

National Alzheimer's Project Act Advisory Council on Alzheimer's Research, Care, and Services

Long-Term Services and Supports Federal Update

January 28, 2019

Administration for Community Living

Alzheimer's Disease Programs Initiative (ADPI)

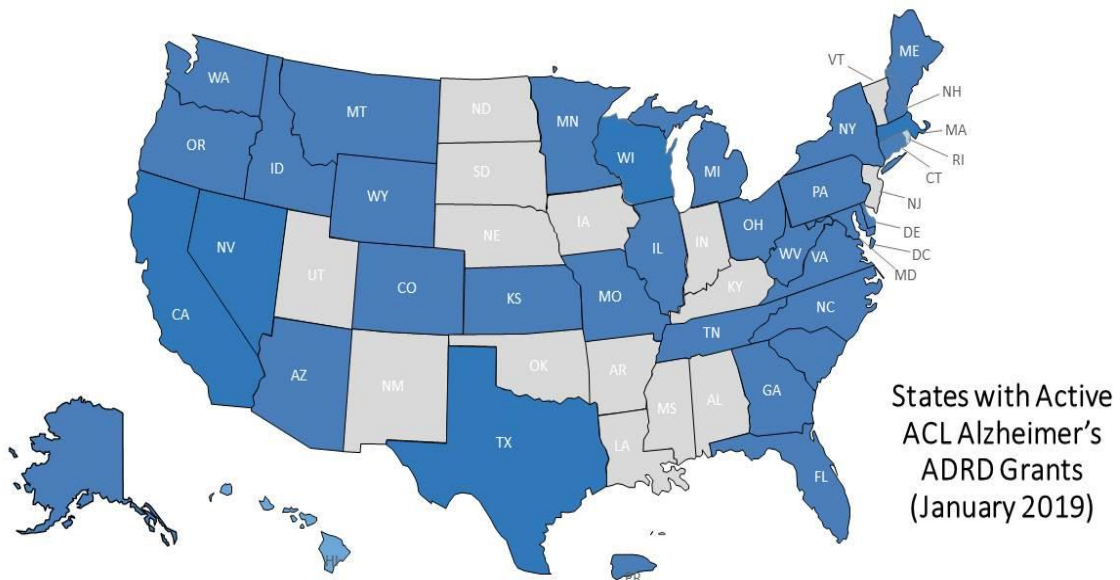
- ❖ 2019 States and Community Expansion Grants – January 26
- ❖ 2019 Grants to NEW States and Communities - UPCOMING

Administration for Community Living

Grants to States and Communities Dementia Capability Assessment *Improvement Scores*

Domain	Percentage Improvement
Identifying people with dementia	15%
Staff Training	2%
Providing Specialized Services	24%
Other Dementia Capability Activities	26%

Administration on Aging



Administration for Community Living

Handbook for Helping People Living Alone with Dementia Who Have No Known Support

- ❖ Practical guidance and tools for helping persons living alone with no informal supports, including people with dementia who have a caregiver that cannot provide support.
 - 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.

<https://nadrc.acl.gov/node/157>

Administration for Community Living

Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia

- ❖ Guide to assist community organizations in collaborating with first responders to better serve people living with dementia
 - Why this issue is gaining attention,
 - Strategies for building successful partnerships,
 - Types of programs that can benefit people living with dementia.
 - Resources:
 - Training materials
 - Sample policies
 - Tip sheets and more.

<https://nadrc.acl.gov/node/155>

Administration for Community Living

Disaster Planning Toolkit for People Living with Dementia

- ❖ Tools to assist people living with dementia, their family members, and their caregivers understand what to expect in the event of a disaster and how to prepare for it. Comprised of seven tip sheets and checklists for persons living with dementia, their families, and others who interact with them, including friends and neighbors.
 - Planning for a Disaster
 - Important Contacts
 - Emergency Supplies Checklist
 - My Medical Conditions and Care Needs
 - Disaster Planning Tips for People Living Alone with Dementia
 - Planning for after a Disaster, and
 - Tips for Communication and Responding to Dementia Symptoms.

<https://nadrc.acl.gov/node/151>

Administration for Community Living

NADRC Webinar

Measuring Outcomes to Evaluate Dementia Programs and Interventions: Strategies, Challenges, and Benefits

Wednesday, January 30, 2019, 2:00-3:00 PM ET

- ❖ Webinar will review strategies, challenges, and benefits of measuring outcomes to evaluate dementia programs and interventions.
 - Topics included:
 - Rationale for outcome measurement and the value of different measurement strategies
 - Strategies for selecting outcome measures, including considerations of measurement burden and the frequency and scheduling of data collection
 - Past experience in using measured outcomes during program implementation and expansion

[Register for the Webinar](#)

Administration for Community Living

ELDERCARE LOCATOR Website Redesign

- October launch of redesigned Eldercare Locator website (eldercare.acl.gov) which includes:
- A mobile-optimized design to easily access the Eldercare Locator on a computer, phone, or tablet
- A geographical search bar allows visitors to search for local aging resources from any page on the site

New Materials

- Caregiver Corner answering most frequently asked questions received by the Call Center
- Learn More About section with information on popular topics like transportation, support services, elder rights, housing, health, and insurance and benefits.

Home for the Holidays Campaign

- The 2018 **Home for the Holidays** public education campaign highlighted long-distance caregiving.
 - [Caring Across the Miles: Resources for Long-Distance Caregivers](#), which provides tips, answers frequently asked questions and highlights local resources available to long-distance caregivers.

Administration for Community Living

Long-Term Care Ombudsman Programs (OLTCOP)

- Continue provision of training, technical assistance, to help states' Long-Term Care Ombudsman (LTCO) programs to better meet the needs of individuals living with dementia in long-term care facilities.
- Awarded a supplemental grant for \$70,000 to the National Ombudsman Resource Center (NORC) to address two critical issues in long-term care facility settings, involuntary discharges and opioids. The grant will address:
 - *Nursing Home eviction and discharge* – LTCO programs in a learning collaborative receive TA to address individual and systemic approaches to remedy a commonly reported problem nursing facility residents bring to Ombudsman programs – involuntary, facility-initiated discharge. Include a designated legal assistance programs serving the same geographic areas, to engage in peer-to-peer learning, and in-depth training to develop complaint advocacy and legal tools. The strategies and tools developed through this project will serve as a resource for all Ombudsman programs.
 - *Opioid Use and Pain Management* - The second prong of this grant will fund a short-term project to better understand long-term care facility residents' experiences with pain management. This will include an examination of the use of opioids, causes and results of opioid misuse, and how drug diversion, and other consequences of opioid misuse by others, can impact residents. Obtaining the perspective of people living in nursing homes and residential care communities will be an integral part of this project.

Centers for Disease Control and Prevention

Healthy Brain Initiative Road Map, 2018-2023

Framework: Essential
Services of Public Health



[HBI Road Map 2018-2023](#)



**HEALTHYBRAIN
INITIATIVE**

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map

Healthy Brain Initiative Road Map, 2018-2023

New Products

DISSEMINATION GUIDE



The Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association have created **State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map**, the third in a series of road maps to guide public health leadership in Alzheimer's dementia. The Healthy Brain Initiative 2018-2023 Road Map outlines how state and local public health agencies and their partners can act quickly and strategically to prepare their communities by reducing risk for cognitive decline and dementia, expanding early detection and diagnosis, improving safety and quality of care for people living with dementia, and strengthening caregivers' health and effectiveness.

HELP US SPREAD THE WORD

DISSEMINATION GUIDE ITEMS

Newsletter Template
Use the text and image provided to promote the Road Map within your organization or community newsletter, e-mail, or blog.

Social Media Posts
Sample tweets and Facebook posts are ready to use on your organization's social media platforms.

Podcasts
Select one of the audio resources describing cognitive decline.

Content Simplification
Publish CDC's web content on your website quickly.

Talking Points
Use this bulleted list for quick facts.

[Dissemination Guide](#)

Planning for Action: Initial Steps for Implementing the Healthy Brain Initiative Road Map

TOOL FOR IMPLEMENTATION: PLANNING GUIDE

TABLE OF CONTENTS

- Six Steps to Planning Your Public Health Response to Alzheimer's
- State Alignment Examples
- Know Your State Road Map Success
- Workshop: Planning Road Map Action
- Workshop: Public Health Planning
- State: Personalized Case Studies
- Checklist: Engaging Partners and Stakeholders
- Workshop: Stakeholder Analysis Matrix

SIX STEPS TO PLANNING YOUR PUBLIC HEALTH RESPONSE TO ALZHEIMER'S

Make an impact in addressing Alzheimer's and other dementia using the HRB Road Map with six steps to guide your planning: The Know-Plan-Do-Check-Evaluate (K-P-D-C-E) program cycle. It requires three steps: a **Know-Plan-Do** cycle, a **Check** cycle, and an **Evaluate** cycle.

Step 1: Prioritize potential actions within your area of focus (Know)

Use the HRB Road Map as a tool to guide decisions about where to prioritize your efforts to promote brain health, expand early detection and diagnosis, improve safety and quality of care for people living with dementia, and attend to caregivers' health and well-being.

The key is to begin, whether you first raise awareness of the HRB Road Map within your division or you create a plan around an initial Road Map action. Initial momentum gives you a base on which to keep building where you have capacity and interest.

Start by reviewing the HRB Road Map and its agenda of 25 actions as well as the sampling data presented. Educate your staff and other health professionals about Alzheimer's and other dementia. Then, use the Planning Road Map Actions worksheet (page 5) to identify Road Map actions that are authentic, align with existing areas of focus and priorities (Step 2), and fit with available resources and capacity.

Step 2: Integrate and align strategies into your existing plans (Know, Plan)

You do not have to start from scratch. Many Road Map actions can be integrated into existing plans and initiatives such as programs to promote dementia health prevention, and public safety. Alzheimer's risk plans, or other community health improvement plans. To a state of current initiatives and plans within your organization and by other groups or organizations. Find places where you can align Road Map actions with existing initiatives to grow and add the information to the Planning Road Map Actions worksheet that you started in Step 1. See the Aligning Actions Examples table for examples (page 5).

Not finding enough alignment? Gather a few colleagues for a conversation about using Road Map actions to create a plan that aligns with existing community health improvement plans or other community health improvement programs or opportunities in your community that relate to cognitive health. A letter with Planning Data Sources is on page 10.

[Implementation Planning Guide](#)



HEALTHYBRAIN INITIATIVE

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map

Healthy Brain Initiative Road Map, 2018-2023

New Issue Maps



SUPPORTING CAREGIVERS to Make Alzheimer's Our Next Public Health Success Story

COMPILING DATA

The challenge of caring for someone with Alzheimer's and other dementia can be overwhelming. It is a complex, ongoing, and often stressful experience. It is a public health success story that is still in its early stages. It is a success story that is still in its early stages. It is a success story that is still in its early stages.

KEY TAKEAWAYS

- Approximately 10 million people are caregivers for someone with Alzheimer's or another dementia.
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THE CAREGIVING ACTION AGENDA

The Healthy Brain Initiative (HBI) Road Map and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map (Road Map) are a series of road maps to guide public health leadership in Alzheimer's dementia. The Road Map outlines how state and local public health agencies and their partners can act quickly and strategically to prepare their communities by reducing risk for cognitive decline and dementia, expanding early detection and diagnosis, improving safety and quality of care for people living with dementia, and strengthening caregivers' health and effectiveness.

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PUBLIC HEALTH STRATEGIES TO SUPPORT CAREGIVERS

The following are examples of how public health departments are supporting dementia caregivers.

NEW YORK

The New York State Department of Health (NYSDOH) is leading a statewide effort to support caregivers. The effort includes providing training, resources, and support to caregivers. The effort includes providing training, resources, and support to caregivers.

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[Issue Maps](#)

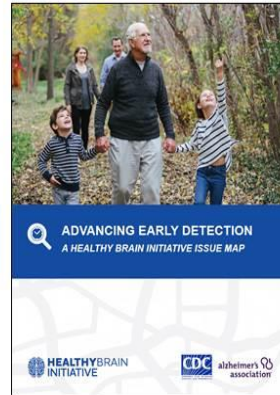
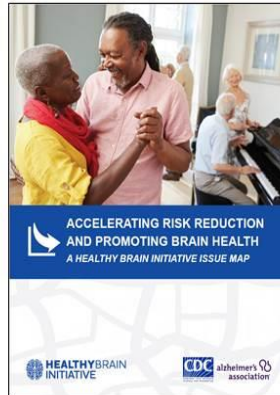


HEALTHYBRAIN INITIATIVE

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map

Healthy Brain Initiative Road Map, 2018-2023

New Issue Maps



[Issue Maps](#)



**HEALTHYBRAIN
INITIATIVE**

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map



Forthcoming: Road Map for Indian Country

*American Indians and Alaska Natives: gains in longevity,
but Elders with higher risks for dementia and heart disease*

- Available in Spring 2019
- Tailored for Tribal and Native health leaders to engage their communities on Alzheimer's and other dementias
- Suggest public health responses to
 - Reduce risk for cognitive decline
 - Advance early detection
 - Support caregivers
 - Monitor and evaluate



**HEALTHYBRAIN
INITIATIVE**

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map



Subjective Cognitive Decline — A Public Health Issue

Subjective Cognitive Decline (SCD) is the self-reported experience of worsening or more frequent confusion or memory loss.¹ It is a form of cognitive impairment and one of the earliest noticeable symptoms of Alzheimer's disease and related dementias.² SCD can have implications for living with and managing chronic disease, or performing everyday activities like cooking or cleaning.³ Because SCD is self-reported, it does not imply a diagnosis of cognitive decline by a health care professional.⁴

Some cognitive decline can occur as adults age, but frequently forgetting how to perform routine tasks, for example, is not a normal part of aging and can affect a person's ability to live and function independently. Some people with cognitive decline may be unable to care for themselves or perform activities of daily living, such as meal preparation, managing medical appointments, or managing their personal finances. Limitations in cognitive ability may impact a person's ability to effectively manage medication regimens which can result in poor health outcomes of common chronic diseases like heart disease or diabetes. By educating people about modifiable risk factors, encouraging early assessment and intervention, and understanding its impact on adults and their families, the health and well-being of many older adults may be improved.⁵

Subjective Cognitive Decline is self-reported confusion or memory problems that have been happening more often or getting worse in the past 12 months.⁶



Caregiving for Family and Friends — A Public Health Issue

Caregiving is an important public health issue that affects the quality of life for millions of individuals. Caregivers provide assistance with another person's social or health needs. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation. It may also involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the recipient's needs increase, which may result in additional strain on the caregiver.^{1,2}

Caregiving can affect the caregiver's life in a myriad of ways including higher ability to work, engage in social interactions and relationships, and maintain good physical and mental health.³ Caregiving also can bring great satisfaction and strengthen relationships, thus enhancing the caregiver's quality of life. As the population ages and disability increases, it is critical to understand the physical and mental health burden on caregivers, the range of tasks caregivers may perform, and the social and economic impacts of long-term chronic disease or disability.⁴ Gathering information on these topics enables us to plan for public health approaches to assist individuals as well as their communities and maintain the health of caregivers and care recipients.⁵

Informal caregivers provide regular care or assistance to a friend or family member who has a health problem or disability.⁶



HEALTHYBRAIN INITIATIVE

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map

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Alzheimer's Disease and Healthy Aging

The screenshot shows the homepage of the Alzheimer's Disease and Healthy Aging website. At the top, there is a navigation bar with social media icons and the title 'Alzheimer's Disease and Healthy Aging'. Below this is a large banner for the 'Healthy Brain Initiative Road Map IN GUIDE', dated 'NEW 2018-2023 RoadMap Released'. The main content area features three columns of featured content: 'Alzheimer's Clinics and Related Dementia', 'Caregiver', and 'Road Map'. Below these are sections for 'Data and Statistics', 'Resources & Publications', and 'Healthy Brain Initiative'. At the bottom, there are four menu items: 'HEALTH INFORMATION', 'INFORMATION FOR HEALTH PROFESSIONALS', 'COMMUNICATIONS CENTER', and 'HEALTHY AGING DATA'.

[New Homepage!](#)



HEALTHYBRAIN INITIATIVE

State and Local Partnerships to Address Dementia: The 2018-2023 Road Map



THANK YOU!