana, South Carolina, and Tennessee. There are now a total of 23 public health programs who are BOLD Program recipients.

CDC will be funding the next round of BOLD Public Health Programs in September 2023. It is anticipated that the FOA will be released in December 2022 and applications due in Spring 2022. Eligible applicants are health departments from states, political subdivisions of states, tribes, and Tribal organizations.

For more information, see:

- https://www.cdc.gov/aging/bold/index.html
- https://www.cdc.gov/aging/funding/phc/index.html
- https://www.cdc.gov/aging/funding/php/index.html

CDC supported UsAgainstAlzheimer’s to develop the Brain Health Equity Center to increase tailored messaging related to cognitive impairment, COVID-19, brain health, and AD/ADRD to populations disproportionately affected by AD/ADRD, including African American and Hispanic people across the United States. In the past year, the Brain Health Equity Center engaged community members, including of African American and Hispanic populations of focus to identify gaps in knowledge and develop AD/ADRD products to address these gaps with assistance from a core group of advisors from National Black Nurses Association (NBNA), the National Association of Hispanic Nurses (NAHN), and members of Alzheimer’s Los Angeles (17 Hispanic and African American people and nine self-identified caregivers).

The Brain Health Equity Center completed the following major activities in the past year.

- Created and disseminated a culturally tailored toolkit was via the BrainGuide web page and through a virtual townhall that had 126 attendees.
- Worked with the University of Minnesota PHCOE on Dementia Caregiving on a Public Health Considerations and Models for Cultural Adaptations in Dementia Caregiving to highlight insights identified by the landscape assessment and message guide. The sessions reached 415 unique participants across three total seminars, including 178 participants during the June 2021 seminar and 139 participants in the August 2021 seminar.
- Presented two posters, a webinar presentation, and resources to the 2021 NBNA and NAHN conferences.

- Conducted four focus groups with consumers, caregivers, and diverse health professionals to validate and prioritize the insights generated to identify the top gaps and to inform the Center's outreach and resource development strategies. For example, this process identified the need for culturally tailored content related to risk modification and for adapting messaging for African American and Latino American people.

The Brain Health Equity Center has produced a variety of products including a toolkit, a practical guide for communicating with Hispanic and African American people about AD/ADRD. They have engaged in Twitter chats, held webinars, hosted presentations, seminars, panel discussions, focus groups, and press events all focused on the how to address AD/ADRD among Hispanic and African American people. One example of the Brain Health Equity Centers success in the past year is the fact that they met and exceeded their outreach goal by 687% (goal 90,00 vs. reached: 709,369) with tailored messaging related to cognitive impairment, COVID-19, brain health, and AD/ADRD for Hispanic and African American people and their caregivers.

The Brain Health Equity Center created and disseminated the following products in the past year.

- Completed the development of its practical guide for tailoring brain health messaging after an extensive review process with external experts from BOLD and HBI awardees and CDC staff.
- Successfully executed a logo licensing agreement with the CDC to co-brand its practical message guide, enabling wider dissemination of the guides in the current and future years.
- Partnered with HBI and BOLD awardees on several occasions to raise awareness of brain health among Latino and African American people.

Reached more than 5,000 nurses with tailored brain health educational messaging through digital communications strategies, direct educational events, and presentations with its partners NAHN and NBNA in the past year.

For more information, see:

- https://www.usagainstalzheimers.org/center-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 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 implementation of evidence-based policies and programs that support people providing care in their communities. This book was published in 2021.

CDC has updated the “Caregiving and Subjective Cognitive Decline” infographic series. The infographics were developed using Behavioral Risk Factor Surveillance System (BRFSS) data from the Caregiving 2015-2018 modules and Subjective Cognitive Decline (2019-2020; SCD) modules. The infographic populations include: national combined data, Black American, AI/AN, AAPI, Hispanic, women, men, rural, LGBT, and veterans. The state infographics for 2020 data

are now available along those from previous years (2015-2019). 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/healthybrain/brfss-faq.htm
- https://www.cdc.gov/aging/publications/briefs.htm

The infographics have all 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 BRFSS Caregiver Optional Module and the 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.

(ONGOING) Action 1.E.4: Facilitate translation, implementation and ongoing evaluation of effective interventions designed to support people living with dementia and caregivers

Lead Agency: ACL
Partners: HRSA, state and community partner organizations

Through its Alzheimer's Disease Programs Initiative (ADPI) states and community grant program ACL makes resources available to enable states and community-based organizations (CBOs) to translate, pilot and evaluate the implementation of a broad range of dementia-specific evidence-based and evidence-informed interventions to support people living with dementia and their caregivers.

To be considered *evidence-based*, an intervention must have been tested through a randomized controlled trial, and: (1) be effective at improving, maintaining, or slowing the decline in the health or functional status of older people or family caregivers; (2) be suitable for deployment through community-based human services organizations and involve non-clinical workers or volunteers in the delivery of the intervention; (3) have results published in a peer-reviewed scientific journal; and (4) be translated into practice and ready for distribution through community-based human services organizations.

Evidence-informed interventions are those that have substantive research evidence that demonstrates an ability to improve, maintain, or slow the decline in the health and functional status of older people or family caregivers. Evidence-informed interventions: (1) have been tested by at least one quasi-experimental design with a comparison group, with at least 50 participants; OR (2) have been adapted or translated from a single evidence-based intervention.

ACL continues its efforts to expand the availability of dementia-specific evidence-based interventions in states and communities. Grantees are afforded the flexibility to choose interventions that meet the unique needs of their communities in terms of target audience, content and delivery modes, including, for example, in-person, telephonic and virtual/computer-based. Through ACL programming evidence-based interventions including, but not limited to, BRI Care Consultations, Care of Persons with Dementia in Their Environments (COPE), Powerful Tools for Caregivers, Resources for Enhancing Alzheimer's Caregivers Health (REACH) Community, and most recently Cognitive Stimulation Therapy are being made available at the community level. These grant-funded activities support ACL's commitment to making research-based interventions available to support people living with dementia and their caregivers, including robust evaluation to demonstrate the interventions impact in the community. The National Alzheimer's and Dementia Resource Center (NADRC) each year publishes the *Grantee-*

Implemented Evidence-Based and Evidence-Informed Dementia Interventions a compendium of evidence-based and evidence-informed interventions implemented by ACL grantees. In addition to the compendium, the NADRC has also developed tools to aid service providers in the selection of interventions to meet the needs of their communities, as well as a compendium of evaluation instruments to support demonstration of program impact.

For more information, see:

- https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=140
- https://nadrc.acl.gov/details?search1=20210126080816
- https://nadrc.acl.gov/details?search1=70

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 professionals with appropriate skills, ranging from direct care workers to community health and social workers to primary care providers and specialists. In order to provide culturally and linguistically appropriate services, providers should have the awareness, knowledge, and skills to work and communicate effectively in cross-cultural situations, as well as cultural humility to understand their own biases and privileges, manage power imbalances, and be open to the aspect of another person's cultural identity that is most important to them.[20] 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 (RNs) 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 (CNAs), 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.

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

Lead Agencies: HRSA, VA
Partners: CMS, NIA, CDC, ACL

In FY 2021, HRSA funded 48 non-competing continuation GWEP awards. All GWEP awardees are educating and training the workforce on how to care for persons living with dementia. Of the $37.79 million GWEP budget, $8.91 million was for dementia education and training activities. In Academic Year 2020-2021 (latest available data), GWEP grants provided 661 AD/ADRD courses and trained 230,515 health care providers in AD/ADRD. In FY 2021, HRSA funded 24 non-competing continuation Geriatrics Academic Career Award (GACA) program awards totaling $1.85 million. GACA grant recipients are encouraged to provide dementia education to the workforce.

NIA produced and disseminates *Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians and Managing Older Patients with Cognitive Impairment*.

[20] U.S. Department of Health and Human Services, Office of Minority Health. *Think Cultural Health: Providing CLAS*. https://thinkculturalhealth.hhs.gov/assets/pdfs/resource-library/providing-clas.pdf.

For more information, see:

- https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals
- http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients

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, which is ongoing. In 2020, the NIA ACTC (described in Goal 1) launched the 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/

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. In 2017, ACL secured approval to collect information on the training of professionals (doctors, nurses, social workers, home health aides, first responders, etc.) through their ADRD grant program. As of December 2021, ACL grantees have reported training 97,658 professionals through their funded state and community programs. Additional professionals have benefited from training through ACL's NADRC's annual webinar series, which offers Continuing Education Units to select professionals. Select training materials developed through ACL-funded AD/ADRD programs can be found on the web page of the 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 in three training programs: (1) intensive individual training with didactics, quality improvement coaching, and clinical practicum experiences; (2) limited team-based training, including Rural Interdisciplinary Team Training (RITT); and (3) self-directed learning through webinars, simulation learning, case studies, and enduring educational materials (such as dissemination of pocket cards on dementia, delirium and depression). VA Geriatric Scholars includes a wide variety of training activities, many of which include or are focused on dementia training. Examples of FY 2022 trainings include webinars, such as "Treating PTSD in the Context of Cognitive Impairment"; "Dementia and the Age Friendly Health Systems Initiative: Integrating the 4M's of Mobility, Mind, Medications, and What Matters into the Care of Older Veterans", and "Enduring Education" case studies and virtual geriatrics conferences, such as Healthcare Planning and Management for Older Adults with Dementia and Geriatric Patient with Cognitive Impairment. Other topics include dementia caregiver coordinator education and rural caregiver education.

The Veterans Health Administration's (VHA's) 20 geriatric Centers of Excellence, called Geriatric Research, Education, and Clinical Centers (GRECCs), 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. For example, the GRECC Connect webinars and enduring education trainings included Examining Diagnostic Approaches to Dementia Care Through Use of Biomarkers, Ethical and Practical Issues in

Disclosure of Dementia Risk, A Whole Health Approach to Dementia: Optimizing Health and Well-Being in Early Stages of Dementia, An Introduction to the Dementia Caregiver Resources Website, and Impact of COVID-19 on Dementia Care: Lessons Learned from Providers.

In response to the COVID-19 pandemic, CMS developed useful guidance for health care providers, health care facilities, labs, and LTSS providers on topics including telehealth, survey and certification, Medicare coverage, Medicaid coverage, and Children's Health Insurance Program coverage, among others. CMS regularly updates the Nursing Home Resource Center web page with COVID-19 related and other updates.

For more information, see:

- https://www.cms.gov/nursing-homes

(NEW) Action 2.A.2: Educate health care providers in the IHS and Tribal care systems

Lead Agency: IHS
Partners: HRSA, VA, CDC

In 2022, IHS established the Alzheimer's Grant Program, which was newly funded in 2021. The IHS initiated a set of education and training efforts aimed at increasing skills and capacity in geriatrics, generally and specifically in care for persons living with dementia and their caregivers in IHS, Tribal, and UIH primary care. These efforts will build on and leverage the significant investments in provider training and education made by our federal partners at HRSA (in the GWEP and Dementia Curriculum for Health Care Professionals and Caregivers), the VA (in the Geriatric Scholars Program, the RITT, and education resources on the TRAIN Learning Network), and the CDC (in the BOLD Centers of Excellence). Education and training efforts will aim to pair didactic education with local system-level improvement in recognition, diagnosis, assessment, and management of care for persons living with dementia and in care for their caregivers.

See Action 2.A.5 for more detailed information on the Indian Health Geriatric Scholars Pilot.

For more information, see:

- https://www.ihs.gov/dccs/alzheimers/alztraining/

(UPDATED) Action 2.A.3: Strengthen state aging, public health, and intellectual and developmental disability workforces

Lead Agency: ACL
Partners: HRSA, CDC

HHS coordinates with states to develop workforces in aging, public health, and intellectual and developmental disability (IDD) that are AD-capable and culturally and linguistically appropriate. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network.

ACL, through the NADRC, offers an annual dementia-specific webinar series that trains over 10,000 persons per year. The series targets AD/ADRD professionals at state and community levels as well as attracting family caregivers. The webinars include information on related dementias, innovative interventions, and a wide variety of caregiving topics. Continuing education units are offered to attendees, and the webinars are archived on the NADRC web page.

In addition to the webinar series, the ACL and the NADRC develop and publish resources to support professionals including a 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. Other examples include a number of first responder training tools and *Brain Health: You Can Make a Difference!*, developed

through an ACL, NIA, CDC collaboration to support professionals educating members of the communities they serve. ACL, through the NADRC website, also makes a broad range of grantee-developed trainings and tools available for implementation and co-branding.

In 2017, ACL received Office of Management and Budget authority to collect data on professionals trained through ADPI grant funding. As of December 2021, ACL grantees have reported training 97,658 professionals through their funded state and community programs. Additional professionals have benefited from training through ACL's NADRC annual webinar series.

NADRC annually develops tools and issue briefs on dementia-specific topics to support paid and unpaid caregivers. New materials 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 developed and delivered by ADPI grantees. ACL makes a point of bringing grantee-developed resources to the public domain, so the non-grantee community is able to benefit from those funded resources. The Alzheimer's Disease Supportive Services Program (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. In 2020, NADRC and ACL ADPI grantees developed a *Guide to Billing Codes for Dementia Services* designed to assist HCBS in the identification of sources of reimbursement for dementia services which remains an ongoing challenge. The Guide includes billing codes that select ACL grantees have used successfully to bill for dementia services. Links to additional resources are offered throughout the guide to provide guidance in using these codes, as well as resources to assist in the development of the infrastructure needed to successfully bill third-party payers.

In 2022, the NADRC published a compilation *Dementia Training Resources for Professionals and Volunteers* which includes short descriptions and links to a variety of trainings and education for professionals and volunteers working with people living with AD/ADRD. Intended to increase the dementia capability of organizations, professionals, and volunteers by providing information on how to recognize, understand, and meet the unique needs of people living with AD/ADRD and their caregivers, the resource includes sections specific to professional audiences including first responders, hospital and health care organizations, primary care providers and other health care professionals, and school personnel. Trainings on topics such as advance planning, ADRC training, caregiving, communication, dementia training, diverse populations and dementia, non-AD dementia, people with dementia who live alone, people with IDD and dementia, person/family-centered care and understanding behavioral symptoms are highlighted within the publication.

In 2022, ACL awarded a 5-year grant totaling over $6 million to establish a national center to expand and strengthen the direct care workforce across the country.

For more information, see:

- https://acl.gov/brain-health
- https://acl.gov/news-and-events/announcements/acl-launches-national-center-strengthen-direct-care-workforce
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=153
- https://nadrc.acl.gov/details?search1=169
- https://nadrc.acl.gov/details?search1=232

Cross-agency collaborations have enhanced workforce dementia training and expertise. In FY 2021, the 48 HRSA GWEP grantees collaborated with 50 Area Agencies on Aging (AAAs) and seven quality improvement organizations (QIOs) to strengthen state aging, public health, and IDD

workforces. In addition, 19 of the 48 GWEPs collaborated with the VA to assist with training on dementia. These collaborations persist in Year 4 of funding (FY 2022).

CDC funded the University of Illinois at Chicago (UIC) in FY 2021 as part of the HBI. Their focus is the People with IDD Healthy Brain Initiative (PwIDD-HBI) which addresses stigma, early diagnosis, and culturally and linguistically appropriate care designed 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 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 the fields of AD/ADRD and IDD into one community of practice for people with IDD, caregivers (paid and unpaid), health care providers, and public health and policy stakeholders. An HBI community of practice for people with IDD will be a "one-stop space" that offers products, trainings, and materials to raise awareness of AD/ADRD among people with IDD decrease disparities for those experiencing AD/ADRD and improve people with IDD and caregiver's quality of life.

Key accomplishments achieved include hosting the virtual HealthMatters Webinar Series, hosting five presentations supporting the HealthMatters Series which reached over 400 attendees, and authored two publications. The HealthMatters COVID-19 2020 Webinar Series provided 19 webinars supporting brain health through the HealthMatters Program for a total of 6,463 attendees on the webinars and 1,762 YouTube views on the HealthMatters Channel. Presentations conducted by UIC and their partners include: "HealthMatters Program Virtual Coach-Health Matters Now More than Ever" (for community support providers, family members, transition to work instructors, educators, policy makers, and researchers); "Heathy Brain Initiative and Virtual Coach HealthMatters Program" (for researchers, educators, and policy makers in the Association of University Centers on Disabilities Aging Special Interest Group); Virtual Coach HealthMatters (for researchers, policy makers, practitioners, and Special Olympics Aging Task Force members); and "COVID-19 and Down Syndrome" (Down Syndrome Affiliates in Action-Board members of Down syndrome associations). Two articles were written and published with an aim to educating and empowering key stakeholders to influence health promotion and brain health policies and partnerships and to develop a competent workforce to support people with IDD in activities that promote brain health.

- Sisirak J, Janicki MP, Murphy R, Marks B, Buckley T. *Impact of COVID-19 on Provider Organizations Serving Adults with Intellectual and Other Disabilities*. White Paper. Washington, DC: ACCESS, 2020.
- Sisirak J, Marks B, Keller S. Optimal Ageing for People with Down Syndrome. In VP Prasher (eds.), *Excelling in Life with Down Syndrome*. United Kingdom: Nova Science, 2021.

For more information, see:

- https://tinyurl.com/yz3jwhz9
- https://www.cdc.gov/aging/funding/hbi/index.html

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

Lead Agency: HRSA
Partners: ACL, CDC, CMS, OWH, NIA, VA

From FY 2015 through FY 2017, HRSA partnered with federal staff at ACL, CDC, CMS, HHS Office on Women's Health, and VA on a contract to develop the 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 2018. From July 2018 to December 2021, there were 27,776 page views on the AD/ADRD curriculum page.

For more information, see:

- https://bhw.hrsa.gov/alzheimers-dementia-training

CMS's Resources for Integrated Care, which partners with health plans and providers, has offered 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. 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/

The 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 on 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 (MFHs) 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, which allowed multiple commercial applications to be used for communication with veterans and their caregivers. 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. Personal Protective Equipment 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.

(ONGOING) 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

Lead Agency: NIA
Partners: CDC, ACL, HRSA, AHRQ, NASEM

CDC has developed a weekly newsletter that is sent out to over 45,000 subscribers, including public health professionals. 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

In 2018, NIA commissioned a systematic evidence review by the Agency for Healthcare Research and Quality (AHRQ) of care and caregiving interventions for dementia in order to determine which of the interventions identified have an evidence base that is sufficient to support widespread dissemination. Findings from the AHRQ evidence review were released in 2020. In 2021, NASEM released *Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward*. The report is the culmination of a collaboration among NIA, AHRQ, and NASEM, to develop a comprehensive understanding of the evidence base for essential care and caregiving interventions for the millions of people living with dementia and their caregivers. In response to recommendations from these reports, NIA has issued new funding opportunities to support the development of rigorous, principle-based dementia care interventions that can be delivered with fidelity in a range of care settings.

For more information, see:

- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol
- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-307.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-308.html
- https://www.nap.edu/catalog/26026/meeting-the-challenge-of-caring-for-persons-living-with-dementia-and-their-care-partners-and-caregivers
- 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 also supports several Roybal Centers that conduct pilot research aimed at strengthening the design of dementia care interventions. In addition, the NIA IMPACT Collaboratory is designed to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems. The IMPACT Collaboratory supports pilot studies to inform the design of larger scale pragmatic dementia care trials and demonstration projects to test, measure, and evaluate the effect of care delivery intervention programs in a health care system for people living with AD/ADRD and their care partners.

For more information, see:

- https://impactcollaboratory.org/
- https://impactcollaboratory.org/grants-and-training/pilot-grants/pilot-grant-awardees/
- https://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translational-research-behavioral-and-social-sciences-aging
- https://www.roybalniaresearchcenters.org/
- https://www.roybalniaresearchcenters.org/funding-opportunities

In 2021, 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 2021, NIA, ACL, CDC, and HRSA revived and expanded the annual Focus on Aging: Federal Partners' Webinar Series. The webinar series, which addresses important topics for public health and health care professionals, aging services organizations, the research community, and other stakeholders in aging, now features approximately three webinars per year and encompasses new federal partners. In addition to general topics of interest for older adults and those who work with them, each webinar includes information specific to individuals with AD/ADRD and their caregivers. Recent webinars focused on the disclosure of research and clinical findings related to cognition, and workforce to support the needs of older adults. All prior webinars are made available to the public on the Focus on Aging: Federal Partners' Webinar Series website.

For more information, see:

- https://effectivehealthcare.ahrq.gov/
- https://www.acpm.org/page/brainhealth
- https://www.nia.nih.gov/focus-aging-federal-partners-webinar-series

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(**ONGOING**) Action 2.A.6: 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

Lead Agencies: IHS, CDC
Partners: VA, public and private partners

IHS incorporated training for AD/ADRD into the online continuing education curriculum for IHS/Tribal/UIH 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. Furthermore, the VA successfully developed grant proposal to the VA Office of Rural Health to develop an IHS-VA Geriatric Scholars Program, which will launch in FY 2023. This pilot program will provide team-based training for primary care and dementia training for public health as part of the IHS Alzheimer's Initiative.

(**NEW**) Action 2.A.7: Train primary care teams in Indian Country in geriatrics

Lead Agency: IHS

In 2022, the IHS launched the Indian Health Geriatric Scholars Pilot, developed with the support and collaboration of the VA Office of Rural Health. Modeled after the highly successful VA Geriatric Scholars Program that has built geriatric expertise into the primary care workforce over the past decade, the Indian Health Geriatric Scholars pilot will provide primary care clinicians at IHS, Tribal, and UIH programs with an individual intensive learning track for professional continuing education, including:

- A week-long intensive training in geriatrics through an approved Geriatrics Board Review course.
- A mentored geriatric improvement project at their local facility.
- A clinical practicum or mentorship in geriatric practice.
- Ongoing education, training, and peer support as an Indian Health Geriatric Scholar.

In this pilot year, the Indian Health GeriScholars Program will accept at least eight physicians, nurse practitioners, physician assistants, or pharmacists sponsored by their IHS, Tribal, or UIH program.

In 2021, the IHS began collaboration with the NPAIHB in a Dementia ECHO for Indian Country. In 2022, the IHS will invest further in the ECHO model of case-based learning to support clinicians in the diagnosis, assessment, and management of dementia and to encourage Indian Health staff to provide coaching and support to caregivers of persons living with dementia.

See Action 1.E.3 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

(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

Lead Agency: IHS

IHS created a survey to assess nursing in IHS, Tribal, and UIH 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.

(ONGOING) 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

Lead Agency: IHS
Partners: HRSA, ACL

IHS, in conjunction with HRSA, worked to pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, and UIH 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. The HRSA Dementia Curriculum and selected VA geriatric training materials are now available as a resource for Indian Health clinical staff through the IHS Alzheimer's Grant Program Education and Training page.

For more information, see:

- https://www.ihs.gov/dccs/alzheimers/alztraining/

In 2020, ACL introduced a new grant program, ADPI: Dementia Capability in Indian Country. The program is designed to bring culturally and linguistically appropriate AD/ADRD training and education and dementia-specific evidence-based interventions to Indian Country. Since the inception of the ACL Dementia Capability in Indian Country efforts six tribes/Tribal entities have received funding to deliver supports and services in Tribal communities. ACL has also initiated the development curriculum for inclusion a Tribal Learning Management System, that will be available to their Older Americans Act (OAA) Title VI programs, to expand dementia capability amongst Title VI providers.

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

Lead Agency: IHS

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

(ONGOING) 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

Lead Agency: IHS
Partner: VA

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 Employee Education System and TRAIN for VA and community clinicians. Training continued into 2020 and included the newly developed ABCD training to support public health nursing in their role of caregiver support. These trainings have since been delayed due to the COVID-19 PHE but are being rescheduled for FY 2023. The RITTs will resume in 2022.

For more information, see:

- http://www.gerischolars.org/course/view.php?id=29
- http://www.ihs.gov/dccs/alzheimers/alztraining

(NEW) Action 2.A.12: Develop Alzheimer's disease and related dementias learning platform dedicated to training home and community service providers in Indian Country in the delivery of culturally and linguistically appropriate dementia-capable services.

Lead Agency: ACL

ACL, through their Office of American Indian, Alaska Native and Native Hawaiian Programs is working with a variety of culturally-competent AD/ADRD experts to develop and make available a broad range of educational curricula and tools to support increasing the dementia capability of Tribal communities across the nation.

(COMPLETED) Action 2.A.13: Understand current nursing facility staffing challenges, including the impact of COVID-19, and best practices to address them

Lead Agency: ASPE

Nursing homes require adequate staffing to provide quality care to their residents. Staffing has been shown to be an important predictor of nursing home quality. Not simply total staffing, but also the mix of professional staff and staffing stability are important factors. Despite the importance of staffing, nursing homes have historically struggled to maintain adequate staffing due to low wages, limited possibilities of advancement, and difficult working conditions. Two important drivers of these challenges have been low Medicaid rates of reimbursement and the increasing medical complexity of residents.

The COVID-19 pandemic exacerbated this staffing challenge, as nursing homes were at the epicenter of the pandemic and faced many challenges. Both policy makers and nursing home leaders acted quickly to attempt to help stabilize staffing. This project will conduct analyses to understand the changes in staffing during COVID-19, factors associated with these changes, and

supplement this analysis with information from key stakeholders. ASPE has posted a report from this project to the ASPE website.

For more information, see:

- https://aspe.hhs.gov/reports/covid-19-intensifies-nursing-home-workforce-challenges-0

(COMPLETED) Action 2.A.14: Improve the safety and quality of nursing homes

Lead Agency: CMS

In February 2022, the White House announced a set of reforms developed by and implemented through HHS to improve the quality and safety of nursing homes, including the need to establish adequate staffing in nursing homes. In 2022, CMS announced plans to launch a multifaceted approach to determine the minimum level and type of staffing needed to help enable safe and quality care in nursing homes, including a RFI, a study to inform future rulemaking on staffing requirements, and a stakeholder listening session.

For more information, see:

- https://www.cms.gov/blog/centers-medicare-medicaid-services-staffing-study-inform-minimum-staffing-requirements-nursing-homes
- https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/

(NEW) Action 2.A.15: Understand impact of the COVID-19 pandemic on direct care staffing in nursing homes

Lead Agency: ASPE

It is well known that in the early weeks of the COVID-19 pandemic in the United States much of the devastation was concentrated in nursing homes. In addition to the staggering death toll, isolation and suffering from COVID-19 among nursing home residents, the pandemic introduced new challenges for nursing home staff and exacerbated ongoing challenges. This study explored the impact of the pandemic on direct care staffing (CNAs, licensed practical nurses and RNs). This ASPE study found that the nursing home workforce, which for decades has experienced chronic shortages, was profoundly impacted by the COVID-19 pandemic. The number of nursing home residents and the number of CNAs declined dramatically, there were slight increases in staffing due to increased workload, existing staffing disparities were exacerbated, and there was a sizable increase in use of contract staff. This evaluation is a follow-up study from that explained in Action 2.A.10 and the reports were posted on the ASPE website.

For more information, see:

- https://aspe.hhs.gov/reports/nh-staffing-covid-pandemic

(COMPLETED) Action 2.A.16: Assess current capacity of dementia specialists in the United States

Lead Agency: ASPE
Partner: HRSA

The Explanatory Statement that accompanied the Consolidated Appropriations Act of 2021 directed HRSA, in consultation with ASPE, to provide a report to the Committees on Appropriations on the current capacity of the Nation's dementia specialists not later than 15 months after enactment (effective December 27, 2020). The report language says that the report should “assess provider shortages and screening capacity, identify barriers for early detection of

Alzheimer's and adequate access to care, and provide recommendations to address any provider shortages and streamline the patient's Alzheimer's diagnostic pathway." This Report to the Committees on Appropriations should be available in early 2023.

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Unfortunately, many people with AD/ADRD are not diagnosed until their symptoms have become severe, particularly people of color and people of low socioeconomic status (SES). 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 -- especially when facing long-term care expenses -- 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

Lead Agency: NIA
Partner: CDC

NIA-supported scientists are making important progress toward the development of highly portable, quick, versatile, and comprehensive measures of neurological and behavioral function to identify AD/ADRD at the earliest stages. Efforts include the development and validation of a combination of tests to assess MCI.

NIA has also funded applications to pursue development and validation studies of cognitive screening instruments or assessments in clinical settings and to translate these screening and assessment tools into EHR systems that can assist physicians in making clinically meaningful care recommendations for patients experiencing cognitive decline.

In addition, researchers are expanding the NIH Toolbox for the Assessment of Neurological and Behavioral Functions, a dynamic set of health assessments for all ages. Now available in English and Spanish, more than 200 clinical studies are using the NIH Toolbox, and more than 250 peer-reviewed articles have been published. The NIH-supported Advancing Reliable Measurement in Alzheimer's Disease and Cognitive Aging study is investigating the use of the NIH Toolbox measures for people with AD/ADRD. Through this effort, researchers are expanding the toolbox so that it will be valid to use with ethnically and racially diverse adults and in adults 86 and older.

For more information, see:

- https://www.clinicaltrials.gov/ct2/show/NCT02814526
- https://www.healthmeasures.net/explore-measurement-systems/nih-toolbox
- https://www.healthmeasures.net/explore-measurement-systems/nih-toolbox/measure-development-and-research/publications-by-year/197-nih-toolbox-publications-by-year
- https://neuroscienceblueprint.nih.gov/resources-tools/blueprint-resources-tools-library/nih-toolbox-assessment-neurological-and
- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals

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(UPDATED) Action 2.B.2: Support Technology to Advance Mobile Monitoring of Cognitive Changes

Lead Agency: NIA

In 2019, NIA funded two new projects with the goal of producing smartphone applications capable of measuring cognitive status and subtle changes in cognition on mobile devices. These grants were awarded in response to a specific FOA seeking projects focused on mobile monitoring of cognitive change. The smartphone Apps supporting the mobile monitoring of cognitive change went into limited release in the Summer 2022 and will go into widespread release to a greater number of researchers in 2023. In 2022, NIA published a new funding opportunity calling for applications to expand the content, design, and implementation of research infrastructure funded under RFA-AG-18-012, Mobile Monitoring of Cognitive Change (U2C), collectively known as the Mobile Toolbox Project, by addressing the need to: (1) add assessments on mobile devices of non-cognitive socioemotional psychological functions, health states, and contextual factors that may modify cognitive performance; and (2) enable widespread dissemination and support for use of the tools developed for monitoring of age, state, context, or health condition-related changes in cognitive and non-cognitive abilities on mobile devices. In 2020, NIA published a funding opportunity for development and validation of cognitive screening instruments or assessments in clinical settings and translation of these tools into EHR systems to assist physicians in making clinically meaningful care recommendations for patients experiencing cognitive decline.

For more information, see:

- 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://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-021.html
- https://reporter.nih.gov/project-details/9781454
- https://reporter.nih.gov/project-details/9781463
- https://reporter.nih.gov/search/BOil54h7vEyegzmJqXQYCg/projects?shared=true

Please see the NACC-developed Down syndrome-specific clinical and cognitive assessment module for research described in Action 1.B.6.

(UPDATED) Action 2.B.3: Identify and study effective approaches to increasing detection of cognitive impairment in clinical settings

Lead Agency: NINDS
Partner: NIA

There is a strong need to increase detection of cognitive impairment and dementia in high-risk populations, including those that experience health disparities, and lessen cultural and logistic barriers that currently impede clinical care and research. To this end, in 2022, NINDS launched the second phase of the Consortium for Detecting Cognitive Impairment, Including Dementia (DetectCID; RFA-NS-22-009) -- a collaborative research network to develop and validate approaches to detect dementia in primary care or other everyday clinical settings. The detection approaches were designed to be simple to use, standardized, and take 10 minutes or less to administer, with the aim to effectively and efficiently link people to follow-up care in ways that fit the local care realities of the individual involved. In 2022, DetectCID investigators published lessons learned through the first phase of the program, including the importance of: (1) engaging primary care teams in research and helping them to both diagnose cognitive disorders as well as provide ongoing care support; (2) integrating newly developed screening tests with EHRs; and (3) ensuring that detection approaches address the needs of diverse populations. In Phase 2, the DetectCID research teams are validating the most promising approaches from Phase 1 in larger pragmatic clinical trials, with at least 50% of the study participants identifying as racial or ethnic minorities.

For more information, see:

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-009.html
- https://pubmed.ncbi.nlm.nih.gov/35124639/
- https://www.detectcid.org/
- https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients
- https://www.ninds.nih.gov/News-Events/News-and-Press-Releases/Press-Releases/NIH-forms-new-consortium-improve-detection

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(**UPDATED**) Action 2.B.4: Identify and disseminate information on early detection of dementia

Lead Agency: CDC

In 2020, CDC funded the BOLD PHCOE to focus on early detection and diagnosis of AD/ADRD. The New York University (NYU) PHCOE on Early Detection of Dementia brings together a broad coalition of stakeholders across the United States to assure widespread awareness of why early detection of dementia matters. The Center created a comprehensive three-part strategy to ensure a thorough scoping review of materials for early detection and diagnosis of AD/ADRD including: (1) collate public facing educational materials from websites including those of CDC, Alzheimer's Association, and NIA; (2) conduct a series of web-based searches for educational materials, tools, checklists, protocols, and resources designed to facilitate detection and early diagnosis of dementia; and (3) search the peer-reviewed literature using primarily PubMed to identify articles providing evidence of successful tools and strategies for early detection. As of April 2021, the Center has initiated this first strategy by gathering 13 pages of weblinks to resources with descriptions. The Center recently launched a website specific to its PHCOE on Early Detection of Dementia and is publishing all educational materials and peer-reviewed literature on the evidence of successful tools and strategies for early detection and diagnosis of AD/ADRD for public access and use.

In the past year, the PHCOE on Early Detection and Diagnosis of Dementia (EDD) has completing the following activities.

1. Launched the NYU PHCOE website on April 22, 2022.
2. Created Executive Committee (seven people) who solicit feedback from their Advisory Council workgroup members on materials developed by the BOLD team and developed actions plans for developing, refining, and disseminating early detection toolkits for health care systems, state/local/Tribal departments of health, and CBOs.
3. Identified common barriers and facilitators to dementia detection across CBOs, departments of health, and health system sectors.
4. Developed a list of cognitive screeners recommended by American Gerontology Society KAER model for primary care within a health care system and the U.S. Preventative Task Force. The list of cognitive screeners is being made into a searchable tool for use on the NYU PHCOE website. The public can use this tool to identify and gain a detailed understanding of the different types of cognitive screens health care providers use to assess people for AD/ADRD.
5. Wrote a manuscript including a timeline of key national policy initiatives that support dementia detection and dementia care planning to be featured in state AD/ADRD analysis paper that was submitted for peer review in May 2022.
6. Created infographics for the PHCOE-EDD website that provide guidance on approaching conversations around dementia detection and brain health.
7. Wrote "Why Detect Dementia" pieces that highlighted the importance of early detection of dementia featured on the website.
8. Began building relationships with new CBOs to develop a deeper understanding of this highly heterogeneous sector.

9. Pilot tested the health systems dementia detection toolkit in IHS.
10. Provided technical assistance and guidance to the Maine BOLD program on their dementia detection program.

PHCOE-EDD is planning a national meeting on early detection and diagnosis of AD/ADRD entitled *Public Health Action to Advance Early Detection of Dementia National Virtual Symposium* on October 25-27, 2022. A total of 312 people registered for the virtual meeting with 179 individuals attending. This meeting was free, and the content will be available to all registrants via the meeting website through December 1, 2022, and available for the general public afterwards. Early evaluation data shows, 71% were extremely satisfied with symposium content and 25% were satisfied, providing them with 96% positive feedback.

For more information, see:

- https://bolddementiadetection.org/

(**UPDATED**) Action 2.B.5: Expand Access to New Technology to Diagnosis Alzheimer's Disease

Lead Agency: FDA

In May, FDA permitted marketing for the first in vitro diagnostic test for early detection of amyloid plaques associated with AD/ADRD. The Lumipulse G β-Amyloid Ratio (1-42/1-40) test is intended to be used in adult patients, aged 55 years and older, presenting with cognitive impairment who are being evaluated for AD/ADRD and other causes of cognitive decline. Prior to the authorization, doctors could only use PET scans, a potentially costly and cumbersome option, to detect/visualize amyloid plaques in a patient's brain, often years before clinical symptom onset, to aid in diagnosing AD/ADRD.

The Lumipulse test is intended to measure the ratio of β-amyloid 1-42 and β-amyloid 1-40 (specific proteins that can accumulate and form plaques) concentrations found in human cerebral spinal fluid (CSF), which can help physicians determine whether a patient is likely to have amyloid plaques, a hallmark sign of AD. Results must be interpreted in conjunction with other patient clinical information.

The FDA evaluated the safety and effectiveness of this test in a clinical study of 292 CSF samples from the NIA-funded ADNI sample bank.

For more information, see:

- https://www.fda.gov/news-events/press-announcements/fda-permits-marketing-new-test-improve-diagnosis-alzheimers-disease

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(**ONGOING**) Action 2.B.6: Educate family and service providers of persons with intellectual and developmental disability about changes that may indicate the onset of dementia

Lead Agency: ACL, AIDD
Partner: NTG

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. 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 tool.

ACL consistently offers educational opportunities and 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 are consistently included in ACL's annual webinar series. Webinars have focused on important topics including early screening, palliative care, family advocacy, and promising practices in care. In October 2020 ACL funded, through the NADRC, a recorded training entitled Adapting Evidence-Based and Informed Caregiver Interventions to Support Caregivers of People with Intellectual and Developmental Disabilities and Dementia to train people to support caregivers of people living with IDD and dementia. Also in 2020, ACL and the NADRC developed and published a 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/details?search1=169
- https://nadrc.acl.gov/details?search1=20210225025851#result

CDC, through its HBI, 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:

- http://aadmd.org/
- https://healthmattersprogram.org/healthybrain/
- https://www.cdc.gov/aging/funding/hbi/index.html

(**UPDATED**) Action 2.B.7: 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

Lead Agencies: IHS, CDC, NIA
Partners: ACL, VA

IHS, with ACL and VA, pilot-tested AD/ADRD awareness strategies in communities in which 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.

In 2022, the IHS began collaboration with the NYU BOLD PHCOE to increase use of simple, valid tools to detect cognitive impairment and guide individuals with cognitive impairment toward services and diagnosis.

ACL continues to bring awareness to AD/ADRD in Indian Country through participation 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, funding four Tribal entities in 2020 and another two in 2021 to develop and implement culturally and linguistically appropriate 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), developed a communication campaign to raise awareness of AD/ADRD for Urban Indian Elders. The campaign includes videos, a social media toolkit, flyer and posters, graphics, and other resources.

For more information, see:

- https://www.cdc.gov/aging/healthybrain/videos/index.html

A number of NIA's ADRCs are working in Native Communities and have developed brochures and videos that encourage the participation of AI/AN in AD/ADRD clinical trials so that the prevalence of the disease in Native communities can be better understood. Additional resources include information about AD/ADRD, caregiver resources, and research education. NIA is also currently holding focus groups and stakeholder interviews to develop tailored materials for AI/AN. Materials developed are made available to the public in both ADORE and Outreach Pro.

For more information, see:

- https://outreachpro.nia.nih.gov
- https://www.nia.nih.gov/research/adore
- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/indigenous-aging-resources

CDC funds a special interest project at the University of Washington School of Medicine through CDC's Prevention Research Centers that aims to improve cognitive impairment detection and referral to resources among older adults by applying the Gerontological Society of America's (GSA's) KAER Model to primary care within a health care system. The project will increase awareness of early signs, detection of cognitive impairment, and support of providers, patients, and caregivers to ultimately improve outcomes for care of dementia. The project will implement an education intervention for primary care providers and clinical staff to increase skills for evaluation and management of dementia. Working with the university clinic managers and information technology, the project will streamline operations and document care utilizing newly developed interdisciplinary workflows and EHR order sets. A Community Advisory Board will assist in the development of a web-based resource directory to be used in-clinic and at home to support providers, staff, patients, families, and caregivers. It is anticipated that by the end of the 2-year project, strategies developed and implemented will help other health care systems initiate steps to integrate the KAER Model and other tools for improving detection and management of dementia through support of primary care.

For more information, see:

- https://familymedicine.uw.edu/cpc/
- 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 2.A.5 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.

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

Sometimes, even though a physician or another health care provider has identified cognitive impairment, the person and/or his/her family and caregivers are not told of the diagnosis. Further, once a diagnosis is made and disclosed, as few as half of people with dementia, and their families/caregivers receive counseling, support, or information about next steps. This information is important, especially for early-stage individuals who may 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 caregivers and

enhancing the ability of other networks to assist people living with AD/ADRD and their families and caregivers to address their needs.

(ONGOING) Action 2.C.1: Educate physicians and other health care providers about accessing long-term services and supports

Lead Agency: HRSA
Partners: CMS, ACL

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. The 2022 *Medicare & You* booklet highlighted this important service for beneficiaries and caregivers, and CMS also created a related video for providers.

For more information, see:

- https://www.medicare.gov/Pubs/pdf/10050-medicare-and-you.pdf
- https://www.youtube.com/watch?v=NmDjhRVax8E

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.

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

Lead Agency: IHS
Partners: ACL, CDC

The focus on increasing support to caregivers in Tribal communities 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 collaborated with the CDC and Alzheimer's Association to develop the *Road Map for Indian Country* designed specifically for Tribal communities. The Road Map 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. The International Association for Indigenous Aging (IA^2), a recipient of HBI support, and the NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities. In 2022, IHS entered into a Memorandum of Understanding with the Alzheimer's Association to work together to address and improve the health and well-being of AI/AN living with dementia and their caregivers. Work has begun to link Alzheimer's Association chapters with tribes, UIH programs, and IHS services.

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, funding four Tribal entities in 2020 and another two in 2021 to develop and implement culturally and linguistically appropriate education programs and deliver evidence-based interventions in support of elders living with dementia and their caregivers. The recipients of the ACL Dementia Capability in Indian Country grants include Tribal Senior Services, a Tribal Health System, Inter-Tribal Councils and a regional association that serves a broad range of Tribal needs.

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://iasquared.org/brain-health/
- https://iasquared.org/brain-health/resource-library/

CDC has partnered with the NCUIH to review, adapt, and disseminate existing culturally and linguistically 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 1-minute videos on:

1. Preventing Alzheimer's.
2. Recognizing the signs of Alzheimer's in Loved Ones.
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, and 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/data/infographic/2018/american-indian-adults-caregiving.html
- https://www.cdc.gov/aging/data/infographic/2018/american-Indian-alaska-native-cognitive-decline.html
- https://www.cdc.gov/aging/data/infographic/2019-2020/ai-an-scd.html
- https://www.cdc.gov/aging/healthybrain/videos/index.html
- https://www.cdc.gov/aging/spanish/infographic/2018/ai-adults-caregiving.html
- https://www.cdc.gov/aging/spanish/infographic/2018/aian-cognitive-decline.html

Also see Action 1.E.3 for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

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 and linguistically appropriate 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 clinicians the information they need at the point of care and ensure continuity between measurement, evaluation, and best practice.

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

Lead Agency: CMS
Partner: ASPE

CMS has included dementia-related measures in the Merit-based Incentives Payment System for Medicare such as cognitive assessment, education and support of caregivers, and other measures that impact people with dementia. In 2022, CMS released a voluntary HCBS quality measure set to promote consistent quality measurement in state Medicaid HCBS programs for older adults and people with disabilities, including people with dementia. CMS has established the CMS Measures Inventory Tool, which inventories measures in use across its programs. In 2022, CMS launched its National Quality Strategy, which aims to promote high-quality outcomes and safer care for all individuals, using a person-centered approach across provider types.

For more information, see:

- https://www.cms.gov/blog/cms-national-quality-strategy-person-centered-approach-improving-quality
- https://cmit.cms.gov/cmit/#/
- https://qpp.cms.gov/mips/quality-measures
- https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf

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

Lead Agency: CMS
Partners: ASPE

CMS's "Meaningful Measures" framework identifies the highest priorities for quality measurement and improvement to assess core issues that are the most critical to providing high-quality care and improving individual outcomes.

For more information, see:

- https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page.html

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

Lead Agency: HRSA

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.

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

Lead Agency: IHS
Partners: HRSA

IHS collaborated with HRSA to engage the HRSA-funded GWEPs on strategies to improve recognition and diagnosis of dementia. Thirteen HRSA GWEPs are currently partnering with federally recognized Tribal organizations. The 13 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.

(UPDATED) Action 2.D.5: Improve nursing home care and transparency during the COVID-19 pandemic

Lead Agencies: CMS, VA
Partner: SAMHSA

During the pandemic, CMS has continued to take steps to help keep nursing home residents and staff healthy and safe, working closely with other HHS partners, including the CDC. In 2022, CMS also published a clarification to guidance about visitation policies in nursing homes to assure flexible policies that protect residents' rights and permit visitation with few and rare exceptions. CMS also issued a Medicaid informational bulletin detailing actions states can take using various statutory authorities to drive improved outcomes for residents and improve staff pay, training, and retention efforts. COVID-19 Nursing Home Data is updated weekly based on CDC data in the National Healthcare Safety Network COVID-19 Long-Term Care Facility Module. CMS also released a Long-Term Care Surveyor Guidance Update, to help improve care for people with mental disorders, and better address situations where nursing home residents are potentially given an inaccurate diagnosis or assessment, including where practitioners or facilities may have inaccurately diagnosed or coded a resident with a condition such as schizophrenia in the resident assessment instrument. In September 2022, Substance Abuse and Mental Health Services Administration (SAMHSA), working with CMS, established the Center of Excellence for Behavioral Health in Nursing Facilities (COE-NF), a national center of excellence for building capacity in nursing homes to furnish care to residents with behavioral health conditions which supports focused resource development and dissemination, training and technical assistance, and workforce development to staff in nursing homes for people with serious mental illness (SMI), serious emotional disturbance, substance use disorders (SUD), and co-occurring disorders.

For more information, see:

- https://data.cms.gov/covid-19/covid-19-nursing-home-data
- https://quality.allianthealth.org/topic/center-of-excellence-for-behavioral-health-in-nursing-facilities/

- https://www.cms.gov/files/document/nursing-home-visitation-faq-1223.pdf?eType=EmailBlastContent&eId=880d86e7-d5d7-4d7d-bc8e-86fea9f17e64
- https://www.cms.gov/medicareprovider-enrollment-and-certificationsurveycertificationgeninfopolicy-and-memos-states-and/revised-long-term-care-surveyor-guidance-revisions-surveyor-guidance-phases-2-3-arbitration
- https://www.medicaid.gov/federal-policy-guidance/downloads/cib08222022.pdf
- https://www.samhsa.gov/grants/grant-announcements/sm-22-011

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' 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.

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.

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

Lead Agency: CMMI
Partners: NIA

Since its inception, CMS's Innovation Center has tested several payment and care delivery models, including preliminary model concepts aimed at improving the quality of care for Medicare beneficiaries with AD/ADRD. Several awards under the Innovation Center's Health Care Innovation Awards Rounds 1 and 2 were focused on people with AD/ADRD and their caregivers. In 2022, CMS held a National Listening Session to learn from stakeholders about their experiences in important areas like transformation in whole-person care, health outcomes domains, promising practices, resource connections, and participation in specialized care.

For more information, see:

- https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/
- https://innovation.cms.gov/innovation-models/health-care-innovation-awards/round-2
- https://www.cms.gov/files/document/transcriptoalisteningsessiondementiacareandservices05242022.pdf

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

Lead Agency: CMMI

The Independence at Home Demonstration is testing a payment incentive and service delivery model that uses physicians and nurse practitioners to deliver HBPC for Medicare beneficiaries with multiple chronic conditions. CMS has released the results from Year 7 of the demonstration.

For more information, see:

- https://innovation.cms.gov/innovation-models/independence-at-home

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(UPDATED) Action 2.E.3: Understand the role of certified community behavioral health clinics in providing access to care

Lead Agency: ASPE

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 multi-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 both interim reports and a final report are posted on ASPE's website. The first Report to Congress was published in 2017; four additional Reports to Congress have been transmitted, and two interim reports were published in September 2020. The final report will be posted on ASPE's website shortly. Since the demonstration was extended and expanded several times, including most recently in the Safer Communities Act, ASPE is undertaking further evaluation of the extended and expanded demonstration.

For more information, see:

- 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/certified-community-behavioral-health-clinics-demonstration-program-report-congress-2018
- https://aspe.hhs.gov/report/implementation-findings-national-evaluation-certified-community-behavioral-health-clinic-demonstration
- https://aspe.hhs.gov/reports/fourth-ccbhc-program-report-congress-2020
- https://aspe.hhs.gov/reports/interim-ccbhc-cost-quality-findings
- https://aspe.hhs.gov/sites/default/files/documents/5a239c68e1111a1a4896001bc47fc6c7/ccbhc-report-congress-2021.pdf
- https://aspe.hhs.gov/sites/default/files/documents/60f121a777ee63b20008e43ad45518bf/ccbhc-implementation-impacts-findings.pdf
- https://www.samhsa.gov/sites/default/files/ccbh_clinicdemonstrationprogram_071118.pdf

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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 department 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 older adults and people with AD/ADRD, who often have multiple chronic conditions. Transitions include moves into acute care hospitals, from hospitals to post-acute care 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.

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

Lead Agency: CMMI
Partner: ACL

CMS Accountable Health Communities Model was based on addressing health-related social needs through enhanced community linkages. In 2022, CMS posted a "spotlight" report on making the case for addressing health-related social needs.

For more information, see:

- https://innovation.cms.gov/media/document/ahc-reading-hosp-spotlight

ACL's state dementia system grants continue to require a care transitions component and an evaluation of the effectiveness of these programs. Numerous innovative evidence-based and evidence-informed models of care transitions interventions are presently being implemented through ACL's state projects. Information on promising program practices is 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, which is presently being translated into an Indiana AAA. In 2021, an AAA in Indiana received funding to implement Hospital2Home in support of dementia-capable care transitions in the community they serve.

For more information, see:

- http://hospital2home.org/about/
- https://nadrc.acl.gov

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

Lead Agency: ACL
Partner: CMS

National Center on Advancing Person-Centered Practices and Systems (NCAPPS), an initiative between CMS and ACL to implement person-centered practices, issued a 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. NCAPPS has other resources on direct support professional recruitment and retention, person-centered planning facilitation, and inclusion.

For more information, see:

- https://ncapps.acl.gov/

(COMPLETED) Action 2.F.3: Release Guide to Billing Codes for Dementia Services

Lead Agency: ACL

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 certain dementia services. It may also be useful for organizations that are considering developing a medical billing system for services. In October 2020, the NADRC hosted a webinar entitled Sustaining Programs for People Living with Dementia and their Caregivers: Billing for Dementia Services.

For more information, see:

- https://nadrc.acl.gov/details?search1=20210421105717#result
- https://nadrc.acl.gov/details?search1=232#result

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

Lead Agency: 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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(ONGOING) 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

Lead Agency: ONC
Partners: CMS, ASPE

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.

For more information, see:

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

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 affected by AD/ADRD, including racial and ethnic minorities and people with IDD. Most racial and ethnic minority groups 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

Lead Agency: ACL, IHS

As of 2022, ACL has funded a total of 167 AD/ADRD community-based projects, in support of people living with dementia and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 167 are six Tribal entities which applied for and received funding beginning in 2020.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Future grants through ADPI are contingent on availability of funding.

In May 2022, the IHS announced funding through a Notice of Funding Opportunity (for tribes, Tribal Organizations, and Urban Indian Organizations) and program awards (for federally operated IHS clinics and hospitals) for the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of persons living with dementia and their caregivers.

For more information, see:

- https://acl.gov/news-and-events/announcements/alzheimers-disease-programs-initiative-adpi-dementia-capability-0
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20210602113141#result
- https://www.ihs.gov/dccs/alzheimers/alzfunding/

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

Lead Agency: ACL

Through its AD/ADRD grant programs and NADRC, ACL continues to target program resources to addressing IDD and dementia. For example, the NADRC includes an IDD and dementia-specific webinar in their annual webinar series, which can be found on the NADRC website.

Many ACL-funded programs use their resources to develop tools designed to support people living with IDD and dementia. Tools that demonstrate positive impact on the intended audience are made available to the public through the NADRC website.

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.

Through the NADRC, ACL-funded a recorded training entitled Adapting Evidence-Based and Informed Caregiver Interventions to Support Caregivers of People with Intellectual and Developmental Disabilities and Dementia in October 2020. The training educated viewers on ways to support caregivers of people living with IDD and dementia.

ACL continues to address the gap in services and supports for people living with IDD and dementia or at high risk of developing dementia. Since the inception of community programing, 99 grants received funding to include activities designed to close the gap in services for this population.

For more information, see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=169#result
- https://nadrc.acl.gov/details?search1=20210225025851#result

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

(ONGOING) Action 2.H.3: Adapt care provision strategies for Tribal members during the COVID-19 pandemic

Lead Agency: IHS

IHS's Tribal, and UIH programs rapidly shifted care from in-person to telephone and video-based visits to limit risk of exposing 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 to limit risk of exposure to COVID-19. The collaborative also 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.

(ONGOING) Action 2.H.4: Review and report on federal programs and initiatives aimed at decreasing health disparities in Alzheimer's disease and related dementias

Lead Agency: ASPE, CMS

ASPE convened federal partners and inventory completed and ongoing programs and initiatives to address racial and ethnic disparities in clinical care, research, LTSS, public awareness, and risk burden for people with dementia. ASPE provided a report on this inventory on its website in 2022 and presented findings at the July 2022 Advisory Council meeting.

For more information, see:

- https://aspe.hhs.gov/reports/federal-efforts-address-adrd-disparities

CMS continues to refine its Mapping Medicare Disparities Tool, a starting point to help understand racial and ethnic differences in health outcomes by population (including dementia) and geography.

For more information, see:

- https://data.cms.gov/tools/mapping-medicare-disparities-by-population

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(ONGOING) Action 2.H.5: Improve detection, diagnosis, and care for Alzheimer's disease and related dementia in Tribal health systems

Lead Agency: IHS

IHS initiated the Alzheimer's Grants Program with an initial cycle of funding was announced in May 2022. Funding will be awarded as cooperative agreements to Tribal and UIH programs and as program awards to IHS facilities working in close coordination with the tribes they serve. Awardees will develop comprehensive and sustainable approaches to address AD/ADRD, including detection, diagnosis, assessment, management, and support for caregivers, and will create best practice models for replication by others. The remaining funds will support these efforts with training and technical assistance in the detection, diagnosis, and management of dementia in primary care, support for caregivers, increased awareness and recognition of dementia in Tribal communities, and development of data resources using the clinical data available through the IHS.

For more information, see:

- https://www.ihs.gov/dccs/alzheimers/

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

People with AD/ADRD and their families and caregivers need support that go beyond the care provided in formal settings such as doctors' offices, hospitals, or nursing homes. Families and unpaid caregivers play a central role. Supporting people with AD/ADRD and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and helping to ensure 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 and Linguistically appropriate Education, Training, and Support Materials

Caregivers often report that they feel unprepared for some of the challenges of caring for a person with AD/ADRD; for example, caring for a person with sleep disturbances, behavioral changes, in need of physical assistance, or with advanced dementia can be an enormous challenge. Giving caregivers the information and training that they need in a culturally and linguistically appropriate 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 and linguistically appropriate materials, and distributing these materials widely to caregivers.

(UPDATED) Action 3.A.1: Distribute federally-developed educational materials

Lead Agencies: NIA, ACL
Partners: ADEAR, public partners

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 bimonthly email alert specifically on caregiving issues, and social media. See Action 1.E.2 for more information on ADEAR. NIA also operates several social media platforms to share federally-developed educational materials on AD/ADRD.

For more information, see:

- https://twitter.com/NIHAging
- https://www.facebook.com/NIHAging
- https://www.nia.nih.gov/health/about-adear-center
- 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. Dementia Training Resources for Professionals and Volunteers.
2. Emergency Preparedness Toolkit for People Living with Dementia.
3. Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia.
4. Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals.
5. Handbook for Helping People Living Alone with Dementia Who Have No Known Support.
6. Guide to Billing Codes for Dementia Services.

In addition to developing new resources each year, the NADRC also undertakes regular updates of existing resources to ensure that they are making available tools with relevant, current

information. The library of NADRC-developed 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/details?search1=151#result
- https://nadrc.acl.gov/details?search1=153
- https://nadrc.acl.gov/details?search1=155#result
- https://nadrc.acl.gov/details?search1=157#result
- https://nadrc.acl.gov/details?search1=169&result
- https://nadrc.acl.gov/details?search1=232#result

IA^2, a recipient of the HBI support, and NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities.

For more information, see:

- https://www.cdc.gov/aging/funding/hbi/index.html

Also see Action 1.E.3 for updates on the Caregiving and SCD infographics, and Action 1.E.3 for information on CDC's contribution to the Public Health Perspectives on the Family Care Gap textbook.

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

Lead Agency: AHRQ
Partners: NIA, VA

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 and to conduct a study on the services. The study was a randomized control trial of adults aged 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 a 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 was 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-aging
- https://digital.ahrq.gov/ahrq-funded-projects/examining-clinical-workflow-and-outcomes-integrating-health-information

NIA has supported initiatives to advance progress toward NIA AD/ADRD research implementation milestone 13.I, which calls for research on technology-based dementia assessment, care, and management. Most recently, NIA funded the Artificial Intelligence and Technology Collaboratories (AITC) at the end of FY 2021. These centers will serve as a national resource to promote the development and implementation of artificial intelligence approaches and technology to improve care and health outcomes for older Americans, including persons living with dementia and their care partners.

For more information, see:

- 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://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-009.html
- https://reporter.nih.gov/search/dCAsh6HZiEelEK8OJ4SWpA/projects?shared=true
- https://www.a2collective.ai/
- https://www.nia.nih.gov/research/milestones/dementia-care-and-impact-disease/milestone-13-i
- https://www.ohsu.edu/collaborative-aging-research-using-technology

NIA's SBIR/STTR team has also funded several projects that have become commercial successes. For example, NIA funded the development of several platforms that have the potential to revolutionize the aging-at-home experience for older adults and caregivers. NIA funding also supported the development of devices, such as a wearable device that monitors activity and location to help with the proactive management of NPS of dementia and/or falls.

For more information, see:

- https://www.nia.nih.gov/research/sbir/nia-small-business-showcase/digital-health-sensing-technologies

NIA collaborated with ACL to issue a SBIR FOA that addresses the fundamental need for the development of technologies that enhance caregiver training and address the financial and legal aspects of caregiving. NIA and ACL published this funding opportunity to encourage and fund research and development of technology and tools for the currently under-developed market serving caregivers and their family members suffering from AD/ADRD. Through their collaboration, NIA and ACL funded seven awards in FY 2021 to stimulate research and development of technology and tools that adapt to a range of levels of expertise/experience, specific care demands, and needs of family caregivers.

For more information, see:

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-025.html

In May 2022, NIA convened an exploratory workshop, Gaps and Opportunities for Real-World Data Infrastructure. The workshop considered gaps that exist in current real-world data infrastructure and opportunities to expand the availability of real-world data sources for aging and AD/ADRD research. A meeting summary is forthcoming.

For more information, see:

- https://www.nia.nih.gov/gaps-opportunities-stakeholder-workshop

The VA Caregiver Center, located at the Memphis VA Medical Center and supported by the VA's Caregiver Support Program, implemented a supportive texting intervention for caregivers of veterans with dementia. Caregivers 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 occurred in March 2021. As of July 2022, over 800 caregivers of veterans have been enrolled.

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 in their home or other community settings, often the round-the-clock care needs of the person with AD/ADRD proves very challenging. 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 unpaid 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

Lead Agency: NIA
Partners: AHRQ, CMS, CDC, ACL, DoD

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 develop and test care interventions in real-world settings such as hospitals, assisted living facilities, nursing homes, and adult daycare centers. In general, a pragmatic clinical trial means that 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. To date, the Collaboratory has supported multiple pilot projects and career development awards for researchers from varied disciplines. The IMPACT Collaboratory continues to expand in 2022 with multiple career development and pilot and demonstration funding opportunities to support investigators interested in conducting Embedded Pragmatic Clinical Trials in health care systems, assisted living facilities, adult day programs, emergency departments, hospitals, home care, nursing homes, and other settings.

For more information, see:

- https://impactcollaboratory.org/
- https://impactcollaboratory.org/grants-program/pilot-grant-awardees/
- https://reporter.nih.gov/project-details/9774609

In 2019, 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. Specifically:

- University of Pennsylvania Roybal: Supports the development of interventions to help persons with dementia receive much-needed palliative care services, as well as to help their family caregivers.
- University of Rochester Roybal: Seeks to develop behavioral interventions that promote social connectedness, particularly among family caregivers of persons with AD/ADRD.
- Emory University Roybal: Supports the development of interventions to improve the role-mastery of informal caregivers of persons living with AD/ADRD.
- Oregon Roybal: Seeks to leverage innovations in technology to improve dementia care provider support.

Key publications can be found on the Roybal Science Advances website.

For more information, see:

- https://grants.nih.gov/grants/guide/RFA-files/RFA-AG-19-007.html
- https://reporter.nih.gov/search/m-zoWEyxzkOMTlkCABpxEw/projects?shared=true
- https://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translational-research-behavioral-and-social-sciences-aging
- https://www.roybalniaresearchcenters.org/
- https://www.roybalniaresearchcenters.org/publications

In 2021, NIA awarded three AITCs for Aging Research: Johns Hopkins University, University of Massachusetts Amherst, and University of Pennsylvania. The AITCs have pilot cores that will support projects to develop, validate, and disseminate innovative artificial intelligence technology for monitoring persons living with AD/ADRD in their home and community settings and enhance connections between older adults, care partners, and clinicians. The AITCs will serve as a national resource to promote the development and implementation of artificial intelligence approaches and technology through demonstration projects to improve care and health outcomes for older Americans, including persons living with dementia and their care partners.

For more information, see:

- https://aitc.jhu.edu/
- https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-21-009.html
- https://massaitc.org/
- https://www.a2collective.ai/
- https://www.pennaitech.org/

In addition to these activities, NIA released several FOAs 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. Two specific funding opportunities (PAR-21-307 and PAR-21-308) emphasize research that improves rigor and real-world applicability across broad and diverse populations. These include Dementia Care and Caregiver Support Interventions Research, to lay the groundwork for implementable interventions, and Pragmatic Trials for Dementia Care and Caregiver Support, which seeks phased award applications for dementia care pragmatic trials in multiple settings.

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/par-20-266.html
- https://grants.nih.gov/grants/guide/pa-files/par-21-099.html
- https://grants.nih.gov/grants/guide/pa-files/par-21-100.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-307.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-308.html
- https://grants.nih.gov/grants/guide/pa-files/par-22-105.html

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-106.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-109.html
- https://www.nia.nih.gov/health/alzheimers/caregiving

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. As of 2022, ACL has funded a total of 167 AD/ADRD community-based projects, in support of people living with dementia and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 167 are six Tribal entities which applied for and received funding beginning in 2020.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Subject to appropriations, ACL anticipates continuing the programs 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 support the implementation of 20 evidence-based interventions, preparing some to be taken to scale across the Nation. For example, NIA funded the research behind interventions BRI Care Consultations, COPE, Powerful Tools for Caregivers, REACH Community, and most recently Cognitive Stimulation Therapy which are ACL-funded provider pilot programs that enable formal and informal caregivers and people living with dementia to benefit from the intervention. The NADRC developed and regularly updates a compendium resource that consists of a list of evidence-based and evidence-informed interventions that meet ACL criteria and have been implemented by ADSSP, ADI-SSS, and ADPI grantees between 2007-2022.

For more information, see:

- http://nadrc.acl.gov
- https://nadrc.acl.gov/details?search1=140#result
- https://nadrc.acl.gov/details?search1=222
- https://nadrc.acl.gov/details?search1=223

The U.S. Department of Defense (DoD) -- CDMRP PRARP 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, combines two behavioral interventions, REACH 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 is being conducted by investigators at the VA Caregiver Center at the Memphis VA Medical Center, which is funded by the VA's Caregiver Support program, and investigators at Virginia Commonwealth University and University of Virginia.

CDC has also developed guidance and numerous documents for the public to help protect persons with dementia and their caregivers from COVID-19. This guidance addresses how both paid and unpaid 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/assisted-living.html
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/memory-care.html
- https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-home-long-term-care.html

- https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html

CDMRP PRARP prioritizes research in the caregiver space, particular for caregivers of veterans with dementia in the individual, family, and care support focus area. Some recent interventions funding include trialing updates to the EMMA (Electronic Memory and Management aid, formally known as the Digital Memory Notebook) App in individuals with AD/ADRD and their caregivers. In addition, the PRARP has funded projects in comparative efficacy of telehealth-delivered quality of life care coordination for persons with dementia and their care partners.

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

Lead Agency: ACL

ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. 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. As of 2022, ACL has funded a total of 167 AD/ADRD community-based projects, in support of people living with dementia and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 167 are six Tribal entities which applied for and received funding beginning in 2020.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Subject to appropriations, ACL anticipates continuing the programs to increase the availability of evidence-based interventions across the country.

For more information, see:

- https://nadrc.acl.gov/details?search1=140#result
- https://nadrc.acl.gov/details?search1=20210907025132
- https://nadrc.acl.gov/details?search1=222
- https://nadrc.acl.gov/details?search1=223

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

Lead Agency: ACL
Partners: IHS, CMS

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 OAA 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 [NICOA]). 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-appropriate AD/ADRD training and education to Indian Country. Since its inception in 2020, six tribes have applied for and received 3-year awards.

(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

Lead Agency: ACL
Partners: private partners

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.

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

Lead Agency: ACL
Partner: CMS

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.

For more information, see:

- https://nadrc.acl.gov/details?search1=20210907025132
- https://nadrc.acl.gov/details?search1=222
- https://nadrc.acl.gov/details?search1=223

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

Lead Agency: IHS
Partners: ACL, VA, University of Tennessee Health Sciences Center

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 implementing strategies to increase penetration of REACH in the communities where there are certified coaches and building additional, sustainable options for evidence-based caregiver support services. IHS continues work developing the Extension for Community Healthcare Outcomes project 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 training targeted at Public Health Nurses who provide support for caregivers of persons living with dementia.

In 2020, ACL-funded grantees to train REACH-certified caregiver support coaches to deliver the intervention to Aleutian Pribilof Islands Association members. The grantee provides health services (primary care, behavioral health, community wellness, and prevention) in four communities (Atka, Nikolski, St. George, and Unalaska) across the Aleutian and Pribilof Islands.

For more information, see:

- https://www.apiai.org/
- 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

Lead Agency: CDC
Partner: ACL

CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency department 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, developing 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/aging/publications/podcasts.htm
- https://www.cdc.gov/features/caregivers-month/index.html

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.
4. Guide to Billing Codes for Dementia Services.

For more information, see:

- https://nadrc.acl.gov/
- https://www.nia.nih.gov/health/alzheimers/caregiving

(ONGOING) Action 3.B.8: Support enhanced financial literacy and preparedness of family caregivers

Lead Agency: ACL
Partners: private partners, NIA

Family caregivers often lack adequate information and resources to properly manage the financial concerns of their loved ones. In 2018, ACL introduced a new program to address the need to advance understanding financial literacy of family caregivers. The ongoing program addresses that need through the development and testing of new interventions, as well as identification and dissemination of best practices.

See Action 3.A.2 for information on an NIA/ACL SBIR FOA that addresses the fundamental need for the development of technologies that enhance caregiver training and address the financial and legal aspects of caregiving.

(ONGOING) Action 3.B.9: Provide caregivers of veterans living with dementia with information about Department of Veterans Affairs Caregiver Support Program resources available to them

Lead Agency: VA

CSP offers multiple activities, education, tools, and resources that are geared towards all caregivers, and can provide specific information and support to caregivers of veterans living with dementia. The CSP website connects caregivers to diagnosis specific tools and handouts, and the following resources are examples of what CSP provides:

- REACH-VA -- intervention delivered directly to the caregiver 1:1 or via telephone groups.
- Caregiver Support Line -- clinical staff to connect caregivers to resources and staff for coordination; monthly presentations (live and recorded) and handouts.
- Building Better Caregivers -- workshops to help the caregiver manage challenging emotions, self-care, stress, etc.
- Peer Support Mentoring (PSM) -- peer support, as well as monthly PSM/Spirituality Calls.
- Caregiver Resources by Topic.
- National Family Caregivers Month -- local CSP Teams may offer dementia-related focused topics, speakers, activities.

For more information, see:

- https://www.caregiver.va.gov/
- https://www.caregiver.va.gov/help_landing.asp
- https://www.caregiver.va.gov/Publications_Resources_Topic.asp
- https://www.caregiver.va.gov/Publications_Resources_Topic.asp#Understanding%20Diagnoses
- https://www.caregiver.va.gov/support/Communicating_Managing_Emotions.asp
- https://www.caregiver.va.gov/support-line/handouts.asp
- https://www.caregiver.va.gov/support/New_CSC_Page.asp

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.

(ONGOING) Action 3.C.1: Empowering people to make better informed health care decisions

Lead Agency: CMS

CMS's Care Compare provides 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 nursing homes, home health, hospice, hospitals, and other provider types, as well as staffing information in nursing homes.

For more information, see:

- https://www.medicare.gov/care-compare/

(ONGOING) Action 3.C.2: Expand availability of care planning tools for people with dementia

Lead Agency: CDC

CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency department 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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(UPDATED) Action 3.C.3: Model future expenditures on long-term services and supports and use of informal caregivers

Lead Agency: ASPE

As the United States population ages, a larger proportion of individuals will likely need and use LTSS. Much of this support is provided by informal (i.e., unpaid) caregivers. For those that need paid LTSS, most Americans pay out-of-pocket. Some people may do so until their personal resources are completely exhausted, and then rely on the Medicaid program, which differs from where benefits and eligibility vary from state to state. Reliance on Medicaid for people with little income or limited assets may result in increased federal and state spending for LTSS. As such, there is a pressing need to understand the current cost of long-term care, national expenditures on LTSS, and future projections of the availability of unpaid caregivers. This project will build off previous ASPE work modeling LTSS needs and expenditures, as well as work that explores how key demographic changes will affect the supply of informal caregivers for older Americans. One of the primary goals of the project is to provide current and improved estimates of the value of informal caregiving and diversity in caregiving provision, as well as projections that show how changing demographics could affect older Americans' need for LTSS, the supply of future caregivers, and Medicaid spending. In addition, future work will consider the impacts of potential policy changes regarding LTSS benefits, including three reform proposals designed to address the need for, and costs of, LTSS: the Washington State Long-Term Care Trust Act, the Well-Being Insurance for Seniors to be at Home Act, and the Medicare Long-Term Care Services Supports Act of 2022.

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, among others, in these facilities. State licensing agencies may investigate complaints of abuse in other types of facilities, such as assisted living. State long-term care ombudsmen 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.

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

Lead Agency: CMS
Partners: ACL, NORC

CMS's National Partnership to Improve Dementia Care in Nursing Homes has a mission to deliver health care that is person-centered, comprehensive and interdisciplinary with a specific focus on protecting residents from being prescribed antipsychotic medications unless there is a valid, clinical indication and a systematic process to evaluate each individual's need.

For more information, see:

- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes
- https://store.samhsa.gov/product/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/PEP19-INAPPUSE-BR

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 funds to conduct activities that support and protect nursing home residents. This program builds on other CMS initiatives such as the National Partnership.

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

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

Lead Agency: ACL
Partners: private partners

ACL continues to expand awareness and detection of elder abuse and neglect among the population of people with dementia. ACL encourages 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.

In 2021, the NADRC hosted a webinar entitled Elder Abuse in People Living with Dementia: Prevention, Detection, and Intervention, in which a physician and an attorney discussed indicators that should raise concern, provided practical tips on when and how to intervene, and pay particular attention to the complicated issue of capacity.

For more information, see:

- https://nadrc.acl.gov/details?search1=20210719034914#result
- https://ncea.acl.gov/

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

Lead Agency: ACL
Partners: NIA, DoJ, private partners

ACL, NIH, and the U.S. Department of Justice (DoJ) have funded research focused on the abuse, neglect, and exploitation of older adults. HHS will work with the private sector to translate these findings into educational materials and resources, as well as other intervention programs related to the abuse of people with AD/ADRD.

ACL continues to fund programs designed to address elder abuse. The National Center on Elder Abuse 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* and web page, to educate the public and disseminate information about identifying and addressing types of elder abuse and dealing with caregiver stress.

For more information, see:

- https://www.nia.nih.gov/health/infographics/spotting-signs-elder-abuse

NIA is also currently supporting new research in this area via recent FOAs. For example, NIA published RFA-AG-22-024 (Primary Care-Based Screening and Intervention Development for Prevention of Abuse in Older and Vulnerable Adults in the Context of AD/ADRD) in 2021, which solicited research that can lead to the development of evidence-based primary care screening tools and behavioral interventions to prevent abuse in at-risk older and vulnerable adults with MCI and AD/ADRD and their families. With RFA-AG-22-020 (Triadic Interactions in Clinical Encounters Involving People with AD/ADRD, Clinicians, and Care Partners) and RFA-AG-20-006 (Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships [R01 Clinical Trial Optional]), NIA invited research on clinician screening tools for abuse and behavioral interventions for unhealthy caregiving relationships. NOT-AG-20-039 (Notice of Special Interest: Fundamental and Translational Research on Decision Making in Aging and/or AD/ADRD) invited research focused on social and other factors that render older adults vulnerable to financial exploitation and other forms of mistreatment and abuse. NIA is also soliciting research on risk, protective, and resilience factors related to elder mistreatment via NOT-AG-21-047 (Notice to Specify High Priority Research Topic for PAR-19-070 and PAR-19-071).

In 2022, NIA also released a funding opportunity to establish a network to develop better measures of decision capacity in individuals with cognitive impairment and to help identify opportunities to intervene at earlier stages and teach skills that would directly enhance the current level of decision making quality or provide support to establish safeguards against fraud or facilitate programs to establish power of attorney relationships to help extend the interval during which independence could be maintained.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-039.html
- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-047.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-020.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-024.html

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-007.html
- https://www.nia.nih.gov/health/elder-abuse
- https://www.nia.nih.gov/health/infographics/spotting-signs-elder-abuse

DoJ launched a guardianship page on the Elder Justice Initiative (EJI) website in July 2021 for the general public, providing information and resources related to guardianship itself and to abuse perpetrated by guardians. The web page features four sections: an overview, least restrictive options, key concepts and resources, and mistreatment and abuse by guardians and other fiduciaries.

For more information, see:

- https://www.justice.gov/elderjustice/guardianship

DoJ's National Institute of Justice (NIJ) maintains a web page 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/financial-exploitation-elderly
- https://nij.ojp.gov/topics/articles/overview-elder-abuse

The EJI website hosts the Elder Abuse Resource Roadmap dedicated to identifying where to report financial exploitation in addition to information resources on a variety of financial exploitation topics. The website also hosts an elder justice research web page featuring foundational articles, some of which address elder abuse and dementia.

For more information, see:

- https://www.justice.gov/elderjustice
- https://www.justice.gov/elderjustice/foundational-articles
- https://www.justice.gov/elderjustice/research-related-literature
- https://www.justice.gov/elderjustice/roadmap

In addition, EJI's renowned webinar series features several webinars on this topic presented by elder justice experts:

1. The Neuroscience Behind Financial Scams.
2. Responding to Elder Abuse Victims with Alzheimer's Disease or Other Dementias.
3. Increasing Access to Capacity Assessments via New Technologies.
4. Digging Deeper: When Consent is Not Consent.
5. Assessing Cognitive Capacity in Elder Abuse Cases.
6. Innovations in Guardianship: Maximizing Autonomy and Ensuring Accountability.
7. Identifying and Prosecuting Power of Attorney Abuse.
8. Trauma Informed Counseling for Older Adults.
9. Innovations in Guardianship: Maximizing Autonomy and Ensuring Accountability.

For more information, see:

- https://ovcttac.adobeconnect.com/px6tzz3q5y94/
- https://www.justice.gov/elderjustice/video/assessing-cognitive-capacity-elder-abuse-cases
- https://www.justice.gov/elderjustice/video/digging-deeper-when-consent-not-consent
- https://www.justice.gov/elderjustice/video/identifying-and-prosecuting-power-attorney-abuse
- https://www.justice.gov/elderjustice/video/innovations-guardianship-maximizing-autonomy-and-ensuring-accountability
- https://www.justice.gov/elderjustice/video/neuroscience-behind-financial-scams

- https://www.justice.gov/elderjustice/video/responding-elder-abuse-victims-alzheimer-s-disease-or-other-dementias
- https://www.justice.gov/elderjustice/video/trauma-informed-counseling-older-adults

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

DoJ's Office for Victims of Crime launched the Elder Fraud Hotline in March 2020. This no-cost national resource is available to all older adults who may be victims of financial fraud. The hotline (1-833-FRAUD-11; 1-833-372-8311) is staffed with experienced case managers who provide personalized support to assist callers in reporting suspected fraud to the relevant agencies and offer resources and referrals to other appropriate services as needed.

For more information, see:

- https://ovc.ojp.gov/program/stop-elder-fraud/providing-help-restoring-hope

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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

Lead Agency: ACL
Partners: NLRC, legal assistance developers

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.

The NADRC partnered with the American Bar Association 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:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/node/137
- https://ncler.acl.gov/

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

Lead Agency: DoJ
Partner: ACL

DoJ continues to educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD and to provide current information and resources to help law enforcement agencies and the communities they serve. This education includes 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 DoJ Office of Justice Programs' Bureau of Justice Assistance.

ACL grantees are using grant funds to engage with and train 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". Another grantee has developed Gun Violence Restraining Order training and partnered with the Deputy City Attorney for its delivery. The NADRC website is home to a number of grantee-developed training materials and other resources dedicated to bringing dementia capability for first responder agencies. ACL ADPI grantees consistently include first responder education in their funded programs. Recent advances include efforts to engage and train Tribal law enforcement in dementia education, through ACL's Dementia Capability in Indian Country grantee efforts.

For more information, see:

- https://nadrc.acl.gov/
- https://www.youtube.com/playlist?list=PLyUU5QfNKxwhm7NTgcmUGUsfKxs_qCb20

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 AD/ADRD. For example, EJI currently hosts relevant resources on the law enforcement web page, including:

1. Safe Return: Alzheimer's Disease Guide for Law Enforcement (Alzheimer's Association).
2. A Booming Problem: Alzheimer's, Dementia, and Elder Abuse (DoJ Office of Community Oriented Policing Services).
3. Approaching Alzheimer's: First Responder Training Program (Alzheimer's Association).
4. Communicating with Someone with Dementia (Alzheimer's Association).

For more information, see:

- 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
- http://www.alz.org/national/documents/SafeReturn_lawenforcement.pdf
- https://www.justice.gov/elderjustice/law-enforcement-1

In August 2022, EJI released Safe Accessible Interviewing for Older Adults (SAFE), developed to meet the growing need for victim-centered interview techniques for use with older adults in criminal contexts. SAFE is grounded in forensic interviewing best practices with considerations and adaptations to account for age-related changes, with particular attention to the nuance of interviewing individuals living with AD/ADRD.

For more information, see:

- https://www.justice.gov/elderjustice/safe-training

On April 19-21, 2022, EJI convened a groundbreaking virtual symposium entitled *Elder Justice Decision-Making Capacity Symposium: The Role of Decision-Making Capacity in Elder Justice Cases that Reach Civil and Criminal Courts*, attended by over 1,500 individuals from every state in the Nation. The symposium was designed to raise awareness of how older adults are profoundly and negatively impacted in both the criminal and civil justice systems based on mistaken assumptions and inadequate assessments of their capacity to make decisions for themselves. The session recordings and relevant resources are available on the symposium web page. An article summarizing the symposium specifically for law enforcement entitled *Elder Justice Decision-Making Capacity Symposium: Capacity for What?* is also featured on the page.

For more information, see:

- https://cops.usdoj.gov/html/dispatch/06-2022/Elder_Justice_Symposium.html
- https://www.justice.gov/elderjustice/symposium

In April 2022, EJI released the Judicial Guardianship Evaluation Worksheet, intended for judges and other court personnel. Probate judges are routinely required to make determinations regarding an individual's capacity and where appropriate, to appoint a guardian to protect individuals who are unable to make decisions on their own behalf or are unable to manage their personal needs to support their welfare. Designed to assist judges in making these determinations, the Worksheet was developed over 2 years with input from and testing by judges. The Worksheet is an evidence-based two-page fillable and printable PDF that provides judges with an organizational framework of the relevant factors to consider in adjudicating guardianship cases. The tool also helps judges consider less-restrictive alternatives and weigh factors which can forewarn abuse in guardianship prior to appointment. In June 2022, the developer was featured on a webinar titled Judicial Guardianship Evaluation -- A New Tool for Judges describing the Worksheet's development and how to use it.

For more information, see:

- https://vimeo.com/722938044
- https://www.justice.gov/elderjustice/help-judges-hearing-guardianship-cases

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

Lead Agency: ACL
Partners: DoJ, CDC

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 is 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/details?search1=155#result
- https://nadrc.acl.gov/details?search1=196#result
- https://www.youtube.com/playlist?list=PLyUU5QfNKxwhm7NTgcmUGUsfKxs_qCb20

EJI's Multidisciplinary Team (MDT) Technical Assistance Center 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

CDC recently launched the Healthy Brain Resource Center (HBRC), an easy-to-navigate website that helps users find credible public information and materials to support implementing the HBI Road Map actions. The CDC and its partners designed the HBRC to help state, local, Tribal, public health agencies and other organizations have easy access to resources and materials to help people with AD/ADRD better utilize the HBI Road Map Series. The HBRC will continue to be updated with new and additional resources over the next 2 years.

For more information, see:

- https://www.cdc.gov/aging/healthy-brain-resource-center/index.html

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(ONGOING) Action 3.D.7: Understand the predictors and outcomes of inpatient psychiatric facility placement among people living with dementia

Lead Agency: ASPE

Some people with dementia may have severe behavioral and psychological symptoms of dementia (BPSD) such as aggression, agitation, depression, or psychosis. These symptoms are associated with hospital admission and nursing home placement in addition to caregiver distress and poor health. In some cases, individuals with BPSD require intensive care and are admitted to an inpatient psychiatric facility (IPF). Previous ASPE analyses found that dementia is a common diagnosis in IPFs. In 2008, 15% of Medicare beneficiaries receiving care from an IPF had a primary diagnosis of AD/ADRD and 25% had any AD/ADRD diagnosis. However, little is known about the care settings and events that proceed an individual's transition to, and from, an IPF. Most Medicare beneficiaries receiving care from an IPF also received care from an inpatient setting or emergency department in the 30 days preceding their IPF admission. Readmissions after an IPF stay are common.

There are anecdotal reports about poor care experiences prior to being admitted to an IPF, or during a stay. While CMS publicly displays information on certain quality measures under the Inpatient Psychiatric Facility Quality Reporting Program on its Care Compare website, more analysis is needed on how often, and under what conditions, people with dementia are going to IPFs, including how often they are admitted to IPFs from nursing homes. Similarly, little is known about the long-term care settings where people with dementia go following an IPF stay. The purpose of this ASPE study is to analyze CMS Medicare fee-for-service (FFS) data to understand the characteristics of Medicare beneficiaries with and without dementia who use IPFs, the diagnoses and service utilization that precede psychiatric inpatient stays, and the outcomes, including health care utilization and mortality, following a stay.

(ONGOING) Action 3.D.8: Develop a Supported Decision-Making Model as an alternative to guardianship

Lead Agency: ACL

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 SDM 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/

Strategy 3.E: Assess and Address the Long-Term Services and Supports Needs of People with Alzheimer's Disease and Related Dementias

LTSS are essential to helping people with AD/ADRD receive the assistance that they need. HCBS help people with AD/ADRD remain in their homes in the community, where many prefer to be. For those who need additional support, a residential care or nursing facility may be a better fit. Through the actions below, HHS will assess the availability and quality of services across residential settings to ensure all people with AD/ADRD receive the care they need in the setting they prefer.

(COMPLETED) Action 3.E.1: Understand contributing factors to and policy implications of nursing facility closures

Lead Agency: ASPE

In Spring 2022, ASPE completed 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. ASPE identified a total of 1,220 closures and 1,168 openings from 2011 to 2019. Closures were relatively stable from 2011 to 2017, averaging 121 facilities or 0.82% per year. Closures increased to 172 facilities (1.15%) in 2018 and 200 facilities (1.36%) in 2019. Openings decreased from 2011 to 2019, averaging 135 facilities (0.91%) per year from 2011-

2018 and then dropping to 87 facilities (0.59%) in 2019. The resulting impact on individual-level access to nursing homes is less clear. In the aggregate, the nursing home supply may be appropriately meeting demand; however, there may be cases where closures could cause immediate access problems. ASPE is currently extending the study to include years after 2019 to determine if the COVID-19 pandemic was a major contributor to closures.

(ONGOING) Action 3.E.2: Determine progress made in rebalancing Medicaid long-term care toward home and community-based services among older adults

Lead Agency: ASPE

Through this project, launched in Fall 2021, ASPE is assessing the extent to which states have "rebalanced" Medicaid-funded LTSS from institutional LTSS to HCBS between 2015 and 2019. Analyses will use Transformed Medicaid Statistical Information System (T-MSIS) data to examine Medicaid LTSS expenditures that went toward HCBS and nursing facility care, as well as the use of both settings among all Medicaid LTSS users and various subgroups (e.g., older adults, younger adults with adult-onset disabilities, and individuals with IDD). Analyses will involve identifying characteristics of state LTSS programs that correlate with greater rebalancing toward HCBS and calculating transition rates from the community to nursing facilities among older adults. This project will also examine patterns of transition from the community to long-stay nursing home care over a 3-year period, controlling for use of HCBS to gauge whether some states' use of HCBS appears to be more effective than others in preventing or postponing long-stay nursing home admissions.

In 2022, CMS announced a $25 million award in planning grants to five new states and territories, to expand access to HCBS through Medicaid's "Money Follows the Person" (MFP) demonstration program. With the new awards, 41 states and territories will now participate in MFP, increasing access to community-based care for people in the setting of their choice.

For more information, see:

- https://www.cms.gov/newsroom/press-releases/hhs-expands-home-and-community-based-services-five-new-states-and-territories-older-adults-and

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(ONGOING) Action 3.E.3: Measure differences in medical and long-term care use and expenditures of older adults over time

Lead Agency: ASPE

Newly available data linkages between Medicaid T-MSIS (which includes both FFS claims and managed care encounter data), Medicare Advantage encounter data, and the NHATS longitudinal data present an opportunity for researchers to learn more about the medical and long-term care service use patterns and patient outcomes of older Americans with complex care needs, and to evaluate the effectiveness of interventions and services. This ASPE project follows Medicare-Medicaid dual eligible and Medicare-only respondents of the NHATS over the period of 2015-2019, to measure differences in medical and long-term care use and expenditure patterns over time. The analyses will have two separate but related focal points: (1) the impact of growth in enrollment in Medicare and Medicaid managed care plans on acute and long-term care service use patterns for both Medicare-only and Medicare-Medicaid dual eligible older adults (aged 65+); and (2) factors associated with older adults, both Medicare-only and dual eligible, transitioning from the community to long-stay nursing home care that may potentially be subject to policy interventions (e.g., supports for family caregivers).

(ONGOING) Action 3.E.4: Strengthen states' ability to provide and sustain dementia-capable home and community-based services

Lead Agency: ACL

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/details?search1=117#result

(UPDATED) Action 3.E.5: Fill service gaps in dementia-capable systems by expanding the availability of specialized services and supports to target previously under-served populations

Lead Agency: ACL
Partner: CMS

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.

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. As of 2022, ACL has funded a total of 167 AD/ADRD community-based projects, in support of people living with dementia and their caregivers, including training professionals, since 2014 when funding was expanded beyond states. Included in the 167 are six Tribal entities which applied for and received funding beginning in 2020.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Subject to appropriations, ACL anticipates continuing the programs to increase the availability of evidence-based interventions across the country.

For more information, see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20210907025132
- https://nadrc.acl.gov/details?search1=222
- https://nadrc.acl.gov/details?search1=223

(UPDATED) Action 3.E.6: Improve home and community-based services provided through state Medicaid waivers

Lead Agency: CMS

In 2022, CMS notified states they have an additional year -- through March 2025 -- to use funding from the American Rescue Plan to enhance, expand, and strengthen Medicaid HCBS, promoting community living for older adults and people with disabilities, including people with dementia.

For more information, see:

- https://www.medicaid.gov/federal-policy-guidance/downloads/smd22002.pdf

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(ONGOING) Action 3.E.7: Expand resources to support person-centered care

Lead Agency: ACL

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. In May 2021, the NADRC and the NCAPPS partnered on a webinar entitled Person-Centered Goal Discovery for People Living with Dementia. The webinar presented foundational person-centered principles and provided examples of how to plan for people who are living with dementia in the community and other settings.

For more information, see:

- https://nadrc.acl.gov/details?search1=20210708100209#result
- https://ncapps.acl.gov/home.html

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 both to delayed diagnosis, and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is essential because it forms the basis for advancing the other goals of the National Plan. A better understanding of AD/ADRD will help engage stakeholders who can work to 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

Lead Agencies: ACL, NIA, CDC
Partners: multiple cross-agency and funded partners

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.

For more information, see:

- https://nadrc.acl.gov

NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. See Action 1.E.2 for more information about ADEAR.

In 2020, NIA, working with other federal agencies, led efforts to update and enhance the Alzheimers.gov website. NIA launched this new portal to Federal Government information and resources in February 2021. The site features:

- Information about AD/ADRD.
- Tips and resources for caregivers and people living with dementia.
- Updates on Federal Government activities to address AD/ADRD.
- How to take part in clinical research and how to find studies.
- Resources for health care providers, community and public health workers, and researchers.

In October 2021, NIA also launched a Spanish version of the Alzheimers.gov website.

For more information, see:

- https://www.alzheimers.gov/
- https://www.alzheimers.gov/es
- https://www.nia.nih.gov/news/alzheimers-gov-website-now-available-spanish

CDC's Alzheimer's Disease Program publishes web features, a series of podcasts, weekly newsletters to more than 45,000 subscribers, and social media to more than 27,000 followers with the goal of increasing awareness and engagement by the public and its stakeholders about AD/ADRD. Web features for 2021-2022 include the following, most of which are also available in Spanish:

1. **Web Features**
    - Dementia Risk Reduction (June 2022)
    - Memory Loss Among Caregivers (May 2022)
    - Down Syndrome and Risk for Alzheimer's (September 2021)
    - Barriers to Equity in Alzheimer's and Dementia Care
    - Baby Boomers Who Are Caregivers Report Poor Health
    - Healthy Body, Healthy Brain
    - Loneliness and Social Isolation in Older Adults

2. **Podcasts** (Aging and Health Matters Series)
    - Modifiable Risk Factors for Alzheimer's Disease and Related Dementias
    - Memory Loss Among Caregivers
    - How Are You Feeling Right Now? Coping Strategies for Caregivers
    - Social Isolation and Loneliness Among Older Adults and What You Can Do to Help
    - Baby Boomers Who Are Caregivers Report Being in Poor Health
    - 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

For more information, see:

- https://podcasts.apple.com/us/podcast/ep38-cdc-highlights-social-isolation-loneliness-among/id1508046828?i=1000501704755
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/405188
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/406088
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/407659
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/412477
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/594685
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/730355
- https://solesourcepodcast.buzzsprout.com/789140/8142833-ep55-caring-for-caregivers-with-the-cdc
- https://www.cdc.gov/aging/publications/features/barriers-to-equity-in-alzheimers-dementia-care/index.html
- https://www.cdc.gov/aging/publications/features/caregivers-baby-boomers-report-poor-health/index.html
- https://www.cdc.gov/aging/publications/features/dementia-risk-reduction-june-2022/index.html
- 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/memory-loss-among-caregivers/index.html

Additionally, CDC provided communication guidance and technical assistance to all its funded partners.

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: baby boomers who are caregivers, brain health, memory loss, chronic conditions in relation to memory loss, and how dementia disproportionately effects minority populations and women.

CDC is taking steps to proactively address issues arising from COVID-19 affecting persons with dementia and their caregivers. CDC's Alzheimer's Disease Program developed a dedicated COVID-19 web page highlighting CDC's COVID-19 guidance for older adults. Since its launch, there have been over 10,000 page views. 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. The Alzheimer's Disease Program disseminates a weekly newsletter to more than 45,000 subscribers. It is a primary channel for disseminating information about COVID-19 web updates and webinars. The Alzheimer's Disease Program continues to provide older adult Subject Matter Experts to the COVID-19 pandemic response in CDC's Emergency Operations Center.

For more information, see:
- https://www.cdc.gov/aging/covid19-guidance.html
- https://www.cdc.gov/aging/index.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 from COVID-19. CDC is also collaborating on several projects to reduce social isolation and maintain mental health among older adults. CDC works closely with the CDC Foundation and other partners to ensure that disproportionately impacted communities receive the resources and technical assistance necessary to provide COVID-19 related services to older adults.

In 2020, NIA, ACL, CDC, and HRSA revived and expanded the annual Focus on Aging: Federal Partners' webinar series. The series, which addresses important topics for public health and health care professionals, aging services organizations, the research community, and other stakeholders in aging, now features approximately three webinars per year and encompasses new federal partners. In addition to general topics of interest for older adults and those who work with them, each webinar includes information specific to individuals with AD/ADRD and their caregivers. All prior webinars are made available to the public on the Focus on Aging: Federal Partners' Webinar Series website.

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

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

Lead Agency: CDC
Partners: private partners

Since 2019, CDC has translated the national caregiving and SCD infographics into Spanish and develop corresponding infographics for Black, AI/AN, AAPI, Hispanic, and LGBT individuals, as well as women, men, residents of rural areas, 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/agingdata/index.html
- https://www.cdc.gov/aging/data/index.htm

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.

The 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 National Association of Chronic Disease Directors (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. These briefs are currently being updated.

For more information, see:

- https://www.cdc.gov/aging/publications/briefs.htm

CDC also supported the Alzheimer's Association to develop the *Needs Assessment Toolkit: 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 so as to enhance their ability to gather and use information specifically related to AD/ADRD.

Also see Action 1.E.3 for information on resources developed using BRFSS data.

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

Lead Agency: ASPE
Partners: CDC, NIH/NIA, ACL, CMS, HRSA, AHRQ, IHS, SAMHSA, OASH, VA, NSF, DoD

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.

(NEW) Action 4.B.2: Convene state and local partners

Lead Agency: ASPE

ASPE convened the Cities and States in Action Roundtable in July 2022. The Roundtable convened representatives from Chicago, Illinois, Washington State, Tennessee, Georgia, and Massachusetts to discuss their state and local efforts to address AD/ADRD. Presenters highlighted successful programs and partnerships in their states, such as the Engage-IL, which is leading the development of age-friendly and dementia-friendly communities in Chicago, and the Georgia Memory Network, which connects primary care providers, Memory Assessment Clinics, and AAAs in order to link people with potential cognitive impairment to services. The report, *An HHS Roundtable on 10 Years of the National Plan to Address Alzheimer's Disease: States in Action*", will be posted to the ASPE website and the NAPA Anniversary Page in late 2022.

For each more information see:

- https://www.hhs.gov/aging/napa/index.html
- https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plan#np-10th-anniversary

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(UPDATED) Action 4.B.3: Build upon lessons learned to improve the dementia-capacity of state and local service systems

Lead Agencies: ACL, CDC
Partner: CMS

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.

ADPI grantees, partners and other collaborators work in peer-led groups on specific activities to make state and local-level improvements related to dementia capability. The peer-led groups 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
- https://nadrc.acl.gov/details?search1=117#result

CDC BOLD program awardees are funded to create and maintain jurisdiction-wide coalitions to collaborate on setting AD/ADRD priorities informed by data for their area. The state and local jurisdictions of Colorado, Georgia, Los Angeles County, Maine, Mississippi, Nevada, Iowa, Oklahoma, Vermont, Wisconsin, and North Carolina have all created statewide AD/ADRD coalitions to guide strategic planning for people with AD/ADRD and their caregivers. The BOLD program awardees are all working on updating their statewide AD/ADRD plans to include a minimum of four actions from the *State and Local Public Health Partnership to Address Dementia: The 2018-2023 Road Map*. In the past year, Iowa, Los Angeles County, Maine, Mississippi, Nevada, Oklahoma, and Vermont worked with their coalitions to draft their updated state/local AD/ADRD strategic plans to include NIHB Road Map Actions. All of these BOLD programs will have final updated AD/ADRD strategic plans by the end of 2022.

The BOLD Center on Risk Reduction provided a technical assistance document with sample actions and activities that could be included in jurisdictional plans, as well as information on the scientific evidence and the potential public health impact for each risk factor.

For more information, see:

- https://www.alz.org/media/Documents/compiled-evidence-based-reports.pdf
- https://www.alz.org/professionals/public-health/public-health-approach/alz-association-efforts#phcoe

In the past year, the North Carolina BOLD program successfully completed their update of their state strategic AD/ADRD plan and North Carolina's Institute of Medicine's report at the end of March 2022. Revisions to the state plan include background on the BOLD initiative, a synopsis of current and planned BOLD activities, an explanation of the update process, and a new brain health chapter with recommendations and revisions to five existing recommendations from the 2016 plan. All four of the required HBI Road Map Actions were integrated into the new brain health chapter along with a fifth strategy related to brain health messaging. Each of these five overarching strategies includes a subset of additional strategies and recommendations for a total of 24 new HBI-guided recommendations. The updated plan has been published in an electronic format with plans to make print version available later in the year. Promotion and dissemination efforts have begun and will continue through the remainder 2022.

In the past year, BOLD program awardees have completed the following activities.

- The Iowa BOLD AD/ADRD program has partnered with local libraries across the state to promote AD/ADRD messaging via bookmarks, handouts, and posters with the catchphrase "Brains Love Bookworms!" that encourages people to keep their brain active through reading. The bookmarks, posters, and handouts were disseminated at the Iowa Library Conference and afterward Iowa AD/ADRD staff sent emails to every library in Iowa offering to send as many bookmarks, posters, and handouts as they requested to give to their community members. Additionally, the Iowa AD/ADRD program developed posters to address risk reduction and empowerment. Working with graphic designers, the posters are framed to encourage people of all ages to live a healthier lifestyle in order to decrease risk for dementia. The theme is "Alzheimer's prevention should always be on your brain" with a series of characters of different races and genders happily posing with items on their heads that represent activities they can do. They are intended to be displayed in doctors' offices, waiting rooms, senior centers, public gathering spaces, etc. The posters were finalized in late March 2022 with final printing and distribution happening in April.
- The North Carolina BOLD program produced a data brief using the SCD Module data from the BRFSS. The data brief was reviewed by staff at the North Carolina Department

of Public Health, North Carolina Department of Aging and Adult Services, and CDC. The data brief was disseminated to more than 20 partners and to many of their Listserv members. It was also posted on the North Carolina Center for Health and Wellness website and was included in a Healthy Aging North Carolina newsletter distributed to a network of over 300 professionals who care for people with aging-related health challenges.

- The Maine BOLD program worked with their HBI Stakeholder group to produce over 200 recommendations for the State Plan by adopting a coordinated approach to accomplish the task of revising and updating the 2012 State Plan. The group met over the course of a 6-month period in five subcommittees that each addressed a key topic: access to care and family caregivers, legal and safety issues, public awareness, research and data collection, and workforce development. The overall success of the process was associated with the high level of engagement of the stakeholders as demonstrated by additional work performed by subcommittee leadership after the process ended to condense, re-organize, and prioritize recommendations. The Alzheimer's Program and its evaluator, Public Consulting Group, are currently working on the next step of creating a framework for the recommendations and anticipate a fall release of the Maine AD/ADRD State Plan.
- In Vermont, the BOLD Public Health Analyst prepared their first data brief titled *Risk Factors for Subjective Cognitive Decline in Vermonters*. The data brief cross tabulates behavioral risk and demographic measures that assisted the program and stakeholders in gaining a deeper state-specific understanding of AD/ADRD, risk behaviors, brain injury and lifestyle behaviors. Development and release of this brief achieved two of their prioritized data goals -- communication of data to AD/ADRD partners and the public health workforce and to support data-driven decision making. Additionally, the brief lays the groundwork for forwarding AD/ADRD-related measures to the committee charged with honing the Healthy Vermonters 2030 State Plan, which will begin deliberating in late Spring 2022. Additionally, the Vermont BOLD program analyst produced and delivered several data presentations to the Alzheimer's and Healthy Aging Workgroup, followed by an interactive data presentation with the Governor's Commission on ADRD. A Health Disparities and Aging data presentation was delivered to the Vermont Action Plan on Aging Well Advisory Council in January 2022 and to our Hub & Spoke workgroup in February. This data presentation included the rate of hospitalizations and emergency department visits among Vermonters 65 years and older diagnosed with AD/ADRD (2016-2019).
- In Oklahoma, the BOLD program partnered with Oklahoma State Department of Health Communications for weekly social media content on Thursdays called Healthy Brain Tip of the Week. These posts began in November 2021 with the announcement of the Oklahoma Healthy Brain Program and National Caregivers Month. In November 2021 through February 2022, they reached 104,383 people on Facebook with their posts. In March, the focus of the month was the Caregiver Survey in which three posts were made. They saw an influx of survey responses immediately following these posts on Facebook, Instagram and LinkedIn.

(**ONGOING**) Action 4.B.4: 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

Lead Agencies: IHS, ACL
Partners: ASPE, VA

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, in collaboration with CDC, has started meetings with the United South and Eastern Tribes and with the NPAIHB. There has been increased Tribal representation on the CDC HBI *Road Map for Indian Country* work.

The IHS undertook Tribal Consultation and Urban Confer to gain insight into needs and opportunities to improve the care and services for AI/AN people living with dementia and their caregivers and guide the allocation of resources for the IHS Alzheimer's Grant Program.

(**ONGOING**) Action 4.B.5: Develop and update a public health road map for assisting state, Tribal, and local health departments in prioritizing actions

Lead Agency: CDC

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 was released in 2019 and disseminated to multiple stakeholders and Tribal leaders. This Road Map has been designed specifically for public health systems serving AI/AN 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

In Summer 2022, the Alzheimer's Association and CDC initiated the development of the next HBI Road Map for State and Local Public Health. This will be the fourth edition of the HBI Road Map Series, and will serve as an expert guidebook for state and local public health practitioners to advance the vision of the HBI: fully integrate cognitive health and caregiving into public health practice. Gathering input from multiple sectors remains a key feature of the development process to identify priorities, inform strategy, and support sustainable implementation and impact of the HBI Road Maps. Four methods are being used to engage, elicit input, and foster collaboration.

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 National Plan, HHS and its federal partners will coordinate with global partners to enhance these plans, avoid duplication of effort, and optimize existing resources.

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

Lead Agencies: ASPE, NIA

The United States participated in the World Health Organization'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.

See Action 1.D.2 for information on the HRS HCAP initiative, an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide.

HCAP is being fielded again in 2022. 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 2022. HCAP will provide extensive new data to better assess trajectories of cognitive decline. These data afford an unprecedented opportunity to describe trends more clearly in the incidence and prevalence of dementia around the world.

See Action 1.D.2 for information on administration of HCAP in other developed and developing countries. In most of these studies, important biomarker data, including DNA for genotyping and future sequencing, is also being collected; genotype information is already available for the United States, England, and Mexico studies.

See Action 1.D.2 for information on the HCAP network, which aims to develop international data resources for the study of AD/ADRD that will expand research opportunities to exploit cross-country variation in key life-course factors that likely affect cognitive function and the risk for AD/ADRD.

For more information, see:

- https://g2aging.org/
- https://hcap.isr.umich.edu/
- https://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.118334926.654419972.1601312536-181621991.1601312536
- https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology

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 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 people with dementia, 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 both 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.

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

Lead Agency: ASPE
Partners: CMS, CDC, NIA, ACL, VA, IHS

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.

CDC submitted an application for inclusion of subjective and objective measures of cognition for the 2024 National Health and Nutrition Examination Survey (NHANES). Additionally, a proposal was submitted to cognitively test caregiving questions for potential inclusion on the NHANES in 2024.

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

Lead Agency: ASPE
Partners: CDC, NCHS, NIA

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.

CDC, in partnership with the Alzheimer's Association, revised the cognitive decline module of the BRFSS with a series of expert panel meetings, presented the revised module to the BRFSS state coordinators in Spring 2022 and the revised module was approved for use in the 2023 survey as an optional module.

CDC, in partnership with the Alzheimer's Association, revised the caregiver module of the BRFSS with a series of expert panel meetings and submitted a proposal to the BRFSS coordinators for administration in the 2023 survey as an optional module.

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

Lead Agency: CDC

CDC continues to summarize and provide infographics from data on cognitive impairment across states. See 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.

To bolster data activities, CDC is supporting a large data modernization project that will result in better estimates of AD/ADRD in the United States through combining various data sources through modeling.

(ONGOING) Action 5.A.4: Summarize existing data on people with Alzheimer's disease and related dementias and their caregivers

Lead Agencies: CDC, ODPHP
Partners: ASPE, NCHS, NIA, ACL

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 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 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.3 for update on the caregiving and SCD infographics.

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

Lead Agency: CDC
Partner: NACDD

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. These briefs are in the process of revision in 2022-2023.

For more information, see:

- https://www.cdc.gov/aging/publications/briefs.htm

Strategy 5.B: Monitor Progress on the National Plan

The National Plan is intended to be a road map for accomplishing its six 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

Lead Agency: ASPE

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 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. Progress on each of these actions will be reported to the Advisory Council.

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

Lead Agency: ASPE

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.

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

Lead Agency: ASPE

ASPE convened federal partners to identify key indicators of progress on the National Plan. 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 with members of the NAPA Advisory Council.

(ONGOING) Action 5.B.4: Track decennial National Plan progress

Lead Agency: ASPE

HHS commemorated the 10th Anniversary of the National Plan in May 2022 through a series of publications and presentations highlighting HHS agencies' accomplishments in addressing AD/ADRD. HHS will continue to track accomplishments and use them to inform opportunities for expanding federal work to improve the trajectory of AD/ADRD research, care, and services.

See Appendix 2 for a list of milestones and achievements for the first 10 years of NAPA.

For each more information see:

- https://www.hhs.gov/aging/napa/index.html
- https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plan#np-10th-anniversary

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Goal 6: Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias

While there is currently insufficient evidence that dementia can be prevented, a growing body of research has identified modifiable risk factors for AD/ADRD and suggests that strategies to reduce the burden of these risk factors may delay onset or slow progression of AD/ADRD and its symptoms. The relationship between hypertension management and cognitive health is among the most robust studied; activities to address other potential risk factors for AD/ADRD include cognitive training and engaging in physical activity. These same activities to preserve cognitive health are also conducive to healthy aging overall. Evidence on the relationship between modifiable risk factors and the incidence of AD/ADRD is evolving, as is research on the effectiveness of interventions to reduce risk.

Under this Goal, the Federal Government will accelerate research on risk factors for AD/ADRD, and strengthen the infrastructure that is necessary to rapidly translate and disseminate information about risk factors, interventions to reduce the burden of risk factors, and related health promotion activities to health care providers, community-based providers, and public health networks.

The burden of risk factors for AD/ADRD is disproportionately high among certain racial and ethnic groups (e.g., Black, Hispanic, and AI/AN populations), and among adults with lower SES. These disparities in the prevalence of risk factors -- which are grounded in generations of structural racism and inequality in health care -- contribute to disparities in the incidence of AD/ADRD that are further amplified by disparities in AD/ADRD diagnosis, treatment, and access to care and resources. It is therefore of critical importance that research, interventions, and infrastructure to address modifiable risk factors for AD/ADRD are culturally responsive and grounded in improving equity by addressing the social determinants of health (SDOH). Accordingly, future efforts to reduce the burden of risk factors for AD/ADRD will focus on understanding not only what actions individuals can take to reduce their risks, but also what community and system-level investments are needed to facilitate risk reduction and support healthy aging.

Strategy 6.A: Identify Research Priorities and Expand Research on Risk Factors for Alzheimer's Disease and Related Dementias

While NIH has supported dementia risk reduction research for decades, identifying the priorities and milestones to achieve Goal 6 requires increased attention by the research community. Much of the current evidence on modifiable risk factors is low to moderate quality, so more research is needed to better understand the relationship between potential risk factors and AD/ADRD. The Actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders are involved in the planning process aimed at identifying and addressing modifiable risk factors. Through this work, NIH and partner agencies will develop research priorities and a plan for implementing each phase of research in a coordinated manner.

(**UPDATED**) Action 6.A.1: Enhance the focus on risk reduction in existing research summits

Lead Agencies: NIA, NINDS, NIH
Partner: CDC

Under Action 1.A.1, NIH convenes a series of annual research summits to address a wide range of critical research issues in AD/ADRD, including basic, translational, and clinical research, as well as research on care and LTSS. Gaps and opportunities identified by participants providing individual input at these summits are used to inform research planning at the NIH. In order to advance research on risk reduction, beginning with the next ADRD Research Summit in 2024, NIA and NINDS will ensure that risk reduction is integrated into the summits. As NIH develops plans for future summits, it will continue to engage a diverse mix of investigators, representatives from non-governmental organizations, industry, people living with dementia and their caregivers,

and other communities in both organizing the meeting and in leading the individual meeting sessions. Consideration will be given to gender diversity, as well as ensuring diverse representation from underrepresented racial and ethnic groups, individuals with disabilities, and individuals from socially and economically disadvantaged backgrounds.

At the 2022 ADRD Summit, risk reduction and SDOH were strong themes in the first cross-cutting session of the Summit, which was dedicated to developing research recommendations to improve health equity in AD/ADRD. Summit participants discussed several related research priorities, for example, the need to identify life-course risk factors (including social, structural, and systemic factors) and multi-level pathways to AD/ADRD inequities, as well as using such discoveries to reduce or prevent these inequities. Each AD/ADRD disease-focused session (e.g., FTD, VCID, LBD) also discussed prioritizing risk factor research, SDOH, and the need to greatly increase representation of minoritized populations in clinical and prevention research.

The BOLD PHCOE on Risk Reduction hosted a free public meeting on the impact of the SDOH on AD/ADRD, as a preconference event at AAIC 2022. This meeting presented the latest science with presentations from experts on each of the identified risk factors. The BOLD Center will be providing the session as enduring content for those unable to attend.

(**UPDATED**) Action 6.A.2: Monitor and improve access to public health surveillance data to identify risk factors and establish research priorities

Lead Agency: CDC

CDC monitors data from the Cognitive Decline Module of the BRFSS and the Cognitive Performance and SCD module to the NHANES. In 2022, CDC published a report in the *Morbidity and Mortality Weekly Report* titled, “Modifiable Risk Factors for Alzheimer Disease and Related Dementias Among Adults Aged ≥45 Years -- United States, 2019.” The report examined the status of eight potential modifiable risk factors for AD/ADRD among adults 45 years and older by SCD status using data from the 2019 BRFSS. As of July 2022, this report has an Altmetric score of 861 (in the top 0.02% of all research outputs scored by Altmetric) and was featured in 44 news stories from 44 outlets. Based on key findings from this report, a follow-up analysis using novel cognitive functioning data from the 2019-2020 NHANES is underway.

To improve access to the monitoring capabilities of the BRFSS data, in early 2021, CDC released a revised Technical Assistance Document for both the Caregiving and Cognitive Decline Modules designed to provide guidance for BRFSS coordinators and researchers who would like to conduct analyses of the data collected through the 2015-2020 BRFSS Caregiver or Cognitive Decline Optional Modules. These documents provide basic computer code for analyzing the data with a goal to enable consistency in analytic methods and results reported. The BRFSS data is publicly available for users.

CDC has made data from the BRFSS Caregiver and Cognitive Decline Modules available in user-friendly formats, to facilitate broader use of these data. These include a searchable data portal, data briefs, and infographics with national estimates, by state, sex, rural status, veteran status, and race/ethnicity.

CDC has also convened expert workgroups to provide feedback on existing Caregiver and Cognitive Decline Module questions, identify gaps, and suggest improvements to the modules to better align with current literature and needs. CDC has submitted a revised version of its Cognitive Decline Module which has been approved by BRFSS State Coordinators and is planned to enter the field in 2023.

For more information, see:

- https://www.cdc.gov/aging/agingdata/index.html
- https://www.cdc.gov/aging/data/BRFSS-statistical-brief-cognitive-decline-508.pdf
- https://www.cdc.gov/aging/data/index.htm
- https://www.cdc.gov/aging/healthybrain/brfss-faq-cognitive.htm
- https://www.cdc.gov/aging/publications/BRFSS-caregiver-brief-508.pdf
- https://www.cdc.gov/aging/publications/briefs.htm
- https://www.cdc.gov/brfss/
- https://www.cdc.gov/nchs/nhanes/

(ONGOING) Action 6.A.3: Expand and diversify clinical research studies on promising interventions to reduce individual and community-level risk

Lead Agencies: NIA, NINDS, NIH

NIH is funding a wide range of clinical research studies and trials designed to better understand the complex interplay of risk and protective factors for AD/ADRD, and to test interventions to reduce the burden of those risk factors and ultimately decrease the incidence of disease downstream and promote cognitive health. Both NIA and NINDS will continue to monitor emerging evidence in the field, including newly identified risk and protective factors, and expand future research investments in the most promising areas.

(UPDATED) Action 6.A.4: Enhance research to better understand the varying levels of or types of dementia risk across demographic groups

Lead Agencies: NIA, NINDS, NIH

Emerging research suggests that differences in the risks of AD/ADRD reflects differences in both modifiable (e.g., physical activity and education) and non-modifiable factors (e.g., genetics). NIH's strategic planning efforts around AD/ADRD reflect a prioritization of issues related to the racial and ethnic disparities of these conditions. For example, NIA has developed a National Strategy to improve recruitment of racial and ethnic minorities in its research (referenced above), both intramural and external. Both NIA and NINDS will continue to invest in these areas of research at the basic, translational, clinical, and epidemiological levels to understand these risk factors and the impact they have on disparities in AD/ADRD between these populations.

Several new and ongoing clinical studies are seeking to determine risk profiles for AD/ADRD, especially in regard to vascular risk factors. For approximately 20 years, NINDS has supported the Reasons for Geographic and Racial Differences in Stroke, a longitudinal prospective study of stroke risk in racial and ethnic minorities as well as low SES and rural populations. NINDS and NIA have expanded the study's goals to now include understanding disparities in the risk for dementia and cognitive decline as well as stroke.

A variety of exposures in the environments where people live, work, pray, and play across their lives shape health outcomes, including cognitive health and AD/ADRD risk. Together, this comprehensive set of exposures across domains (e.g., physical, chemical, social, psychological, economic) constitute the "exposome." In 2020, NIA held a virtual workshop, Understanding the Role of the Exposome in Brain Aging, AD, and ADRD, to explore aspects of the exposome salient to AD/ADRD, ranging from various toxicants (e.g., metals, air pollution, pesticides) and pathogens to the individual (e.g., early life adversity, occupational history, lifestyle factors) and macro (e.g., structural racism, climate change) level. NIA issued a Notice of Special Interest in 2022 to support research infrastructure with the potential to elucidate the role of the exposome in AD/ADRD outcomes and AD/ADRD health disparities. Because exposures differ across populations, this research is especially important for understanding factors involved in racial/ethnic, socioeconomics, and geographic inequities in AD/ADRD. More research is needed to fully

capture the impacts of the exposome on AD/ADRD risk and resilience, as well as the intermediate biological, psychosocial, economic, and behavioral mechanisms.

For more information, see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-22-022.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-048.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html
- https://pubmed.ncbi.nlm.nih.gov/32282019/
- https://reporter.nih.gov/project-details/10118228
- https://reporter.nih.gov/project-details/9918026
- https://www.nia.nih.gov/sites/default/files/2021-12/Understanding-the-Role-of-the-Exposome-Meeting-Summary.pdf

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(**UPDATED**) Action 6.A.5: Expand research on traumatic brain injury as a risk factor for neurodegeneration

Lead Agencies: DoD, NINDS, NIH
Partner: VA

Several research studies have suggested a connection between TBI and later incidence of dementia, but additional investigation is needed to confirm and better understand the mechanism involved. DoD, NINDS, and VA are supporting further research to understand the brain changes resulting from TBI and potential relationships with subsequent neurodegeneration. For example, in 2022 NINDS released a funding announcement to invite new research studies to examine the association of dementia risk with biological and clinical measures of TBI-related and chronic traumatic encephalopathy (CTE)-related progressive neurodegeneration and neurocognitive decline. Data from these studies, which will be made publicly available, will help researchers better understand the prevalence of TBI-associated dementia and cognitive decline in these populations. A key goal of this research is to understand whether protective factors or interventions can improve the course and/or severity of neurodegenerative outcomes.

The CDMRP PRARP continues to support preclinical and clinical research investigating the intersection of military Service, TBI, and long-term effects including AD/ADRD. For FY 2022, the focus areas for the program include Individual, Family, and Care Support, Foundational Science, and Environmental/Diagnostic/Prognostic Factors. Currently supported research investigates the etiology, epidemiology, and potential quality of life impacts in this space.

The VA Office of Research Development continues its multi-pronged approach for TBI-related AD/ADRD. Key initiatives include longitudinal epidemiological studies, intra- and extra-mural research consortia, and therapeutics.

The VA continues to provide intramural investigators the opportunity to conduct studies on the Chronic Effects of Neurotrauma via a Request for Applications (RFA). The RFA encourages researchers to work on chronic injury models of TBI with emphasis on the long-term effects of co-occurring conditions. Funding is provided over a 5-year period. The mechanism encourages the development of databases, identification of functional outcomes for rehabilitation, epidemiological studies, and the exploration of co-morbid psychological conditions.

The VA partners with DoD through the Long-term Impact of Military-relevant Brain Injury Consortium/Chronic Effects of Neurotrauma Consortium (LIMBIC-CENC). LIMBIC is the continuation of the original CENC Initiative that began in 2013. With over a dozen study sites nationally (current sites: 12 VA, nine DoD, five academic) and a cohort of 2000+ veterans and service members, these participants are characterized longitudinally using neuroimaging, fluid, and physiological biomarkers. The biomarkers are coupled to neurobehavioral testing, and all assessments are done every 2 years after the initial baseline for each participant. LIMBIC-CENC

also focuses on estimating the frequency of dementia occurring in veterans and service members with a medical history of TBI. Further discoveries will draw upon multiple VA-centered datasets (EHRs, utilization of VA clinical care services, and pharmacy data) to develop TBI phenotypes and to determine clinical trajectories that track progression from MCI to dementias.

The VA also supports an intramural, two-site center, the Translational Research Center for TBI and Stress Disorders (TRACTS). The TRACTS veteran cohort has over 800 participants, each has been longitudinally and deeply characterized since TRACTS inception in FY 2010. Veterans have participated in studies that have helped advance a variety of TBI-related research domains that include cognitive neuroscience, diagnostics, epidemiology, cerebrovascular risk factors, neuropsychological/physiological assessments, psychiatry, and ADLs. TRACTS provides veterans direct access to promising non-pharmacological interventions.

The VA has been supporting a collaborative research program to examine blast-induced tau-related pathological changes, leveraging the VA Open-Field Blast Core facility. Specific focus is on CTE and Alzheimer-pathology using animal models and human post-mortem tissues.

In addition, VA also maintains strategic investments in chronic TBI therapies, with an emphasis on reducing the co-morbid conditions chronic TBI shares with progressive dementias. The pharmaceutical preparation of allopregnanolone has the potential to block neuroinflammation-related neurodegeneration and may also be effective in treating chronic pain and depression. Additionally, VA investigators are assessing the effects of human growth hormone replacement on common TBI-related co-morbidities. The primary and secondary outcomes for quality of life impacts in this study are brain health-related, which may represent a nexus between TBI and dementias. The outcomes include: obesity, cardiovascular disease, fatigue, sleep disturbances, cognitive deficits, chronic pain, and depression.

For more information, see:

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-024.html

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(**ONGOING**) Action 6.A.6: Expand research on the impact of emerging potential risk factors such as COVID-19

Lead Agencies: NINDS, NIA, NIH

Over the past 2 years it has become evident that many diverse individuals who have contracted SARS-CoV-2 experience either a greatly prolonged period of illness (i.e., Long COVID) or longer-term post-acute sequelae following acute COVID-19 related illness (i.e., PASC) that include but are not limited to neuropathological insult and significant cognitive changes. To investigate these further, NIH has recently launched RECOVER, a research initiative designed to understand, prevent, and treat the post-acute effects of SARS-CoV-2. NINDS and NIA will continue to participate actively in this critical effort and will consider gaps emerging from PASC findings for future investments at the institute level.

For more information, see:

- https://recovercovid.org/

(**UPDATED**) Action 6.A.7: Continue clinical trials on the most promising health promotion interventions

Lead Agency: NIA
Partner: VA

See Action 1.B.5 for updates regarding the ACTC and ongoing clinical trials supported by NIA. Over 130 of the approximately 200 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/pa-files/par-21-207.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-016.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

In 2019, two major reports were published from the SPRINT-MIND clinical research study, which was the first randomized control trial of its size and scope to examine a modifiable risk factor for dementia. The study established that intensively lowering blood pressure in participants aged 50 and above decreased their risk for MCI by approximately 20% and reduced progression of white-matter hyperintensities, which are associated with vascular damage in the brain. 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 aged 75 and older with high blood pressure.

For more information, see:

- https://pubmed.ncbi.nlm.nih.gov/30688979/
- https://pubmed.ncbi.nlm.nih.gov/31408137/
- https://www.nia.nih.gov/news/intensive-blood-pressure-control-slowed-white-matter-disease-adults-age-75-and-older
- https://www.nih.gov/news-events/news-releases/intensive-blood-pressure-control-may-slow-age-related-brain-damage

As noted above, NIA funds many clinical trials on health-related behaviors and dementia, including combinations of healthy behaviors. Because these behaviors may need to start decades before disease onset, understanding the factors that support long-term adherence to lifestyle change will be critical. In early 2021, NIA released new funding opportunities to support research, including behavior change clinical trials, on the psychology of motivation, value-based decision making, and social support. The hope is that findings from this line of research will help investigators develop ways to help people adopt and sustain healthy behaviors over many years. NIA also supports trials exploring cognitive training as a risk reduction strategy. Recent data analyses from the Advanced Cognitive Training in Vital Elderly study demonstrated that a specific cognitive intervention, speed of processing training, may significantly delay the incidence of cognitive impairment across 10 years. As a follow up, NIA funded the Preventing Alzheimer's with Cognitive Training trial to determine whether this cognitive training technique successfully delays the onset of clinically defined MCI or dementia across 3 years.

For more information, see:

- https://clinicaltrials.gov/ct2/show/NCT03848312
- https://grants.nih.gov/grants/guide/pa-files/PAR-21-207.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-016.html
- https://hscweb3.hsc.usf.edu/blog/2021/04/06/usf-awarded-five-year-44-4-million-nih-grant-to-test-whether-computerized-brain-training-can-reduce-dementia-risk-in-older-adults/
- https://reporter.nih.gov/project-details/10334504
- https://www.nia.nih.gov/research/ongoing-AD-trials#section3

NIA's HCAP Network aims to harmonize international data resources for the study of AD/ADRD that will expand research on key life-course factors that are thought to affect cognitive function and increase risk for AD/ADRD. This support for global research provides a broader data resource regarding health-related behaviors, diets, and environmental factors, expanding insight on potential risk and protective factors of AD/ADRD. See Action 1.D.2 for more detail and resources.

Since 2020, VA has been one of the recruitment networks for the NIA-funded the PREVENTABLE trial, which aims to determine whether statins can prevent dementia and disabilities 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. VA continues to support clinical trials of interventions to reduce risks for developing AD/ADRD or alleviating the symptoms.

The VA continues to support clinical trials that aim to prevent the progression of MCI to dementia and to promote brain health. Interventional approaches include water-based exercise and non-invasive brain stimulation coupled with cognitive training to improve cognitive function in veterans diagnosed with MCI. In addition, VA continues to support studies on promising approaches that could lead to health promotion interventional trials.

For more information, see:

- https://pubmed.ncbi.nlm.nih.gov/34880498/

Strategy 6.B: Facilitate Translation of Risk Reduction Research Findings into Clinical Practice

As understanding of potential modifiable risk factors emerges, the Federal Government will quickly disseminate information and educate health care providers about risk factors and interventions to reduce their burden, so that when appropriate measures can be considered in clinical settings through informed and shared decision making. Dissemination of research findings to clinical settings will also provide individuals with information about what may help in delaying the onset and/or slowing the progression of AD/ADRD, and resources available to support them.

(ONGOING) Action 6.B.1: Educate the health care workforce about risk reduction

Lead Agencies: HRSA, CDC

It is essential for the health care workforce to understand the risk factors for dementia in order to promote risk reduction among adults. HRSA will use its network of GWEPs to develop and disseminate curricula to train the health care workforce in using a "whole-person" approach that encompasses all of the patient's needs to address individuals' brain and behavioral health. HRSA will require geriatrics workforce development programs to include training on the AWV.

To increase providers awareness of brain health, CDC supported the American College of Preventive Medicine (ACPM) to develop a Brain Health Continuing Education Course and Resource Website to increase physician and health care professionals' awareness of brain health as a serious health condition. In 2021, the ACPM and CDC published an article, Cognitive Decline and Dementia Risk Reduction: Promoting Healthy Lifestyles and Blood Pressure Control, which describes how healthy choices can reduce the risk of cognitive decline and the importance of treating and managing hypertension in midlife. These brain health resources have been disseminated through the CDC's weekly newsletter and ACPM mechanisms. This activity is being revised and expanded in 2022-2023.

For more information, see:

- https://www.acpm.org/initiatives/brain-health/
- https://www.acpm.org/initiatives/brain-health/brain-health-resources/
- https://www.sciencedirect.com/science/article/pii/S0749379721002002?via%3Dihub

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(ONGOING) Action 6.B.2: Increase access to hearing aids for individuals with hearing loss

Lead Agency: FDA

Hearing loss has been identified as a risk factor for AD/ADRD, and recent research has demonstrated that hearing aid use is associated with reduced dementia risk. Hearing aids are often expensive, making them inaccessible to many individuals who could benefit.

FDA recently issued a Final Rule, effective in October 2022, that established a new regulatory category for over-the-counter (OTC) hearing aids and made related amendments to update the regulatory framework for hearing aids. Among other things, the Final Rule provides for reasonable assurance of safety and effectiveness of OTC hearing aids and aims to foster innovation in hearing aid technology. It also is expected to improve access to hearing aids, as OTC options are easier to obtain and less expensive.

For more information, see:

- https://pubmed.ncbi.nlm.nih.gov/33614893/
- https://www.federalregister.gov/documents/2022/08/17/2022-17230/medical-devices-ear-nose-and-throat-devices-establishing-over-the-counter-hearing-aids

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(ONGOING) Action 6.B.3: Disseminate research on co-occurring chronic conditions and dementias

Lead Agency: CDC

CDC has partnered with NACDD to develop a series of customizable 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, which are in both Spanish and English, are designed to educate patients about risk reduction practices related to AD/ADRD, including the importance of blood pressure control, physical activity, healthy diet, blood sugar management, and smoking cessation. The Rack Cards are being adapted by state health departments with technical assistance from CDC and NACDD. These risk reduction messages can then be integrated alongside existing health promotion messaging efforts among states and other partners.

In collaboration with the Alzheimer's Association, Association of State and Territorial Health Officials (ASTHO), and IA^2, developed a series of four customizable templates and two instruction guides for Healthy Heart, Healthy Brain for use by health care providers and public health professionals. The templates include steps patients can take to promote heart, brain, and overall health.

For more information, see:

- https://www.cdc.gov/aging/partnership/nacdd-partner-resources/index.html
- https://www.cdc.gov/aging/partnership/partner-resources/index.html

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(UPDATED) Action 6.B.4: Encourage treatment of co-occurring behavioral health conditions

Lead Agency: SAMHSA
Partners: CMS, HRSA, ACL

Behavioral health conditions, including depression, other mental illnesses, and SUD, are risk factors for AD/ADRD.[21,22,19][23] Approaches to treatment for depression can be found in SAMHSA's Treatment of Depression in Older Adults Evidence-Based Practices (EBP) Kit. The kit offers information about an array of EBP for treatment and services to improve outcomes for older adults experiencing depression, including dysthymia. It considers planning, implementation, and maintenance. Treatment approaches for older adults with dementia or other cognitive impairments are included in the case examples.

If a person is in an early stage of AD/ADRD, psychosocial therapies for SMI may still be effective, although the interventions may not be appropriate if a person is in a more advanced stage of dementia. SAMHSA's guide for practitioners on psychosocial interventions for older adults with SMI provides considerations and strategies for interdisciplinary teams, peer specialists, clinicians, RNs, behavioral health organizations, and policy makers in understanding, selecting, and implementing evidence-based interventions that support older adults with SMI. In addition, SAMHSA, CMS, HRSA, and ACL collaborated to publish *Guidance on Inappropriate Use of Antipsychotics: Older Adults and People with IDD in Community Settings*. The Guidance reviews non-pharmacologic behavioral approaches and strategies to avoid and reduce prescribing of antipsychotics whenever possible for older adults with dementia and people with IDD.

SAMHSA, in collaboration with CMS, established the new COE-NF. While not specifically focused on older adults or people with AD/ADRD, the new COE-NF will provide evidence-based resources to assist nursing home staff to assist residents of all ages in need of mental health and substance use treatment and support.

For more information, see:

- https://quality.allianthealth.org/topic/center-of-excellence-for-behavioral-health-in-nursing-facilities/
- https://store.samhsa.gov/product/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/PEP19-INAPPUSE-BR
- https://store.samhsa.gov/product/psychosocial-interventions-older-adults-serious-mental-illness/PEP21-06-05-001?referer=from_search_result
- https://store.samhsa.gov/product/Treatment-Depression-Older-Adults-Evidence-Based-Practices-EBP-Kit/SMA11-4631

Some individuals with AD/ADRD may have SUD, which should also continue to be treated. As we age, the body's ability to process alcohol and other substances becomes less effective; cognitive impairment can also alter the impacts of alcohol and other substances. Effective treatment approaches can be found in Treatment Improvement Protocol (TIP) 26: Treating SUD in Older Adults. TIP 26 is designed to help providers better understand how to identify, manage, and prevent SUD in older adults. The TIP describes the unique ways in which the signs and symptoms of SUD may manifest in older adults, drug and alcohol use disorder screening tools,

[21] Ahearn EP, Szymanski BR, Chen P, Sajatovic M, Katz IR, McCarthy JF. "Increased risk of dementia among veterans with bipolar disorder or schizophrenia receiving care in the VA health system." *Psychiatric Services*, 2020; 71(10): 998-1004. doi:10.1176/appi.ps.201900325.

[22] Kuring JK, Mathias JL, Ward L. "Risk of dementia in persons who have previously experienced clinically-significant depression, anxiety, or PTSD: A systematic review and meta-analysis." *Journal of Affective Disorders*, 2020; 274: 247-261. doi:10.1016/j.jad.2020.05.020.

[23] Rehm J, Hasan OSM, Black SE, Shield KD, Schwarzinger M. "Alcohol use and dementia: A systematic scoping review." *Alzheimers Research Therapy*, 2019; 11(1). doi:10.1186/s13195-018-0453-0.

assessments, and treatments tailored for older adults' needs, the interaction between SUDs and cognitive impairment, and strategies to help providers improve their older clients' social functioning and overall wellness. A related resource from SAMHSA is the toolkit, Get Connected: Linking Older Adults with Resources on Medication, Alcohol, and Mental Health. The toolkit is designed for organizations that provide services to older adults and offers information and materials to help understanding the issues associated with substance misuse and mental illness in older adults.

SAMHSA partnered with HRSA to develop *Growing Older: Providing Integrated Care for an Aging Population*. The report is designed for clinicians and explains approaches to providing integrated care to older adults living with SUD and mental illness. It highlights the importance of assessing patients for cognitive deficits and adapting behavioral interventions to help improve treatment outcomes. The report also stresses the importance of including family caregivers, when possible, in the diagnostic and treatment process.

For more information, see:

- https://store.samhsa.gov/product/Get-Connected-Linking-Older-Adults-with-Resources-on-Medication-Alcohol-and-Mental-Health-2019-Edition/SMA03-3824
- https://store.samhsa.gov/product/Growing-Older-Providing-Integrated-Care-for-An-Aging-Population/SMA16-4982
- https://store.samhsa.gov/product/treatment-improvement-protocol-tip-26-treating-substance-use-disorder-in-older-adults/PEP20-02-01-011

Strategy 6.C: Accelerate Public Health Action to Address the Risk Factors for Alzheimer's Disease and Related Dementias

While clinical health focuses on the individual, public health focuses on a population with the aim of protecting and promoting healthy people and communities. Developing the public health infrastructure and educating the public health workforce about AD/ADRD risk factors can ensure that as high-quality research emerges, public health systems can more rapidly advance interventions and investments targeting communities with greatest need to achieve more equitable outcomes.

(**ONGOING**) Action 6.C.1: Convene summit to establish public health priorities for reducing Alzheimer's disease and related dementias risk factors

Lead Agency: CDC

To establish and update priorities and milestones, CDC is convening a *National Summit on Risk Reduction* on May 16-17, 2023. This Summit will include academic and public health partners gathering, as well as public health practitioners, state, local, and Tribal public health officials, ASTHO, and National Association of County and City Health Officials (NACCHO). This Summit will yield a list of public health strategies determined to be most appropriate for translation based on the state of the latest science, to be implemented by state, local, and Tribal public health entities. A second Summit will be held in 2025.

(**UPDATED**) Action 6.C.2: Accelerate dissemination of information on risk reduction to public health entities

Lead Agencies: CDC, ODPHP
Partners: NACDD, ASTHO, NACCHO

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, health communication materials for AI/AN communities, healthy aging, and a series of recorded webinars to promote the importance of public health in addressing brain health. The communication materials for AI/AN communities are now customizable.

CDC supported the NACDD to develop brain health messaging that could be integrated into existing public health messaging. The initial Rack Cards were released in 2020 for four key risk factors related to brain health, in 2021 these are now customizable, and in 2022 NACDD is working to integrate these messages within state and local public health departments.

In 2021, in collaboration with NACCHO, CDC awarded the inaugural cohort of the HBI Road Map Strategists. The Road Map Strategist initiative is the first nationwide effort to build local health department capacity to address cognitive health and dementia. Eight local health departments were selected through a competitive application process for the cohort. This will supplement the ongoing technical assistance provided by CDC in guiding, developing, and integrating risk reduction into new BOLD state plans. The second cohort will be awarded in late 2022.

Beginning in 2022, CDC is funding the Dementia Risk Reduction Research Thematic Network, a national network of academic, public health, and community partners that will improve interventions and management for people at increased risk for developing AD/ADRD with the ultimate goal of reducing the burden of AD/ADRD, especially for populations disproportionately impacted. Three Collaborating Centers are being funding to kick-start this Network.

For more information, see:

- https://astho.org/Healthy-Aging/
- https://www.astho.org/topic/report/od2a-bpi-federal-award-spenddown-analysis/
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
- https://www.cdc.gov/aging/partnership/partner-resources/index.html
- https://learn.astho.org/p/hbi-action-plan#tab-product_tab_overview

CDC's weekly newsletter, *Alzheimer's Disease and Healthy Aging*, disseminated information on brain health, risk reduction, caregiving, SCD, general health, emergencies, care planning, and COVID-19 guidance to over 45,000 subscribers, which includes many public health professionals. The newsletters are a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health to an active and engaged audience.

In 2022, CDC published a report in the *Morbidity and Mortality Weekly Report* titled, "Modifiable Risk Factors for Alzheimer Disease and Related Dementias Among Adults Aged ≥45 Years -- United States, 2019." The report examined the status of eight potential modifiable risk factors for AD/ADRD among adults 45 years and older by SCD status using data from the 2019 BRFSS. Findings from this report were presented at the 2022 BRFSS Annual Meeting and future presentations are planned for the 2022 MAIA and 2022 GSA conferences. Additional activities to further disseminate the report include a recorded podcast, CDC Tweet and graphic, and accompanying web feature on the Alzheimer's Disease Program's website regarding dementia risk reduction. The report has also been selected for a continuing education activity by Medscape. The findings of this research will be used to establish programmatic priorities and to monitor progress at the state and national levels.

(ONGOING) Action 6.C.3: Educate the public health workforces on Alzheimer's disease and related dementias risk factors

Lead Agency: CDC

CDC has developed a Public Health Curriculum, a comprehensive course addressing cognitive health, cognitive impairment, and dementia, for use by undergraduate faculty in schools and

programs of public health and related disciplines. This curriculum is aligned with the Core Competencies for Public Health Professionals. The curriculum is available free of charge and consists of four modules designed to be used individually or as a whole, each with slides and a faculty guide. The curriculum is also relevant to other audiences for broader reach. The course was available updated in late 2019, with additional enhancements, including video modules, added in 2021.

For more information, see:

- https://www.cdc.gov/aging/services/index.htm
- http://www.phf.org/resourcestools/Pages/Core_Public_Health_Competencies.aspx

CDC is collaborating with the Dementia Risk Reduction PHCOE to translate existing and emerging science around modifiable risk factors for cognitive decline and dementia into actionable and targeted public health interventions, messaging, and campaigns; make these approaches highly accessible to the public health community and the general public; work with public health agencies and their partners to increase the use of these risk reduction strategies; and continuously update and improve the approaches through feedback, evaluation, and quality improvement.

For more information, see:

- https://www.cdc.gov/aging/funding/phc/index.html

(ONGOING) Action 6.C.4: Improve nutrition by facilitating lowering sodium content in food

Lead Agency: FDA

Excess sodium can raise blood pressure, which can increase the risk for multiple chronic conditions including AD/ADRD. Lowering blood pressure has been found to reduce the risk of developing cognitive impairment, a common precursor of AD/ADRD. According to the Dietary Guidelines for Americans, people living in the United States consume on average 3,400 milligrams (mg) of sodium per day -- nearly 50% more than the 2,300mg limit recommended by for people 14 years and older. The majority of sodium consumed comes from processed, packaged, and prepared foods, which makes it difficult to monitor and limit sodium intake.

To address this, the FDA is taking an iterative approach that includes establishing voluntary sodium targets for industry, monitoring and evaluating progress, and engaging with stakeholders, in order to facilitate the gradual reduction of sodium in the food supply, including processed and restaurant foods. The FDA issued a final guidance with voluntary short-term targets for reducing sodium in commercially processed, packaged, and prepared food over the next 2.5 years. The approach supports sodium reduction efforts already made by industry, provides common targets for defining and measuring progress, and provides companies with the flexibility and time to meet these targets. The FDA expects to issue revised subsequent targets in the next few years to facilitate a gradual, iterative process to reduce sodium intake.

For more information, see:

- https://www.fda.gov/food/food-additives-petitions/sodium-reduction

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(ONGOING) Action 6.C.5: Promote physical activity among older adults

Lead Agency: ODPHP

HHS released the *Physical Activity Guidelines for Americans* 2nd edition in 2018. The Physical Activity Guidelines for Americans is a flagship resource for health professionals and policy makers that provides recommendations on how everyone can improve their health through regular physical activity. The Guidelines describe the brain health benefits of physical activity,

including reduced risk of AD/ADRD and improved cognition (executive function, attention, memory, crystallized intelligence, and processing speed).

The PAGAC Brain Health subcommittee examined the literature related to physical activity and cognition, identified key research recommendations and rationales for future exploration. HHS intends to release a midcourse report in 2023 focused on strategies to increase physical activity among older adults.

Building off the evidence for the protective effect of physical activity on brain health outcomes, the Office of Disease Prevention and Health Promotion (ODPHP) is leading the development of a Physical Activity Guidelines midcourse report, which will focus on what works to improve physical activity behaviors in the older adult population. The Science Board subcommittee of the President's Council on Sports, Fitness and Nutrition conducted a systematic literature review in 2022 to inform the midcourse report. HHS expects to release the midcourse report in 2023. While it does not focus specifically on any health outcomes (i.e., AD/ADRD), it will highlight evidence-based settings and strategies that facilitate increased physical activity among older adults.

For more information, see:

- https://health.gov/
- https://health.gov/our-work/nutrition-physical-activity/physical-activity-guidelines/current-guidelines
- https://health.gov/sites/default/files/2019-09/09_F-3_Brain_Health.pdf
- https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf

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Strategy 6.D: Expand Interventions to Reduce Risk Factors, Manage Chronic Conditions, and Improve Well-Being through the Aging Network

The Aging Network is a national structure of state and local agencies that provide services to older adults with the aim of helping them remain in their homes and communities. Many older adults are already connected to Aging Network providers in their communities. These existing connections of trust provide an invaluable foundation for spreading awareness and implementing interventions on risk reductions to older adults, tribes, communities, states, and territories. By engaging with existing community organizations, risk reduction interventions can be tailored to fit the sociocultural needs of local communities.

(**ONGOING**) Action 6.D.1: Ensure older adults have access to nutritious meals through home-delivered and congregate meal programs

Lead Agency: ACL

Through the OAA Nutrition Program, ACL's Administration on Aging provides grants to states to help support nutrition services (home-delivered and congregate meals) for older people throughout the country. Nutrition services provide an opportunity to link to other supportive in-home and community-based supports from which older people may benefit.

Designed to promote the general health and well-being of older individuals, the services address hunger, food insecurity and malnutrition of older adults; promote the health and well-being, promoting healthy nutrition behaviors. The onset of COVID-19 highlighted the increased nutritional needs of the nation's older adults, bringing hidden hunger and the needs of under-served individuals into the spotlight.

(ONGOING) Action 6.D.2: Expand the delivery of health and wellness programs to older adults in every community

Lead Agency: ACL

Through their Capacity-Building and Sustainable Systems initiatives ACL continues to expand delivery of health and wellness programs in more communities across the Nation. The Capacity-Building grants support building capacity in areas with no or limited program infrastructure to introduce and deliver evidence-based health and wellness programs, as well as chronic disease self-management support programs within under-served geographic areas and/or populations. The Sustainable Systems grants focus on the development of integrated, sustainable systems for delivering evidence-based self-management support programs. Expanded availability of health and wellness programs in historically under-served communities, many of whom are at high risk of developing cognitive impairment.

(ONGOING) Action 6.D.3: Identify the most promising health promotion and disease prevention interventions for dissemination through the Aging Network

Lead Agency: ACL

ACL, through grants with the National Council on Aging and the Evidence-Based Leadership Council, supports the vetting and identification of promising health and wellness community-based evidenced-based programs to support older adults and people with disabilities remaining in their homes and communities. Interventions are assessed to determine whether they meet the OAA Title III-D criteria for evidence-based programs, thus making them eligible for funding with OAA Title III-D dollars.

(ONGOING) Action 6.D.4: Expand access to evidence-based health promotion and disease prevention programs

Lead Agency: ACL

The OAA, under Title III, makes funds available to support the delivery of evidence-based programs designed to improve health and well-being, and reduce disease and injury. Through Title III, the aging services network is able to advance wider implementation of disease prevention and health promotion evidence-based programs demonstrated to improve the health of older adults. ACL developed an evidence-based definition to assist states in developing their own Title III-D guidance through which a variety of interventions are implemented and older adults are learning to manage chronic conditions (diabetes, heart disease, arthritis, chronic pain, and depression) which are known to contribute to increased risk for cognitive impairment later in life.

Strategy 6.E: Address Inequities in Risk Factors for Alzheimer's Disease and Related Dementias Among Marginalized Populations

Black, Hispanic, and low income populations face a higher risk of AD/ADRD. Structural inequities are an important cause of this difference, including but not limited to underinvestment in education systems, less walkable communities, decreased access to nutritious food, barriers to health care access and low quality of care in their communities. To reduce existing disparities in the incidence of AD/ADRD risk reduction, interventions should be tailored to meet the needs of each community with cultural competence and equity as the primary focuses. This requires that addressing SDOH, entrenched systemic racism, and other forms of discrimination be prioritized, rather than focusing solely on individual behaviors.

(ONGOING) Action 6.E.1: Support the development of programs and materials designed to increase awareness of the importance of brain health in culturally and linguistically appropriate ways

Lead Agency: CDC

CDC's National Brain Health Center for African Americans (NBHCAA) is raising awareness of the issues of cognitive health among Black Americans by working through networks of faith-based institutions, and by establishing partnerships with organizations and individuals dedicated to NBHCAA's mission. CDC is working on a training program geared towards Black American health professionals to raise awareness and diagnostic proficiency regarding cognitive health. CDC is expanding on the foundational work of NBHCAA to further education of health professionals about risk reduction as part of the HBI.

CDC's HBI is increasing tailored messaging related to cognitive impairment, COVID-19, brain health, and AD/ADRD to Black and Hispanic populations across the United States. In 2021, three digital education events -- #SaludTues Twitter Chats -- amplified educational content, including CDC resources, about cognitive impairment and AD/ADRD as public health issues among diverse audiences. These three events were held in partnership with more than ten community-partners, generating 19.7 million impressions. Relatedly, a virtual congressional briefing was held in July 2021 entitled Brain Health Equity and the Social Determinants of Health, Congressional Districts and Alzheimer's Prevalence Among Communities of Color.

In 2020, CDC funded three organizations for 5 years to tailor brain health messaging for four populations disproportionately affected by dementia: persons with IDD and Hispanic, Black, and AI/AN individuals. In 2021, a virtual congressional briefing was held in July entitled Brain Health Equity and the Social Determinants of Health, Congressional Districts and Alzheimer's Prevalence Among Communities of Color. There was also the virtual HealthMatters Webinar Series, which reached over 400 attendees, and authored two publications on persons with IDD and AD/ADRD.

For more information, see:

- http://brainhealthcenterforafricanamericans.org/

(ONGOING) Action 6.E.2: Support the development of programs and materials designed to increase awareness of the importance of brain health for Tribal communities in culturally sensitive ways

Lead Agencies: CDC, IHS
Partners: private organizations, ASTHO

Through CDC's HBI, in 2021 IA^2, which provides support to AI/AN adults, developed a new website, AI/AN Brain Health, which features a robust online brain health resource library. IA^2 has collaborated with the Dementia Friends Program to provide tribes, UIH organizations, and Alaska Native communities with training and content from this program. IA^2 also gathers, creates and distributes information and resources developed by and for AI/AN communities to improve the public health response to AD/ADRD. These resources are continuously updated to their brain health resource library for Tribal and UIH organizations.

Multiple sessions and trainings on AD/ADRD were hosted at the American Indian Elders Conference hosted by NICOA.

CDC partnered with the ASTHO and the Alzheimer's Association to develop culturally sensitive materials to educate and empower tribes and Tribal populations about brain health and caregiving. In 2021, the materials were adapted to be customizable templates with logos, websites and images that focus on cardiovascular risk factors related to brain health and caregiving issues for 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. IA^2, a recipient of the HBI support, and the NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities. 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.

For more information, see:

- https://iasquared.org/brain-health/resource-library/
- http://www.aianbrainhealth.org/
- https://www.astho.org/healthy-aging/healthy-heart-healthy-brain/
- https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html
- https://www.cdc.gov/aging/partnership/partner-resources/index.html
- https://www.dfamerica.org/

(ONGOING) Action 6.E.3: Reduce financial barriers to hearing aids for individuals with hearing loss

Lead Agency: FDA

As described in further detail under Action 6.B.2 above, the FDA recently issued a Final Rule, effective October 2022 that established a new regulatory category for OTC hearing aids and made related amendments to update the regulatory framework for hearing aids. This Final Rule is expected to increase the availability of less costly, OTC options for hearing aids, and therefore promote broader and more equitable access to these devices.

Strategy 6.F: Engage the Public about Ways to Reduce Risks for Alzheimer's Disease and Related Dementias

Greater public awareness about potential risk factors and steps to modify those risk factors may encourage individuals and families to make changes that preserve cognitive health and promote healthy aging overall and connect them to resources and services that can help. Dementia is one of people's most feared health conditions, which may influence an individual's views about risk reduction messages and their interest in interventions to reduce their individual burden of risk factors for AD/ADRD. Furthermore, sharing information on SDOH and system-level risk factors can focus and help coordinate facilitate positive community and infrastructure changes.

(ONGOING) Action 6.F.1: Target and coordinate public health campaigns aimed at reducing risk factors

Lead Agencies: ACL, NINDS, NIA, NIH, CDC

Several federal agencies have developed public messaging campaigns to raise awareness of actions that individuals and communities can take to improve brain health and potentially reduce the risk of dementia. Federal agencies will expand partnerships and coordinate messaging efforts across public and private entities. Recent efforts have also included a stronger emphasis on tailoring messages to at-risk individuals, such as Black and Hispanic individuals and women. New

and ongoing public messaging efforts should continue to enhance the cultural competence and assess the effectiveness of messaging across different populations.

(UPDATED) Action 6.F.2: Provide information to the public on brain health

Lead Agencies: CDC, HRSA, NINDS, NIA, NIH, ACL

CDC disseminates a weekly newsletter, *Alzheimer's Disease and Healthy Aging*, to more than 45,000 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. CDC has a second newsletter, *Alzheimer's Disease and Healthy Aging Tribal Newsletter*, is sent regularly to more than 470 subscribers interested in issues for AI/AN elders.

CDC partners with the 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/
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/397843
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/402234
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892
- https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101

Grant recipients of HRSA's GWEP are expanding their social media footprint by developing Tweets, public service announcements, videos, and public radio and television spots. In 2021, HRSA grantees continued to incorporate approaches to identify and mitigate AD/ADRD risk factors into their training materials and disseminate information on risk reduction through social media channels.

The campaign, "What is Brain Health?" formerly managed by ACL was transferred to NIA in 2017 and retired in 2020. NIA maintains a web portal on Cognitive Health and Older Adults, which was updated in 2020. Also in 2020, NIA published 11 lay-friendly stories that highlight recent research results in brain and cognitive health.

For more information, see:

- https://www.nia.nih.gov/health/brain-health-resource
- https://www.nia.nih.gov/health/cognitive-health
- https://www.nia.nih.gov/health/topics/brain-health

NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. See Action 1.E.2 for more information about ADEAR.

In 2020, NIA, working with other federal agencies, led efforts to update and enhance the Alzheimers.gov website. NIA launched this new portal to Federal Government information and resources in February 2021. The site features:

- Information about AD/ADRD.

- Tips and resources for caregivers and people living with dementia.
- Updates on Federal Government activities to address AD/ADRD.
- How to take part in clinical research and how to find studies.
- Resources for health care providers, community and public health workers, and researchers.

In October 2021, NIA also launched a Spanish version of the Alzheimers.gov website.

For more information, see:
- https://www.alzheimers.gov/
- https://www.alzheimers.gov/es
- https://www.nia.nih.gov/news/alzheimers-gov-website-now-available-spanish

In 2012 ACL, in partnership with NIH/NIA and CDC, created their Brain Health: You Can Make a Difference! curriculum/toolkit. The curriculum/toolkit was updated and simplified in 2018 and includes modules on brain health basics; medications and the brain; brain injury; and dementia, as well as complimentary evaluative tools to demonstrate training outcomes. Through ADPI, ACL's grantees use these tools to boost the dementia-capable services and supports in their states and communities. The available tools provide information on the risk factors associated with developing dementia, knowledge of the signs of cognitive impairment, and management of symptoms of people living with dementia.

For more information, see:
- https://acl.gov/brain-health
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/397843
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/402234
- https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892
- https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101

In 2021, all of the 48 HRSA-funded GWEPs are educating and training the public on brain health, including by sharing resources.

In 2021, the VA provided 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
- https://www.va.gov/GERIATRICS/pages/memory_loss_and_brain_health.asp

The 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. These briefs are currently under revision.

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

(UPDATED) Action 6.F.3: Enhance the reach and effectiveness of public health messaging on blood pressure control

Lead Agencies: NINDS, NIH, CDC

Researchers and public health officials have identified hypertension as one of the most modifiable risk factors for brain health and potentially dementia. CDC's Million Hearts® as well as NIH's The Heart Truth® and Mind Your Risks® all educate the public on the importance of reducing blood pressure among other modifiable risk factors. The Mind Your Risks campaign further emphasizes the link between uncontrolled blood pressure in midlife and increased risk for dementia. NINDS launched a "reboot" of Mind Your Risks in May 2021, which now includes an even stronger focus on health equity: the primary audience is Black men ages 28-45, who are at particularly high risk of hypertension, stroke, and dementia over the long term. New materials include an updated website, video, social media content, and educational resources including a flyer and discussion guide for medical appointments. Next steps include strengthening messaging partnerships, especially with community organizations and public stakeholders, and enhancing dissemination efforts.

For more information, see:

- https://www.mindyourrisks.nih.gov/
- https://www.mindyourrisks.nih.gov/resources.html
- https://www.youtube.com/watch?v=mJi9srnvI3Q

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 (AIDD)
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: National Plan to Address Alzheimer's Disease Milestones and Achievements Timeline

2012

HHS released the *National Plan to Address Alzheimer's Disease*, as required by the National Alzheimer's Project Act (NAPA) of 2011.

- https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plans

NIH convened the first *Alzheimer's Disease Research Summit*.

HHS created alzheimers.gov as a resource for people living with AD/ADRD and their caregivers.

- https://www.alzheimers.gov/

CDC developed Healthy People 2020 baseline measures for Dementia, including AD, in collaboration with federal partners.

- https://www.healthypeople.gov/2020/
- https://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease

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2013

NIH convened the first *Alzheimer's Disease-Related Dementias Research Summit*.

VA created Veterans with Dementia: Skills for Managing Challenging Behaviors video in collaboration with South Central Mental Illness Research Education and Clinical Center (MIRECC).

- https://youtu.be/hgVMKEnkvHo

HRSA and ASPE developed the continuing education course Case Challenges in Early Alzheimer's Disease.

- https://www.medscape.org/viewarticle/806464_4

IHS, ACL, and VA launched REACH into Indian Country Pilot of Caregiver Coaching and Support, 2013-2018.

CDC published the second *Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships (2013-2018)*.

- https://www.alz.org/media/Documents/road-map-2013-2018.pdf

2014

NIH researchers developed the first Alzheimer's model containing amyloid and tau, the two proteins that are hallmarks of AD/ADRD.

- https://www.nia.nih.gov/news/groundbreaking-alzheimers-model-petri-dish-points-amyloid-disease-trigger

NIH launched the Accelerating Medicines Partnership Program for Alzheimer's Disease® (AMP-AD).

- https://www.nia.nih.gov/research/amp-ad

ACL, NIH, and CDC collaborated on the development and delivery of Brain Health Resources (curriculum) for delivery in community and professional environments.

- https://acl.gov/brain-health

ACL, with funding from the Affordable Care Act expanded its long-standing Alzheimer's Disease Supportive Services Program (ADSSP) state grant program.

- https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease

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2015

NIH launched the Mind Your Risks® health campaign to educate the public about the importance of controlling blood pressure to help reduce the risk of having a stroke and developing dementia later in life.

- https://www.mindyourrisks.nih.gov/index.html

In partnership with CMS, the VA disseminated *Hand-in-Hand Training* to Community Living Centers (CLCs), with 76% of CLCs adopting training.

- https://qsep.cms.gov/data/AnD/Hand_in_Hand_Instructors_Guide.pdf

CDC made Cognitive Decline and Caregiving modules optional additions to states' annual Behavioral Risk Factor Surveillance System (BRFSS) survey.

ACL launched the National Alzheimer's and Dementia Resource Center website, making a broad range of grantee and center-developed resources available to the general public.

- https://nadrc.acl.gov/

2016

VA deployed Virtual Dementia Simulation for acute care providers.

HRSA and the Office of Women's Health (OWH) launched the continuing education course Bidirectional Impact of Alzheimer's Disease and Common Comorbid Conditions, which focused on assessing, managing, and treating AD/ADRD in the context of multiple chronic conditions.

HRSA released a 16-module AD/ADRD curriculum for health care workers to learn about dementia, including diversity and equity issues.

- https://bhw.hrsa.gov/alzheimers-dementia-training

NIH launched MarkVCID to develop biomarkers to detect vascular damage related to dementia.

- https://markvcid.partners.org/

2017

NIH convened the first *National Research Summit on Dementia Care and Services*.

- https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-additional-information/napa-caregiver-summit/2017-national-caregiver-summit

The Madison, Wisconsin VA Medical Center was recognized as the first dementia-friendly VA facility.

NIH established the Model Organism Development and Evaluation for Late-Onset Alzheimer's Disease (MODEL-AD) consortium to develop new animal models of LOAD.

- https://www.model-ad.org/

NIH launched the Alzheimer's Clinical Trials Consortium (ACTC), a clinical trials infrastructure designed to accelerate and expand studies for therapies in AD/ADRD.

- https://www.nia.nih.gov/research/dn/alzheimers-clinical-trials-consortium-actc

VA's Caring for Older Adults and Caregivers at Home (COACH) program was awarded a Gold Status practice by the VHA Diffusion of Excellence.

- https://www.ruralhealth.va.gov/docs/COACH_Issue_Brief_Final.pdf

IHS and VA released a Rural Interdisciplinary Team Training (RITT) to rural IHS and Tribal sites.

CDC began the *Alzheimer's Disease and Healthy Aging Newsletter*.

ACL created and launched their Dementia Capability Assessment for long-term support systems.

- https://nadrc.acl.gov/details?search1=117

2018

NIH released the National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research.

- https://www.nia.nih.gov/research/recruitment-strategy

NIH-funded first large-scale genetic study of LBD revealed that there is a strong genetic component of LBD with a unique genetic profile that is different from those of AD or Parkinson's disease.

- https://pubmed.ncbi.nlm.nih.gov/29263008/

CDC published the third *Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map*.

- https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf

CDC released four State of Aging and Health in America Data Briefs.

- https://www.cdc.gov/aging/publications/healthy-brain-issue-maps.html

ACL created the Alzheimer's Disease Programs Initiative (ADPI), by consolidating separate AD/ADRD state and community grant programs to create a new single program.

- https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease

An NIH study reported that clearing senescent cells -- cells that are alive but no longer divide or perform their designated functions -- in the brain decreases tau pathology and cognitive decline in animal models.

- https://www.nia.nih.gov/news/clearing-senescent-cells-brain-mice-preserves-cognition

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2019

An NIH study found that a blood test of neurofilament light chain, a protein released when nerve cells are damaged, predicted disease progression and loss of nerve cell function in the brain among cognitively normal people at risk for familial AD/ADRD.

- https://www.nia.nih.gov/news/blood-test-shows-promise-predicting-presymptomatic-disease-progression-people-risk-familial

NIH's SPRINT Memory and Cognition in Decreased Hypertension (MIND) study demonstrated that intensive high blood pressure control may significantly reduce the buildup of white-matter lesions in the brain and the occurrence of MCI, a precursor of dementia.

- https://www.nia.nih.gov/news/intensive-blood-pressure-control-may-slow-age-related-brain-damage

NIH funded the IMbedded Pragmatic Alzheimer's Disease and AD-Related Dementias Clinical Trials (IMPACT) Collaboratory, which is designed to spur innovation to meet the challenges of the complex care management for people living with AD/ADRD.

- https://impactcollaboratory.org/

NIH established Alzheimer's and Dementia Outreach, Recruitment, and Engagement (ADORE), an online, searchable database of resources for engagement, recruitment, and retention of study participants.

- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources

CDC and IHS published the first *Healthy Brain Initiative: Road Map for Indian Country* published.

- https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html

ACL convened the RAISE Family Caregiving Advisory Council.

- https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council

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2020

With partial funding from the NIH, the first blood test for amyloid, PrecivityAD, became commercially available.

- https://www.nia.nih.gov/report-2020-2021-scientific-advances-prevention-treatment-and-care-dementia/biomarker-research#spotlight

FDA-approved flortaucipir is the first radioactive tracer to show the presence of tau protein tangles.

An NIH-funded study led to an advance in the development of a blood test to help detect pathological AD in people showing signs of dementia. The blood test detects the abnormal accumulation of a form of tau protein (ptau181).

- https://www.nia.nih.gov/news/blood-test-method-may-predict-alzheimers-protein-deposits-brain

NIH launched the Center for Alzheimer's Disease and Related Dementias (CARD).

- https://card.nih.gov/

NIH launched the Drug Repurposing for Effective Alzheimer's Medicines (DREAM) study to determine whether medicines currently used to treat conditions other than dementia can help prevent or treat AD/ADRD.

- https://www.nia.nih.gov/news/nia-study-identifies-fda-approved-drugs-may-also-be-helpful-dementia

An NIH-funded study found that individuals who made multiple healthy lifestyle choices (physical activity, not smoking, light-to-moderate alcohol consumption, a high-quality diet, and cognitive activities) may have a much lower risk for AD/ADRD.

- https://www.nia.nih.gov/news/combination-healthy-lifestyle-traits-may-substantially-reduce-alzheimers-disease-risk

ACL expanded ADPI programming to dedicate resources to expanding dementia capability in Indian Country, launching grant and education programs in tribes and Tribal consortiums.

2021

HHS added a sixth goal to the *National Plan to Address Alzheimer's Disease* -- Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias.

- https://aspe.hhs.gov/reports/national-plan-2021-update#goal-6

IHS, in collaboration with Northwest Portland Area Indian Health Board (NPAIHB), created a dementia-focused Project ECHO (Extension for Community Healthcare Outcomes) for clinicians and caregiver support staff in Indian Country.

The RAISE Family Caregiving Advisory Council delivered its initial *Report to Congress*.

- https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council
- https://acl.gov/RAISE/report

NIH launched the second iteration of the AMP Program for Alzheimer's Disease (AMP-AD 2.0).

- https://www.nia.nih.gov/news/nih-invests-next-iteration-public-private-partnership-advance-precision-medicine-research

NIH revamped the Mind Your Risks® health campaign to focus more on health equity. The primary audience is now African American men, who are most at-risk for midlife high blood pressure and late-life dementia.

- https://www.mindyourrisks.nih.gov/index.html

2022

IHS published a funding opportunity, Addressing Dementia in Indian Country: Models of Care, and announced the availability of $5 million to target resources directly to tribes, Tribal organizations, Urban Indian organizations, and IHS direct service facilities to address AD/ADRD within Tribal communities.

- https://www.federalregister.gov/documents/2022/04/18/2022-08249/addressing-dementia-in-indian-country-models-of-care
- https://www.hhs.gov/about/news/2022/05/09/indian-health-service-funding-provides-resources-address-alzheimers-disease.html

VA launched the Dementia Education Portal for VHA dementia educators.

IHS created a collaborative to support Geriatric Emergency Department Accreditation for IHS and Tribal entities.

CDC established the Healthy Brain Resource Center.

- https://www.cdc.gov/aging/healthy-brain-resource-center/index.html

The DoD Congressionally Directed Medical Research Program (CDMRP) required community collaboration (inclusion of persons with dementia, their care partners and/or family members) in all clinical research projects proposed to next PRARP.

NIH renewed the DetectCID consortium to conduct clinical trial testing on early dementia detection approaches in primary care.

- https://www.detectcid.org/

List of Acronyms Used

A4	Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease
AAA	Area Agency on Aging
AAIC	Alzheimer's Association International Conference
AAPI	Asian Americans and Pacific Islanders
ABC-DS	Alzheimer's Biomarker Consortium - Down Syndrome
ABCD	Addressing Challenging Behaviors in Dementia
ACL	HHS Administration for Community Living
ACPM	American College of Preventive Medicine
ACTC	Alzheimer's Clinical Trials Consortium
AD	Alzheimer's Disease
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
AHRQ	HHS Agency for Healthcare Research and Quality
AI/AN	American Indian/Alaska Native
AIDD	ACL Administration on Intellectual and Developmental Disabilities
AITC	Artificial Intelligence and Technology Collaboratory
AlzPED	Alzheimer's Disease Preclinical Efficacy Database
AMP®-AD	Accelerating Medicines Partnership® Program for Alzheimer's Disease
AMP®-PD	Accelerating Medicines Partnership® Program for Parkinson's Disease
APOE	Apolipoprotein E
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
BOLD	Building Our Largest Dementia infrastructure for Alzheimer's act
BPSD	Behavioral and Psychological Symptoms of Dementia
BRFSS	Behavioral Risk Factor Surveillance System
CADHC	Community Adult Day Health Care
CAP	Collaboration for Alzheimer's Prevention
CARD	Center for Alzheimer's and Related Dementias
CBO	Community-Based Organization
CCBHC	Certified Community Behavioral Health Clinic
CDC	HHS Centers for Disease Control and Prevention
CDMRP	Congressionally Directed Medical Research Program
CLC	Community Living Center
CMMI	CMS Center for Medicare and Medicaid Innovation
CMPRP	Civil Monetary Penalty Reinvestment Program
CMS	HHS Centers for Medicare & Medicaid Services
CNA	Certified Nursing Assistant
COE-NF	Center of Excellence for Behavioral Health in Nursing Facilities

COPE	Care of Persons with Dementia in their Environments
COVID-19	Novel Coronavirus
CROMS	Clinical Research Operations and Management System
CSF	Cerebral Spinal Fluid
CSP	Cooperative Studies Program
CTE	Chronic Traumatic Encephalopathy
DetectCID	Consortium for Detecting Cognitive Impairment, Including Dementia
DIAN-TU	Dominantly Inherited Alzhiemer Network Trial Unit
DNA	Deoxyribonucleic Acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DREAM	Drug Repurposing for Effective Alzheimer's Medicines
EBP	Evidence-Based Practices
EDD	Early Detection and Diagnosis of Dementia
EHR	Electronic Health Record
EJI	DoJ Elder Justice Initiative
FDA	HHS Food and Drug Administration
FFS	Fee-For-Service
FIC	Fogarty International Center
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Dementia
FY	Fiscal Year
GACA	Geriatrics Academic Career Award
GACD	Global Alliance for Chronic Diseases
GDO	Global Dementia Observatory
GEOHealth	Global Environmental and Occupational Health
GRECC	Geriatric Research, Education, and Clinical Centers
GSA	Gerontological Society of America
GWEP	Geriatrics Workforce Enhancement Program
HABLE	Health and Aging Brain Among Latino Elders
HABLE-AT(N)	HABLE-Amyloid, Tau, and Neurodegeneration
HBI	Healthy Brain Initiative
HBPC	Home-Based Primary Care
HBRC	Healthy Brain Resource Center
HCAP	Harmonized Cognitive Assessment Protocol
HCBS	Home and Community-Based Services
HHS	U.S. Department of Health and Human Services
HIT	Health Information Technology
HRS	Health and Retirement Study
HRSA	HHS Health Resources and Services Administration
IA^2	International Association for Indigenous Aging
IADRP	International Alzheimer's Disease Research Portfolio
IDD	Intellectual and Developmental Disability
IHS	HHS Indian Health Service
IMPACT	IMbedded Pragmatic Alzheimer's Disease and AD-Related Dementias Clinical Trials
IMPACT-AD	Institute on Methods and Protocols for Advancement of Clinical Trials in AD/ADRD
INCLUDE	Investigation of Co-occurring Conditions across the Lifespan to Understand Down Syndrome

INFINITY	INtensive versus Standard Ambulatory Blood Pressure Lowering to Prevent Functional DeclINe In The ElderlY
IPF	Inpatient Psychiatric Facility
LBD	Lewy Body Dementia
LGBT	Lesbian, Gay, Bisexual, and Transgender
LIMBIC-CENC	Long-term Impact of Military-relevant Brain Injury Consortium/Chronic Effects of Neurotrauma Consortium
LMIC	Low and Middle Income Country
LOAD	Late-Onset Alzheimer's Disease
LTSS	Long-Term Services and Supports
MCI	Mild Cognitive Impairment
MDT	Multi-disciplinary Team
MFH	Medical Foster Home
MFP	Money Follows the Person
mg	Milligrams
MODEL-AD	Model Organism Development and Evaluation for Late-onset Alzheimer's Disease
MRI	Magnetic Resonance Imaging
NACC	National Alzheimer's Coordinating Center
NACCHO	National Association of County and City Health Officials
NACDD	National Association of Chronic Disease Directors
NADRC	National Alzheimer's and Dementia Resource Center
NAHN	National Association of Hispanic Nurses
NAPA	National Alzheimer's Project Act
NASEM	National Academies of Science, Engineering and Medicine
NBHCAA	National Brain Health Center for African Americans
NBNA	National Black Nurses Association
NCAPPS	National Center on Advancing Person-Centered Practices and Systems
NCD-LIFESPAN	Chronic, Noncommunicable Diseases and Disorders Across the Lifespan
NCHS	NIH National Center for Health Statistics
NCRAD	National Centralized Repository for Alzheimer's Disease and Related Dementias
NCUIH	National Council of Urban Indian Health
NHANES	National Health and Nutrition Examination Survey
NHATS	National Health and Aging Trends Study
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
NICOA	National Indian Council on Aging
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
NPAIHB	Northwest Portland Area Indian Health Board
NPS	Neuropsychiatric Symptoms
NRC-SDM	National Resource Center for Supported Decision-Making
NSF	National Science Foundation
NSOC	National Study of Caregiving
NTG	National Task Group on Intellectual Disabilities and Dementia Practices
NYU	New York University

OAA Older Americans Act
OASH HHS Office of the Assistant Secretary for Health
ODPHP HHS Office of Disease Prevention and Health Promotion
ONC HHS Office of the National Coordinator for Health Information Technology
OTC Over-The-Counter
OWH HHS Office on Women's Health

PAGAC (Physical Activity Guidelines Advisory Committee)
PASC Post-Acute Sequelae of COVID-19
PBRN Practice-Based Research Network
PDBP (Parkinson's Disease Biomarkers Program)
PDF (Portable Document Format)
PET Positron Emission Tomography
PHCOE Public Health Center of Excellence
PHE Public Health Emergency
PPS Prospective Payment Systems
PRARP Peer Reviewed Alzheimer's Research Program
PREVENTABLE Pragmatic Evaluation of Events and Benefits of Lipid-lowering in Older Adults
PSM (Peer Support Mentoring)
PTSD Post-Traumatic Stress Disorder
PwIDD-HBI People with Intellectual and Developmental Disability Healthy Brain Initiative

QIO Quality Improvement Organization

RAISE (Recognize, Assist, Include, Support, and Engage)
REACH Resources for Enhancing Alzheimer's Caregivers Health
REACH-VA Resources for Enhancing Alzheimer's Caregivers Health in the VA
RECOVER (Researching COVID to Enhance Recovery)
RFA (Request for Application)
RFI (Request for Information)
RITT Rural Interdisciplinary Team Training
RN (registered nurse)

SAFE (Safe Accessible Interviewing for Older Adults)
SAMHSA HHS Substance Abuse and Mental Health Services Administration
SARS-CoV-2 Severe Acute Respiratory Syndrome Coronavirus 2
SBIR Small Business Innovation Research
SCD Subjective Cognitive Decline
SDM Supported Decision Making
SDOH Social Determinants of Health
SES Socioeconomic Status
SMI Serious Mental Illness
SPRINT-MIND Systolic Blood Pressure Intervention Trial - Memory and Cognition in Decreased Hypertension
STTR Small Business Technology Transfer
SUD Substance Use Disorder

T-MSIS Transformed Medicaid Statistical Information System
TBI Traumatic Brain Injury
TIP Treatment Improvement Protocol
TRACTS (Translational Research Center for TBI and Stress Disorders)
TREAT-AD TaRget Enablement to Accelerate Therapy development for Alzheimer's Disease

UIC	University of Illinois at Chicago
UIH	Urban Indian Health
VA	U.S. Department of Veterans Affairs
VCID	Vascular Contributions to Cognitive Impairment and Dementia
VHA	VA Veterans Health Administration

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