

Overview of the National Alzheimer's Project Act Implementation



U.S. Department of Health and Human Services



OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY

1

Agenda

- History of NAPA
- Advisory Council on Alzheimer's Research, Care & Services
- National Plan to Address Alzheimer's Disease
- Federal Infrastructure
- Progress



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2

National Alzheimer's Project Act (NAPA)

- Requires the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:
- Create and maintain an integrated **national plan to overcome Alzheimer's**;
- Coordinate research and services across all federal agencies;
- Accelerate the development of treatments that would prevent, halt, or reverse the disease;
- Improve early diagnosis and coordination of care and treatment of the disease;
- Improve outcomes for ethnic and racial minority populations at higher risk;
- Coordinate with international bodies to fight Alzheimer's globally; and
- **Create an Advisory Council** to review and comment on the national plan and its implementation

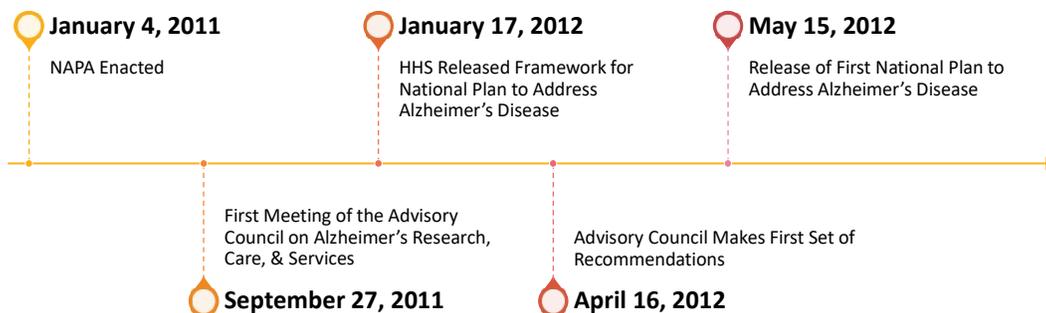


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3

3

NAPA Implementation Timeline



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4

4

National Plan to Address Alzheimer's Disease

GOALS

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. Optimize Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease 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

**National Plan
to Address
Alzheimer's Disease**



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5

5

National Plan to Address Alzheimer's Disease

- Updated annually
- Organized with six major goals
 - Strategies to achieve those goals
 - Specific action steps taken by the federal government
- Summarizes completed, current, and planned work
- Actions arise from:
 - Recommendations from the Advisory Council
 - Public comments
 - Issues in the field
 - Topics raised by federal partners

**National Plan
to Address
Alzheimer's Disease**



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6

Federal Coordination

- HHS and federal partners meet regularly
- Coordination and collaboration across issues
- Leveraging and pooling resources
- Consistent staff and leadership on NAPA = consistently elevated Advisory Council recommendations
- Results in broad federal awareness and interest in the needs of this vulnerable population
- Model for addressing challenging and cross-cutting topics



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7

7

Advisory Council on Alzheimer's Research, Care, and Services



PUBLIC MEMBERS

- 2 Patient Advocates, including a person living with dementia
- 2 Caregivers
- 2 Providers
- 2 State and local government representatives
- 2 Researchers
- 2 Voluntary health association representatives

FEDERAL GOVERNMENT



- Department of Health and Human Services
 - ASPE, ACL, NIH, AHRQ, CMS, HRSA, IHS, FDA, CDC
- Department of Veterans Affairs
- Department of Defense
- National Science Foundation



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8

Subcommittees

RESEARCH

- Historical focus on biomedical research
- Past recommendations include:
 - Adequate funding for NIH research
 - Increasing clinical trial enrollment
 - Brain donations
 - Research infrastructure
- Research is important to LTSS and clinical care, so it is often part of those recommendations

CLINICAL CARE

- Focus on the healthcare infrastructure, encompassing:
 - Detection and diagnosis of dementia
 - Work force
 - Care delivery and financing models
 - Care quality
 - Transitions between care settings
 - Care for other chronic conditions for people with dementia



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9

Subcommittees

LONG-TERM SERVICES & SUPPORTS

- Focus on long-term care providers
 - Home and community-based
 - Institutional (e.g., nursing homes)
- Long-term care workforce
- Challenges with accessing and financing LTSS
- Caregiving and caregiver support

RISK REDUCTION

- Existing and growing research evidence on AD risk factors
- Advancing risk reduction activities
- Creating communities that support healthy aging



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10

Recommendations

- Made by non-Federal members of the Advisory Council
- Made to the Secretary of HHS and Congress
- May be precise, targeted recommendations or higher-level aspirational goals
- Examples:
 - Dementia Care and Services Research Summit
 - GUIDE Model
- <https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-recommendations>



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11



**Overview of NIH AD/ADRD
Research Activities**

*Advisory Council on Alzheimer's Research, Care, and
Services Meeting*

Richard J. Hodes, M.D.
Director, NIA
October 30, 2023

12

NIH Leads Federal AD/ADRD Research Efforts

- The National Plan to Address Alzheimer's Disease calls for **action to accelerate research and improve care and services** for people living with dementia and their families
- **NIH leads research efforts** associated with the National Plan, including the first goal targeted at preventing and treating AD/ADRD
- These efforts, led by the National Institute on Aging (NIA) and National Institute on Neurological Disorders and Stroke (NINDS), **span basic, translational, clinical, and care** research in AD/ADRD



13

NIH AD/ADRD Research Strategy Builds from External and Internal Input

Review input from external sources, including:

- Academic research community
- Industry
- Other federal agencies
- Non-governmental organizations
- Advocates
- General Public
- People with lived experience

Identify research gaps and opportunities

Develop comprehensive research implementation milestones

Release funding opportunities and cultivate partnerships

Support AD/ADRD Science Advances

14

NIH AD/ADRD Research Implementation Milestones

- NIH research implementation milestones are generated with input from hundreds of members of a **multistakeholder community of leading experts working on AD/ADRD and other chronic diseases and public advocates**
- These milestones represent a **research framework detailing specific steps and success criteria** towards achieving National Plan goals
- This research framework **directly informs NIH Funding Opportunities**

Research Implementation Milestones
<https://www.nia.nih.gov/research/milestones>

- Epidemiology/Population Studies
- Disease Mechanisms
- Diagnosis, Assessment, & Disease Monitoring
- Translational Research and Clinical Interventions
- Dementia Care and Impact of Disease
- Research Resources
- AD Related Dementias Focus

15

Increased NIH Investment in AD/ADRD Research Leads to Advances

- Over the past 10 years, NIH significantly expanded its investments in AD/ADRD research.
- Through sustained NIH investment, scientists have made significant strides in understanding AD/ADRD, and progress toward how to effectively diagnose, treat, and prevent them.

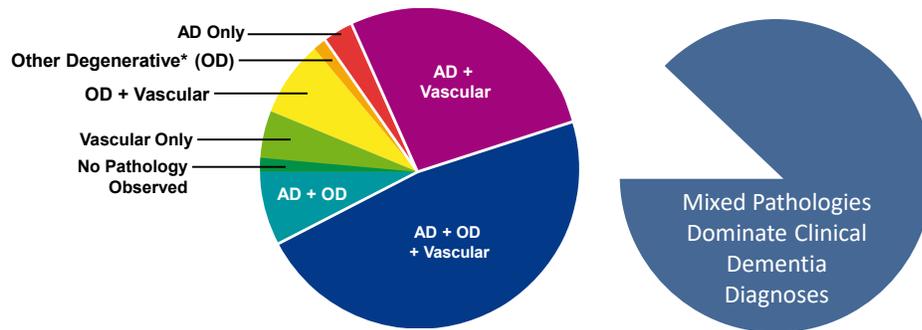
| Research/Disease Areas | FY 2015 | FY 2016 | FY 2017 | FY 2018 | FY 2019 | FY 2020 | FY 2021 | FY 2022 | Difference – FY 2015 to FY 2022 |
|---|---------|---------|---------|---------|---------|---------|---------|---------|---------------------------------|
| AD/ADRD ¹ | \$631 | \$986 | \$1,423 | \$1,911 | \$2,398 | \$2,869 | \$3,251 | \$3,514 | 5.6-fold increase |
| Alzheimer's Disease (AD) | \$589 | \$929 | \$1,361 | \$1,789 | \$2,240 | \$2,683 | \$3,059 | \$3,314 | 5.6-fold increase |
| Alzheimer's Disease Related Dementias (ADRD) ^{2,3} | \$120 | \$175 | \$249 | \$387 | \$515 | \$600 | \$725 | \$730 | 6.1-fold increase |
| Lewy Body Dementia | \$15 | \$22 | \$31 | \$38 | \$66 | \$84 | \$113 | \$118 | 7.9-fold increase |
| Frontotemporal Dementia | \$36 | \$65 | \$91 | \$94 | \$158 | \$166 | \$164 | \$169 | 4.7-fold increase |
| Vascular Cognitive Impairment/Dementia | \$72 | \$89 | \$130 | \$259 | \$299 | \$362 | \$455 | \$445 | 6.2-fold increase |

16

Paradigm Shift: Traditional Perception of 1:1 Relationship Between Brain Pathologies and Clinical Dementia Diagnoses is the **Exception, Not the Rule**

CLINICAL DIAGNOSIS: PROBABLE ALZHEIMER'S DEMENTIA

PATHOLOGICAL DIAGNOSES:



THIS MATTERS FOR DEVELOPMENT OF PRECISION APPROACHES & BIOMARKERS

Increased recognition that more than one disease process is typically present in a person's brain should help move toward effective prevention and treatments.

Adapted from KAPASI A, ET AL. ACTA NEUROPATHOL. 2017 AUG;134(2):171-186. ROS/MAP (N = 447)

*Other Degenerative (OD) included neurodegenerative disease pathologies: Lewy bodies, TDP-43, hippocampal sclerosis

17

Examples of NIH AD/ADRD Research Accomplishments

Disease Mechanisms

- **TEN YEARS AGO:** We knew of only 10 genes associated with Alzheimer's.
- **NOW:** We know of and are **researching more than 70 related genetic variants**, which offer new, diverse targets for intervention.



Diagnosis

- **BEFORE THE EARLY 2000s:** Alzheimer's could only be diagnosed after death.
- **NOW:** NIH research has led to the **development of imaging and biomarkers to enable more precise and earlier diagnoses** and help lower the cost and time needed to screen participants for clinical trials.



18



19

NASEM Study on Research Priorities for Preventing and Treating AD/ADRD

- **Task order established:**
March 27, 2023
 - **Committee establishment:**
September 19, 2023
 - **First committee meeting:**
October 2, 2023
 - **Final report anticipated:**
Jan - March 2025
- In response to a congressional mandate, an ad hoc committee of NASEM will conduct a study and recommend research priorities to advance the prevention and treatment of AD/ADRD. In conducting its study, the committee will:
- 1) Examine and assess the current state of biomedical research aimed at preventing and effectively treating AD/ADRD, along the R&D pipeline from basic to translational to clinical research;
 - 2) Assess the evidence on nonpharmacological interventions aimed at preventing and treating AD/ADRD;
 - 3) Identify key barriers to advancing AD/ADRD prevention and treatment (e.g., infrastructure challenges that impede large scale precision medicine approaches, inadequate biomarkers for assessing response to treatment, lack of diversity in biobanks and clinical trials), and opportunities to address these key barriers and catalyze advances across the field;
 - 4) Explore the most promising areas of research into preventing and treating AD/ADRD.

20

Upcoming Summits



Cognitive Aging
SUMMIT IV
Bethesda North Marriott Hotel & Conference Center | 5701 Marinelli Road | North Bethesda, MD
Save the Date March 20-21, 2024



Save the Date: 2024 NIH Alzheimer's Disease Research Summit



National Institute on Aging

2024 NIH Alzheimer's Disease Research Summit: Path to Precision Medicine for Treatment and Prevention

September 23-25, 2024

21



NIH National Institute on Aging

NINDS-led Programs and Updates

22

22

Added Funds Since FY 2016 Allowed NINDS to Lead and Establish Major ADRD Research Programs



- **DiverseVCID**, impact of vascular changes on developing ADRDs in 2,250 Americans from diverse backgrounds
- **MarkVCID**, national VCID Biomarkers Consortium
- **DISCOVERY** to determine stroke types and comorbidities that cause of **Post-Stroke VCID** including in populations that experience health disparities
- **DetectCID** increase detection of cognitive impairment/dementia in primary care settings and in populations that experience health disparities
- **PET Ligand Development Proteinopathy Structural Biology for ADRD Center Without Walls**
- **FTD Center Without Walls** to study molecular mechanisms that lead to FTD
- **North American Prodromal Synucleinopathy (NAPS)** consortium for REM Sleep Behavior Disorder
- **ALLFTD Natural History Study in FTLD**, together with the NIA
- **LBD Center Without Walls** to characterize α -synuclein and β -amyloid subtypes in LBD
- **LBD biomarker discovery research**
- **CONNECT-TBI**, program with 12 research institutions studying traumatic brain injury (TBI) links to AD/ADRD
- Establish **Center for Alzheimer's Disease Research (CARD)**, intramural center with NIA



Tauopathy and TDP-43 Proteinopathy Structural Biology
Using Cryo-EM & Mass Spectrometry



23



Anti-A β Passive Immunotherapy for Alzheimer's Dementia and Amyloid-Related Imaging Abnormalities (ARIA) Workshop

Summary

- Anti beta-amyloid antibodies aducanumab and lecanemab have received accelerated approval by the FDA for the treatment of mild to moderate Alzheimer's disease.
- During the clinical trials of anti- β -amyloid (A β) immunotherapy, MRI abnormalities as an adverse effect have been reported, termed "amyloid-related imaging abnormalities" (ARIA).

Workshop Goals

- 1) Understand mechanisms of BBB injury associated with anti-A β passive immunotherapy
- 2) Identify patients at risk for ARIA (e.g. with comorbidities/treatments, such as anti-coagulants)
- 3) Potential therapeutic strategies and research ideas to protect patients at risk

The workshop was held on September 28-29, 2023 (NINDS Point of Contact: Francesca Bosetti) and archived here:

<https://videocast.nih.gov/watch=52400> (Day 1)

<https://videocast.nih.gov/watch=52402> (Day 2)

24

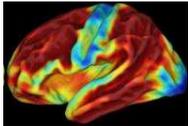
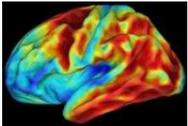
Novel Strategies: Resilience as a Potential Approach to Delay Alzheimer’s Dementia



Mutations in the Presenilin 1 gene (e.g., PSEN1-E280A) cause genetic Alzheimer’s Disease with early onset dementia
 PSEN1-E280A gene carriers with rare variants in two other genes are resilient against dementia longer than expected:

- ❑ **Reelin** (“COLBOS”, H3447R): cognitively intact until 67, two decades longer than expected
- ❑ **ApoE3** (“Christchurch”, R136S): cognitively intact three decades longer than expected

Tau PET PSEN-E280A Carriers

| Resilience Variant: none MCI at typical age (44) | Resilience Variant: COLBOS Later Onset MCI (73) |
|---|---|
|  |  |

0.800 0.920 1.040 1.160 1.280 1.400 1.520 1.640 1.760 1.880 2.000

PHF Tau
(FTP PET SUVR)

 National Institute of Neurological Disorders and Stroke
  National Institute on Aging

<https://www.nia.nih.gov/news/case-study-unlocks-clues-rare-resilience-alzheimers-disease>

PSEN1-E280A carriers in their 70s with these Reelin or ApoE3 variants display Aβ and Tau PET signals like carriers with MCI in their 40s:

NINDS is supporting research to follow-up to these findings and move forward the science of resilience against dementia: RM1NS132996

Lopera et al., *Nature Medicine* 29, 1243–1252 (2023) (Support: NIH grants UH3NS100121, RF1NS110048, DP5OD019833, R01AG054671, RF1AG077627, K99AG073452, R01EY027739, RF1AG041705, R01AG058468, P30AG072980; NSF, Alzheimer’s Association, Fonds de Recherche du Québec-Santé; German Federal Ministry of Education and Research; Banner Alzheimer’s Foundation, NOMIS Foundation and anonymous foundations [state of AZ]). Also see Arboleda-Velasquez et al., *Nature Medicine* 25, 1680–1683 (2019) for APOE3 Christchurch (APOE3Ch) homozygote case report. (Supported by NIH grants UH3 NS100121; RF1 NS110048; R01AG054671; RF01AG057519; R01AG031581; P30AG19610; DP5OD019833; Banner Alzheimer’s Foundation and Nomis Foundation grants)

25

Health Equity, Prevention Public Health Campaign: Mind Your Risks®

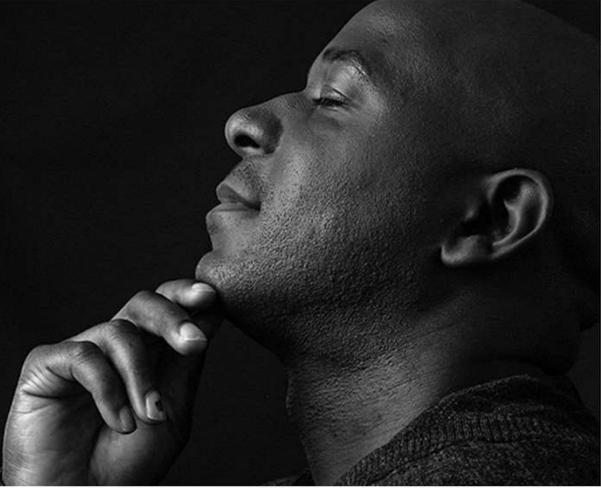


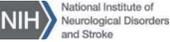
YOU HAVE A
BRILLIANT
mind.

DON'T RISK LOSING IT TO HIGH BLOOD PRESSURE.

Many years before you have a stroke or notice dementia, uncontrolled high blood pressure narrows your arteries, decreasing blood to your brain. If you're a Black man 28-45, take charge of your health today. Because nobody can lower your risk of stroke and dementia like you.

[Know Your Risks](#)
[Take Charge of Your Health](#)





mindyourrisks.nih.gov

<https://www.youtube.com/watch?v=mJi9srnv13Q>

Created By: NINDS ONCE Office

26



Food and Drug Administration

- Responsible for protecting the public health by ensuring:
 - The safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices
 - The safety of our nation's food supply, cosmetics, and products that emit radiation
- Approval of monoclonal antibodies that target amyloid in AD (traditional approval of lecanemab, 2023; accelerated approval of aducanumab, 2021)
- Diagnostic products approved/cleared for use in AD
 - CSF-based diagnostics (Elecsys 2023, Lumipulse 2022)
 - Tau-PET imaging agents (florbetapir 2020)
 - Amyloid-PET imaging agents (florbetaben 2014, flutemetamol 2013, florbetapir 2012)

www.fda.gov

27

27



NAPA Advisory Council Federal Update
October 30, 2023

28

Centers for Medicare and Medicaid Services

- As the largest single purchaser of health care dollars, Medicare plays a key role in transitioning our health care system away from fee-for-service and towards value-based care.
- CMS is the largest purchaser of health care in the world
- CMS programs provide health care coverage to over 130 million people, or 1 of every 3 Americans
- In 2021, almost 64 million people are enrolled in Medicare, with nearly 75 million enrolled in Medicaid
- More than 12 million people are enrolled in both programs, and these individuals have very high rates of chronic illness; most with multiple chronic conditions
- Most Medicare beneficiaries - over 80% - are over age 65
- 55% of the Medicare beneficiaries are women
- Some people come into Medicare first, typically through age, and others become beneficiaries because of disability or other health status (e.g. renal disease)

[Medicare Beneficiary Enrollment Trends and Demographic Characteristics](#)

29

Beta Amyloid Positron Emission Tomography in Dementia and Neurodegenerative Disease

- On October 13 CMS removed the national coverage determination (NCD) ending coverage with evidence development for positron emission tomography (PET) beta amyloid imaging and permitting Medicare coverage determinations for PET beta amyloid imaging to be made by the Medicare Administrative Contractors
- The removal of the NCD also removed the previous restriction of one beta amyloid PET scan per beneficiary per lifetime
- The decision memorandum can be found at
 - <https://www.cms.gov/medicare-coverage-database/view/ncacal-decision-memo.aspx?proposed=N&ncaid=308>

(Strategy 1.E)

30

Medicare 2024 Physician Fee Schedule (PFS) Proposed Rule

- Each year CMS issues a rule that solicits public comment on proposed policy changes for Medicare under the PFS
- On July 13 CMS published a proposed rule soliciting comment under the PFS for policies that would be effective on or after January 1, 2024:
 - **Caregiver Training Services (CTS)** practitioners can train and involve caregivers in supporting people with certain conditions (e.g., dementia) under an individualized treatment or therapy plan of care
 - **Social Determinants of Health (SDOH) risk assessment** standalone G code, optional element Annual Wellness Visit, and SDOH same day E/M visit
 - **Community Health Integration (CHI)** health integration services to help address unmet social needs that affect diagnosis/treatment

31

Medicare 2024 Physician Fee Schedule (PFS) Proposed Rule (cont'd)

- **Principal Illness Navigation (PIN)** services to help people with high-risk conditions
- **Psychotherapy for Crisis Services** furnished at a site other than an office setting, including the home or a mobile unit (according to section 4123 of the 2023 Consolidated Appropriations Act, CAA 2023), with increased payment for services in these settings
- **Health and Behavior Assessment and Intervention (HBAI) code provider expansion** to include clinical social workers, marriage and family therapists (MFT), and mental health counselors (MHT), in addition to psychologists
- **Telehealth changes** (e.g. health and well-being coaching, SDOH risk assessment)
- (Strategy 2.G)

32

Medicare 2024 Physician Fee Schedule (PFS) Proposed Rule (cont'd)

- **Modification of Hospice Conditions of Participation** to include a social worker, MHC, or MFT to serve as team members

CMS also seeks comment on other behavioral health improvements:

- **Request for Information on Digital Therapies** including Cognitive Behavior Therapy (CBT)
- **Safety Planning** follow up after ED/crisis encounter
- **Behavioral Health Integration (BHI)** services increased access
- **Interprofessional consultation** for diagnosis/treatment of mental illness
- **Psychiatrist participation** in Medicare

COMMENT PERIOD CLOSED SEPTEMBER 11

<https://www.federalregister.gov/documents/2023/08/07/2023-14624/medicare-and-medicaid-programs-cy-2024-payment-policies-under-the-physician-fee-schedule-and-other>

33

Promising Practices for Promoting Person-Centered Communication and Care Coordination

- On September 13 CMS's Resources for Integrated Care resource held a webinar on Promising Practices for Promoting Person-Centered Communication and Care Coordination for dually eligible Medicare-Medicaid beneficiaries
- Health plans shared their promising practices for promoting person-centered care coordination, with an emphasis on communication-focused strategies that can be used to overcome common barriers to care coordination across the team
- The Webinar is archived at:
https://www.resourcesforintegratedcare.com/2023_ric_webinar_promising-practices-for-promoting-person-centered-communication-and-care-coordination/

(Strategy 2F)

34

Center of Excellence for Behavioral Health in Nursing Facilities

- The Center offered six training opportunities in October on topics ranging from co-occurring disorders to suicide
- There is a lot of information on the website: <https://nursinghomebehavioralhealth.org/>, and you can sign up for regular updates regarding upcoming trainings and events
- The Center aims to help nursing homes care for individuals with underlying serious mental illness (SMI), and substance use disorders including opioid use disorders

(Strategy 2A)

35

Civil Money Penalty (CMP) Reinvestment Program Revisions

- On September 25 CMS issued updated guidance on the allowable use and non-allowable use criteria, increasing opportunities for resident internet service, and other flexibilities
- A CMP is a monetary penalty CMS may impose against nursing homes for either the number of days or for each instance a nursing home is not in substantial compliance with one or more Medicare/Medicaid participation requirements
- A portion of CMPs collected from nursing homes are returned to the states in which CMPs are imposed and may be “reinvested” to support activities that benefit nursing home residents and that protect or improve their quality of care or quality of life
- The new guidance and more about the program can be found here: <https://www.cms.gov/medicare/health-safety-standards/quality-safety-oversight-general-information/policy-memos-states/civil-money-penalty-reinvestment-program-cmprp-revisions>

(Strategy 2.A)

36

Veterans' Health Administration

- Healthcare and long-term services and supports
 - All Veterans with need are eligible for Home & Community Based Services (HCBS)
 - Only certain specific service-connected Veterans are eligible for nursing home care
 - VA has many HCBS and Nursing Home Care that are either directly provided by VA employees, purchased from the community or in partnership with State Veteran Homes
- Implementing Institute of Healthcare Improvement (IHI) Age-Friendly Health System (AFHS) throughout the enterprise in a multiyear plan



37

Veterans' Health Administration

- VA has programs that cover outpatient, inpatient acute care, home care and extended care services
- Undergoing one of the largest multi-year HCBS expansions with Veteran Directed Care (VDC), Medical Foster Home (MFH) and Home-Based Primary Care (HBPC)
- 20 Geriatric Research, Education, and Clinical Centers (GRECCs)
- Has multiple pilots related to Aging Veterans and Aging in Place
- Multiple research programs are in cooperation with the VA Office of Research and Development



38

Indian Health Service

- Responsible for federal health services to American Indians and Alaska Natives
- Providing a comprehensive health care delivery system for approximately 2.6 million American Indians and Alaska Natives who belong to 574 federally recognized tribes in 37 states.
- Based in the government-to-government relationship between the federal government and federally-recognized Tribes.

<https://www.ihs.gov/aboutihs/>

The system of care for AI/AN includes:

- Indian Health Service direct health care services
 - 24 hospitals, 51 health centers, and 24 health stations
- Tribally operated health care services
 - 22 hospitals, 279 health centers, and 79 health stations
- Urban Indian Health care services and resource centers
 - 41 urban-centered, non-profit Indian Organizations providing health care services at 59 locations

<https://www.ihs.gov/newsroom/factsheets/ihsprofile/>

39

Indian Health Service

- The IHS Alzheimer's Grant Program (first funded in FY2021) in the Office of Clinical and Preventive Services, Division of Clinical and Community Services, operates through four priorities developed through Tribal Consultation and Urban Confer
- Grants and program awards for Indian health programs for the development of comprehensive models of care and specific care and services.
 - 12 Tribes, Tribal Organizations, and Urban Indian Organizations currently funded
- Workforce development, education and training, including:
 - Indian Health Geriatric Scholars
 - Indian Country ECHO programs in clinical care and caregiver support in partnership with the Northwest Portland Indian Health Board
 - Early Dementia Detection Initiative with Division of Oral Health and the Community Health Representatives program
 - Geriatric ED Accreditation Initiative with Division of Nursing
- Outreach and Awareness
- Data and program support resources to support Tribes and Urban Indian Organizations to address dementia.

40

Health Resources and Services Administration

- Mission: To improve health outcomes and achieve health equity through access to quality services, a skilled health workforce, and innovative, high-value programs.
- Since 2011, HRSA's dementia workforce development activities included:
 - Providing over 6000 interprofessional educational offerings on dementia to over 700,000 trainees through its 48 HRSA-funded Geriatrics Workforce Enhancement Program grant recipients
 - Publishing two MedScape articles on dementia:
 - Case Challenges in Early Alzheimer's Disease
 - Bidirectional Impact of Alzheimer's Disease and Common Comorbid Conditions
 - Developing 16-module ADRD curriculum posted on HRSA dementia webpage at [Train Health Care Workers About Dementia | Bureau of Health Workforce \(hrsa.gov\)](#)
 - Developing 9-module HRSA Caregiving Curriculum on the HRSA dementia webpage
- HRSA has overseen the creation of a multimedia, multiple-module COVID-19 Nursing Home training that will be accessed at the HRSA dementia webpage once it has finished the clearance process.



41

41

Administration for Community Living

Established: April 2012, HHS aging and disability programs

- Administration on Aging
- Office on Disability
- Administration on Developmental Disabilities

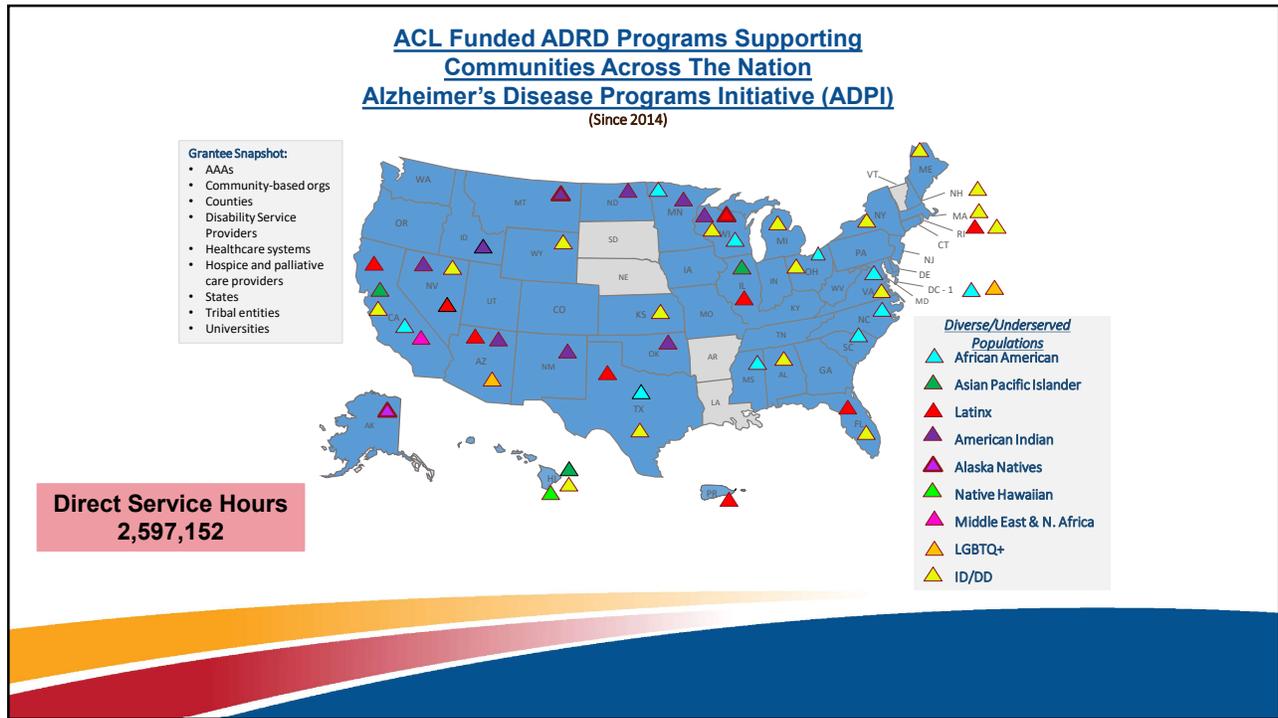
Brought together:

- Federal advocacy for older adults and people with disabilities
- Most federal human services programs for older adults and people with disabilities

Founding principle: People with disabilities and older adults should be able to live where they choose, with the people they choose, and fully participate in their communities.

42

42



43

[HOME](#) [RESOURCES](#) [ACL PROGRAMS SUPPORTED BY NADRC](#)

National Alzheimer's and Dementia Resource Center

The NADRC provides expert technical assistance to AoA/ACL and its grantees, as well as making program information, program deliverables and resources available to individuals and organizations outside the Alzheimer's grantee community.

<https://nadrc.acl.gov/>

44

44

Interventions and Outcomes

| Evidence Based/Informed Interventions | Person with Dementia Outcomes | Caregiver Outcomes | Target Populations |
|--|---|---|--|
| <ul style="list-style-type: none"> • Adult Day Plus • BRI Care Consultations • Building Better Caregivers • Caregiver Stress Prevention Bundle • Care Ecosystem • Cognitive Stimulation Therapy (CST) • COPE • Hospital to Home • Music and Memory • Powerful Tools for Caregivers (PTC) • REACH TX • Reducing Disability in Alzheimer's Disease (RDAD) • Skill2Care • StressBusters | <ul style="list-style-type: none"> • Increased Quality of Life • Increased Enhance Self-efficacy (early stage) • Increased Meaningful Engagement • Decreased Emergency Room Visits • Decreased depression • Decreased stigma • Increased independent functioning • Decreased unmet needs • Decreased behavioral symptoms • Delayed nursing home placement | <ul style="list-style-type: none"> • Delayed Intent to Place • Improved Caregiver Stress • Improved Caregiver Burden • Improved Caregiver Coping • Improved Health • Improved Quality of Life • Increased Confidence/Self-Efficacy • Increased Dementia Knowledge | <ul style="list-style-type: none"> • African American • Asian/Pacific Islander • Filipino • Hispanic • Hmong • Intellectual and Developmentally Disabled (IDD) • Low Income • Native Americans • Persian • Rural • Somali |

[Evaluating Dementia Services and Supports: Instrument Resource List, 3rd Edition](#)
[Grantee-Implemented Evidence-Based and Evidence-Informed Interventions](#)

45

45

Fall 2023 Update

- 18 State and Community Grants Awarded (4 States and 12 CBOs)
- [Promising Programs and Services for People Living Alone with Dementia](#)

This promising practices resource, developed by the National Alzheimer's and Dementia Resource Center (NADRC) is intended to support the work of ACL's ADPI grantees and others who are dedicated to developing and delivering programs and services for PLAWD to support people living with Alzheimer's disease and related dementias and their caregivers.

- [Addressing Social Isolation and Loneliness of People Living with Dementia and Their Caregivers](#)

This paper reviews the unique impact of dementia on social isolation and loneliness, tools for measuring these experiences, and five common types of programs for addressing social isolation and loneliness among people living with dementia and their caregivers.

46

46

National Alzheimer's and Dementia Resource Center

UPCOMING WEBINAR

Applying the National Strategy to Support Family Caregivers to Dementia Programs.

Wednesday, November 1st, 2023, from 3-4 p.m. ET

The 2022 National Strategy to Support Family Caregivers was developed to support caregivers of all ages, regardless of where they live or their specific caregiving situation. The Strategy includes five overarching goals and 350 corresponding actions, while not addressing specific populations of caregivers. While the goals and actions contained within the Strategy are not dementia specific, they can be applied to dementia caregiving. This webinar will focus on the ways in which the goals can apply specifically to caregivers of people living with dementia and services designed to support such caregivers.

Additional information about this webinar and the registration form can be found here: [11-1-23 Applying the National Family Caregiver Strategy to Dementia Programs.](#)

47

47



AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



NAPA AHRQ Update

Arlene S. Bierman, MD, MS
Chief Strategy Officer
Agency for Healthcare Research and Quality

October 30, 2023

48

Agency for Health Care Research and Quality (AHRQ) Mission



www.ahrq.gov

To produce evidence to make health care safer, higher quality, more accessible, equitable and affordable

To work with HHS and other partners to make sure that the evidence is understood and used

49

AHRQ Improves Healthcare Delivery



- **Generating scientific evidence and knowledge:** Funding health services research to understand how **care** is delivered and how it can be delivered better (quality, safety, equity, value)
- **Moving evidence into practice:** Filling the “Evidence to Implementation Gap” – Knowledge, synthesis generation and implementation - Developing tools, training, resources, and assistance.
- **Monitoring and feedback:** Measurement, data, analytics, and reporting

50

50

AHRQ Roundtable Report



Optimizing Health and Function as We Age Roundtable Report



AHRQ's [*Optimizing Health and Function as We Age Roundtable Report*](#) summarizes a roundtable of approximately 40 multidisciplinary experts who discussed how AHRQ can impact the research, dissemination and implementation of evidence to improve the organization and delivery of healthcare with the goal of optimizing the health, functional status and well-being of the U.S. population as it ages.

<https://www.ahrq.gov/news/healthy-aging-roundtable.html>

51

Opportunities Identified



- Developing a truly person-centered care system
 - Address full range of older adults' needs by building connections to community-based organizations
 - Ensure age-friendly healthcare and public health systems
- Generating evidence on what works to transform care
 - Improved data and metrics
 - Research methods include agile implementation, mixed methods, rapid cycle evaluation, co-design and co-creation of evidence
 - Shift academic incentives
- Broadening impact
 - Address barriers to scale and spread of proven programs
 - Focus on promising approaches to health system transformation

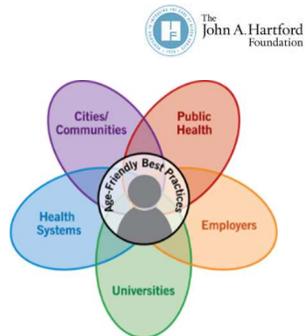
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The Need for an Age-Friendly Ecosystem & Cross-Sector Collaboration



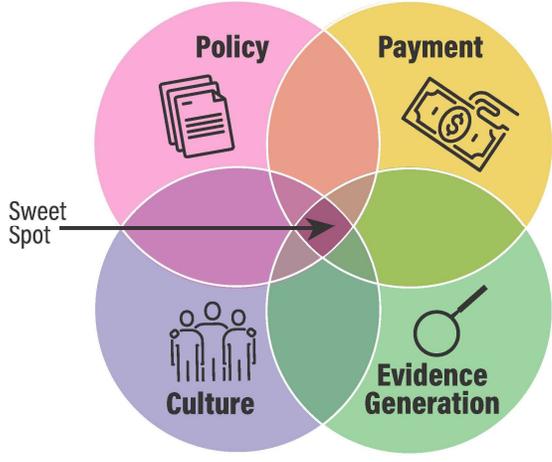
- 2006: WHO guide on global Age-Friendly Cities
- 2012: AARP is U.S. affiliate for Age-Friendly Cities, Communities, States
- 2014: LAO & Funders support FrameWorks Institute study on public's view of aging => GIA/GSA Reframing Aging
- 2016: JAHF & USAging (n4a) establish Aging & Disability Business Institute
- 2016: JAHF & IHI introduce Age-Friendly Health Systems
- 2017: JAHF & TFAH introduce Age-Friendly Public Health Systems
johnhartford.org/agefriendly <https://institute.agefriendly.org>



Fulmer, et al. Moving Toward a Global Age-Friendly Ecosystem, *Journal of the American Geriatrics Society*, July 2020

53

Health System Transformation and Aging Well The "Sweet Spot"

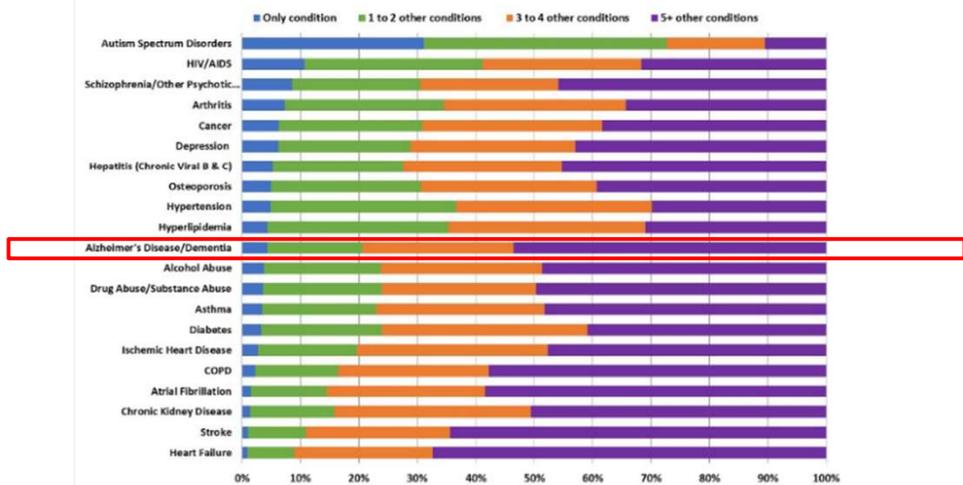


54

ADRD and Multiple Chronic Conditions (MCC)



Figure 15: Co-morbidity among Chronic Conditions for Medicare Fee-for-Service Beneficiaries : 2018



55

AHRQ's Vision for People Living with MCC



A sustainable healthcare system that delivers high-value coordinated, **integrated patient-centered care based in primary care** optimizing individual and population health by preventing and effectively managing multiple chronic conditions (MCC).

56

56

Defining Person-Centered Care



“Person-centered care” means that individuals’ values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires.

“Person-Centered Care: A Definition and Essential Elements” The American Geriatrics Society Expert Panel on Person-Centered Care, December 2015
<https://www.ncbi.nlm.nih.gov/pubmed/26626262>

57

Alignment with Recent NASEM Reports Transforming Health Care to Create Whole Health



- **Whole health**—physical, behavioral, spiritual, and socioeconomic well-being as defined by individuals, families, and communities.
- **whole health care**—an interprofessional, team-based approach anchored in trusted longitudinal relationships to promote resilience, prevent disease, and restore health. It aligns with a person’s life mission, aspiration, and purpose.
- **whole health system**—a collaborative health delivery system that encompasses conventional medical care, comprehensive and integrative health, community programs, social services, and public health. It addresses the five foundational elements of whole health (people-centered, holistic and comprehensive, upstream-focused, equitable and accountable, and team well-being).



58

58

AHRQ's Research Agenda to Transform Care for People Living with Multiple Chronic Conditions



- **Patient, practice, community, and health system level** interventions along with **multilevel interventions** are needed.
- Progress requires **culture change** in practice and training including the integration of behavioral health and primary care.
- **Partnerships and policy are needed to address social determinants of health (SDoH)** and to address pervasive health inequities.
- **Patients, their families and caregivers, clinicians, and communities as coproducers of evidence** can accelerate progress
- **Current payment models present a barrier to innovation** and evidence is needed on different payment models and incentives.
- We not only need to deliver care differently; **we need to do research differently.**

Bierman et al HSR <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8515222/pdf/HESR-56-973.pdf>

59

59

Optimizing Health and Well-Being Addressing the Continuum of Risk



- Prevention interventions targeted at reducing the prevalence of common chronic disease risk factors with a particular focus on interventions to reduce the likelihood those **“at risk”**
- Targeted interventions to improve health and reduce the risk of adverse events and complications who are at **“rising risk”** for developing high needs and/or complex management issues
- Targeted interventions for those who have complex management issues and who are at **“high risk”** for avoidable adverse events, and require a focus on preventing decline, maximizing functioning, and improving quality of life

60

60

Person-Centered Care Planning-RFI



- RFI Federal Register **Request for Information on Person-Centered Care Planning for Multiple Chronic Conditions**
 - ▶ seeks comment on the current state of comprehensive, longitudinal, person-centered care planning for people at risk for or living with MCC across settings of care (e.g., health systems, primary care, home, and other ambulatory practices), including existing models of person-centered care planning, their current scale, and barriers and facilitators to implementation.
 - ▶ seeks comments about innovative models of care, approaches, promising strategies and solutions for clinicians and practices to routinely engage in comprehensive, longitudinal, person-centered care planning to improve the care of people at risk for or living with MCC.

61

61

Person-Centered Care Planning



Stakeholder Engagement and Learning Community

- Gather knowledge about the current state of person-centered care planning in practice, including person-centered care planning models in use across diverse health systems, practices, and settings; scale of existing models; implementation barriers and facilitators; and feasible solutions to implementation barriers;
- Identify innovative, feasible models of person-centered care planning that hold promise for further development, testing, dissemination, and implementation;
- Identify innovative digital solutions that have been leveraged as tools to support and facilitate the success of implementing person centered care planning in practice;
- Identify key organizational, policy, payment, technology, cost, and resource requirements for implementing person-centered care planning across diverse health systems, practices, and settings; and
- Identify key research priorities, strategies, recommendations, and next steps to advance AHRQ's mission of disseminating and implementing person-centered care planning as routine and integral practice in the care of persons with MCC.

62

62

AHRQ/NIDDK eCare Plan for Multiple Chronic Conditions (MCC)



Build capacity for pragmatic, patient-centered outcomes research (PCOR) by developing an **interoperable electronic care plan** to facilitate **aggregation and sharing of critical patient-centered data** across **home-, community-, clinic-, and research-** based settings for people with **multiple chronic conditions (MCC)**.

<https://ecareplan.ahrq.gov/collaborate/>

63

63

Comprehensive Shared Care Plan Definition: US Department of Health and Human Services 2015



1. Gives the person **direct access to health data**
2. Puts the **person's goals at the center** of decision-making
3. Is holistic, including **clinical and nonclinical data** (e.g., home- and community-based, social risks, needs and services)
4. **Follows the person** through both high-need episodes (e.g., acute illness) and periods of health improvement and maintenance
5. Allows **care team coordination**. Team able to 1) view information relevant to their role, 2) identify who is doing what, and 3) update other members of an interdisciplinary team



Baker, et al. Making the Comprehensive Shared Care Plan a Reality. *NEJM Catalyst*. 2016: <https://catalyst.nejm.org/making-the-comprehensive-shared-care-plan-a-reality/>

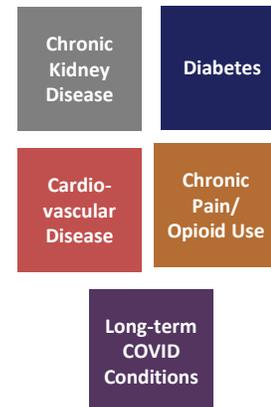
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MCC eCare Project Deliverables



- 1 **Data elements, value sets, and FHIR mappings** to enable standardized transfer of data across health and research settings for kidney disease, diabetes, cardiovascular disease, chronic pain, and long-term COVID.
- 2 **HL7® Fast Health Interoperability Resource (FHIR®) Implementation Guide** based on defined use cases and standardized MCC data elements, balloted for trial use.
- 3 **Pilot tested clinician-facing and patient/caregiver-facing e-care plan applications** that integrate with the EHR to pull, share, and display key patient data.



*All deliverables will be open-source and freely available.

65

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Substance Abuse and Mental Health Services Administration

- SAMHSA is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation.
- Congress established the Substance Abuse and Mental Health Services Administration (SAMHSA) in 1992 to make substance use and mental disorder information, services, and research more accessible.
- In guidance provided by SAMHSA, we seek to address the behavioral health issues faced by those with behavioral health diagnoses, including treatment recommendations for people with Alzheimer's Disease and other cognitive impairments.
- One way SAMHSA seeks to address the needs of those with Alzheimer's Disease and mental health and substance use treatment and recovery needs is through the [Center of Excellence for Behavioral Health Disparities in Aging](#) at Rush University Medical Center.



66

CDC UPDATES

LISA C. MCGUIRE, PHD



67



CDC's Vision

- Equitably protecting health, safety & security.

CDC's Role

- Detecting and responding to new and emerging health threats
- Tackling the biggest health problems causing death and disability for Americans
- Putting science and advanced technology into action to prevent disease
- Promoting healthy and safe behaviors, communities and environment
- Developing leaders and training the public health workforce, including disease detectives
- Taking the health pulse of our nation

68

68

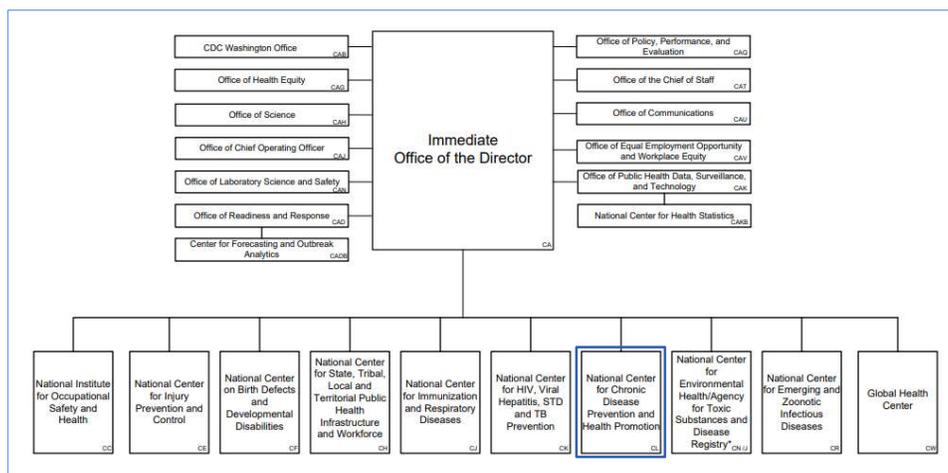
How Public Health Operates?



69

69

Dementia within CDC



70

70



CDC Achievements Since 2011

- Increased funding (over 1000%)
- 3 State and Local Road Maps for Public Health developed in the Series
 - 1st Ever Road Map for Indian Country
 - Revision of Road Map for Indian Country Kicked Off
- Passage of BOLD Act
 - 1st Ever BOLD Public Health Centers of Excellence Awarded (3 Centers—5-year awards)
 - 1st Cycle of BOLD Programs Awarded (23 Programs—3-year awards)
 - 2nd Cycle of BOLD Programs Awarded (43 Programs—5-year awards)
- Expanded Healthy Brain Initiative Awards from 1 to 5
- Launched HRBC
- Launched State and National Data Infographics
- Launched Alzheimer’s Disease Data Portal
- Expansion of DIA Objectives in HP2030 from 2 to 3
- Inclusion of questions of BRFSS, NHANES, and Styles Surveys
- Launched Healthy Brain Research Networks and Risk Reduction Thematic networks within Prevention Research Centers

71

71



Cohort 2 Awarded!

CDC-RFA-DP23-0010



BOLD Public Health Programs to Address Alzheimer’s Disease and Related Dementias

- Fulfills the BOLD Infrastructure for Alzheimer’s Act (P.L. 115-406)
- This NOFO will fund state, local, and tribal public health departments

5-year awards

2 Components:

- Component 1
 - Phase 1 – Planning (years 1–2)
 - Phase 2 – Implementation (years 3–5)
- Component 2 – Implementation (years 1–5)

72

72



Cohort 2 Awarded!



CDC-RFA-DP23-0010

Component 1

- Alabama
- Allegheny County, PA
- Cameron County, TX
- Kansas
- Kentucky
- Maricopa County, AZ
- Marion County, IN
- Michigan
- Montana
- New York City, NY
- Oregon
- Puerto Rico
- South Dakota

Component 2

- Alaska
- Boston, MA
- California
- Colorado
- Connecticut
- DC
- Georgia
- Hawaii
- Illinois
- Idaho
- Iowa
- Los Angeles County, CA
- Louisiana
- Maine
- Maryland
- Minnesota
- Mississippi
- Missouri
- Nevada
- New York
- Northwest Portland Area Indian Health Board
- Oklahoma
- Rhode Island
- South Carolina
- Tennessee
- Texas
- Vermont
- Virginia
- Washington
- Wisconsin

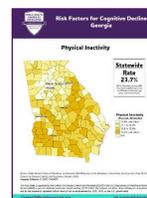
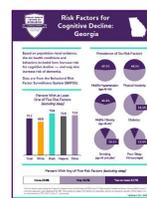
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BOLD Public Health Center of Excellence on Risk Reduction

- State-specific fact sheets on the prevalence of six risk factors (hypertension, obesity, diabetes, smoking, physical inactivity, and poor sleep), available at:
<https://www.alz.org/professionals/public-health/public-health-topics/risk-reduction#prevalence-risk>
- State heat maps (by county) and county heat maps (by census tract) for the six risk factors, available on request by emailing:
CenterOfExcellence@alz.org



74

Healthy Brain Resource Center (HBRC)



<https://www.cdc.gov/aging/healthy-brain-resource-center/>

The Healthy Brain Resource Center (HBRC) is a one-stop, easy-to-navigate website that helps users find credible information and materials to support implementing the Healthy Brain Initiative Road Map.

The HBRC currently features over 300 publicly available resources.

- CDC-verified resources and information all in one location.
- Robust search functions to quickly access information.
- A [user manual](#) and [orientation video](#) provide guidance on how to use the HBRC.
- Rolling content [submissions](#) accepted.



75

75

NEW PUBLICATION



Suchsland et al. *BMC Health Services Research* (2023) 23:1006
<https://doi.org/10.1186/s12913-023-09991-7>

BMC Health Services Research

RESEARCH

Open Access

Developing a cognitive assessment toolkit for primary care: qualitative assessment of providers' needs and perceptions of usability in clinical practice



Monica Zigman Suchsland^{1*}, Barak Gaster², Jaqueline Raetz¹, Basia Belza³, Lisa McGuire⁴, Benjamin Olivari⁴, Karen Tracy⁵ and Annette L. Fitzpatrick^{1,6}

<https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-023-09991-7>

76

76

NEW PUBLICATION



Received: 22 February 2023 | Revised: 28 July 2023 | Accepted: 1 August 2023
DOI: 10.1002/alz.13437

PERSPECTIVE

Alzheimer's & Dementia
THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

The intersection of social determinants of health and family care of people living with Alzheimer's disease and related dementias: A public health opportunity

Joseph E. Gaugler¹ | Soo Borson² | Fayron Epps³ | Regina A. Shih⁴ |
Lauren J. Parker⁵ | Lisa C. McGuire⁶

- ¹Building Our Largest Dementia Infrastructure (BOLD) Public Health Center of Excellence on Dementia Caregiving, School of Public Health, University of Minnesota, Minneapolis, Minnesota, USA
- ²BOLD Public Health Center of Excellence on Early Detection, NYU Grossman School of Medicine, New York, New York, USA
- ³BOLD Public Health Center of Excellence on Dementia Caregiving, Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia, USA
- ⁴BOLD Public Health Center of Excellence on Dementia Caregiving, RAND Social and Behavioral Policy Program, RAND Corporation, Santa Monica, California, USA
- ⁵BOLD Public Health Center of Excellence on Dementia Caregiving, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, USA
- ⁶Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Georgia, USA

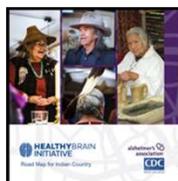
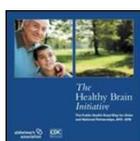
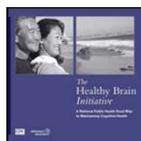
<https://alz-journals.onlinelibrary.wiley.com/doi/epdf/10.1002/alz.13437>

77

77

HEALTHYBRAIN INITIATIVE Road Map Series

Public health strategies to promote brain health, address dementia, and help support caregivers



www.cdc.gov/aging

78

The collage features several key documents from the Healthy Brain Initiative Road Map Series:

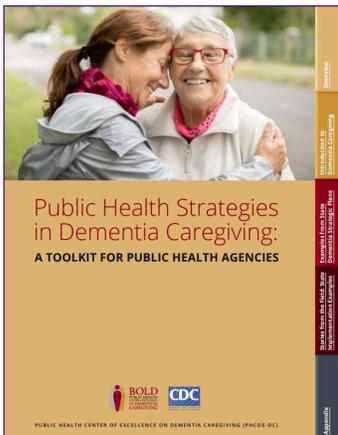
- EXECUTIVE SUMMARY**: A central document providing an overview of the State and Local Road Map for Public Health, 2023-2027.
- ISSUE MAPS**: A collection of seven maps focusing on:
 - Enhancing Community-Clinical Linkages
 - Advancing Health Equity
 - Reducing Risk of Cognitive Impairment
 - Ensuring Early Detection and Diagnosis
 - Supporting Caregivers
- IMPLEMENTATION GUIDE**: A document titled "Prioritizing Action in the Healthy Brain Initiative Road Map: Eight Questions for Thoughtful Action" that provides a framework for implementation.
- WHAT'S NEW**: A document highlighting updates to the State and Local Road Map for Public Health.

Logos for the Alzheimer's Association and CDC are visible throughout the collage.

79

BOLD Public Health Center of Excellence on Dementia Caregiving

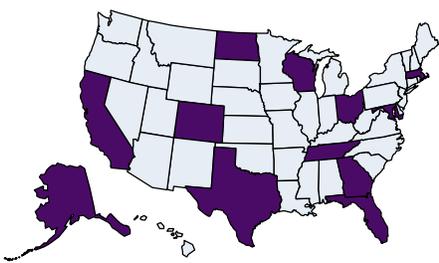
https://bolddementiacaregiving.org/wp-content/uploads/2023/10/UofMN_PHCO-E-DC_Toolkit.pdf

PUBLIC HEALTH CENTER OF EXCELLENCE ON DEMENTIA CAREGIVING (PHCO-DC)

80

ROAD MAP STRATEGISTS



APPLY FOR THE NEXT COHORT TODAY
Applications due Nov 15th
<https://alzpublichealth.submittable.com/submit>



BUILDING LOCAL HEALTH DEPARTMENT CAPACITY TO ADDRESS BRAIN HEALTH



THE HEALTHY BRAIN INITIATIVE 81

81

ROAD MAP FOR INDIAN COUNTRY REVISION



Timeline

- September/October – Leadership committee invited
- November 3rd – 1st Leadership Committee meeting
- Fall/Winter – Open input period on outline and new elements to include
- Late Winter – In person Leadership committee meeting to finalize Actions
- Spring – Writing and design
- Summer – Review
- November 2024 – Publication

THE HEALTHY BRAIN INITIATIVE 82

82

Integrating Alzheimer's Messages into Chronic Disease Programs

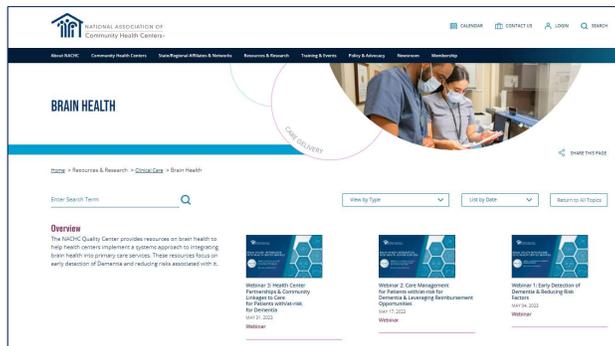


<https://chronicdisease.org/page/healthyaging/nacdd-action-on-healthy-aging-and-brain-health>



83

Integrating Brain Health into Community Health Centers



<https://www.nachc.org/topic/brain-health/>



84

THANK YOU

WWW.CDC.GOV/AGING

LISA C. MCGUIRE, PHD
LMCGUIRE@CDC.GOV










Centers for Disease Control and Prevention



National Center for Chronic Disease Prevention and Health Promotion

Division of Population Health
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

85

Department of Defense - CDMRP







- The Congressionally Directed Medical Research Programs (CDMRP) are an organization of 35 programs that fund biomedical research for near term impact, focusing on healthcare solutions that benefit Service Members, Veterans, their beneficiaries, and the American public.
- The Peer Reviewed Alzheimer’s Research Program (PRARP) was initiated in fiscal year 2011 to address Alzheimer’s and other dementias following military service.
- To date, PRARP has funded 168 awards totaling \$147M.
- In fiscal year 2022, PRARP funded 16 awards, including 3 awards to early career investigators. Topics included epidemiology, biomarker validation, and diagnostics

UNCLASSIFIED

86

National Science Foundation

The NSF supports fundamental research in all areas of science and engineering.

BASIC RESEARCH

Amyloid proteins
Brain physiology & cognition
Tools in imaging, statistics, model systems

ADVANCING DIAGNOSTICS AND TREATMENTS

Novel biomarker development
Early detection/prediction of MCI/AD
Modulating intracellular protein levels
Novel drug delivery mechanisms

IMPROVING QUALITY OF LIFE

Data infrastructure for caregivers
Safety and prevention systems
Socially assistive robots and AI
Caregiver/patient dynamics, well-being

Examples from 2022 and 2023

- **TIP** – chemical analysis methods to detect signs of early Alzheimer’s disease in saliva
- **MPS** – mathematical models describing the evolution of AD-associated amyloid-beta & tau protein pathology on complex human brain networks generated from medical data
- **CISE** – pervasive ambient intelligent environments to improve the quality of life in the elderly or persons suffering from chronic conditions such as Alzheimer’s, Parkinson’s
- **ENG** – determine the fundamental mechanical properties of living brain tissues and the differences in properties between healthy and diseased tissues

Keyword title and abstract search at <https://www.nsf.gov/awardsearch/advancedSearch.jsp>
“dementia” OR “Alzheimer’s”

Awards made 01/01/2012 or later:
498 awards, ~\$223M from
BIO, CISE, EDU, ENG, GEO, MPS, O/D,
SBE, and TIP Directorates



87

87

Questions?



U.S. Department of Health and Human Services



OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY

88

88