



RAISE National Strategy to Support Family Caregivers

January 12th, 2023



Welcome from...



Joseph E. Gaugler, PhD

Director, BOLD Public Health Center of Excellence on
Dementia Caregiving

Professor and Robert L. Kane Endowed Chair in Long-Term
Care & Aging, University of Minnesota

His research examines innovation in dementia care.






Land acknowledgement

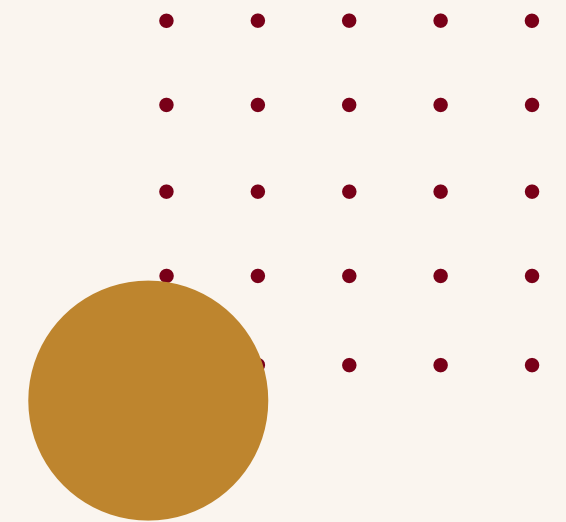
The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.



The BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...

-  Improving access to evidence-based programs and best practices.
-  Facilitating connections and collaboration among public health agencies and a wide range of service organizations.
-  Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies.



Welcome panelists!



Wendy Fox-Grage, MPA, MS

Project Director, Behavioral Health, Aging and Disability Team, National Academy for State Health Policy



John Omura, MPH, MD

Medical Officer, Alzheimer's Disease Team, CDC's Healthy Aging Branch, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health



Liz Head, MPH

Deputy Director, Injury Prevention Division, Georgia Department of Public Health, Georgia Enhanced BOLD Public Health Program



Kina White, DrPH, MHSA, FACHE

Director, Office of Community Health Improvement, Mississippi State Department of Health Principal Investigator, Mississippi Core Capacity BOLD Public Health Program, Institute for Healthcare Improvement's Equity Advisory Group



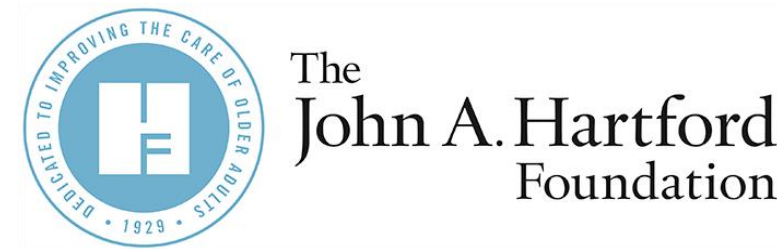
Erin Fay, LMSW

Program Manager, Alzheimer's Disease Program, New York State Department of Health



2022 National Strategy to Support Family Caregivers

January 12, 2023



nashp.org

Wendy Fox-Grage

Senior Policy Fellow

National Academy for State Health Policy

Email: WFGrage@nashp.org



About NASHP

The National Academy for State Health Policy (NASHP) is a nonpartisan organization committed to developing and advancing state health policy innovations and solutions.

NASHP provides a unique forum for the productive exchange of strategies across state government, including the executive and legislative branches.

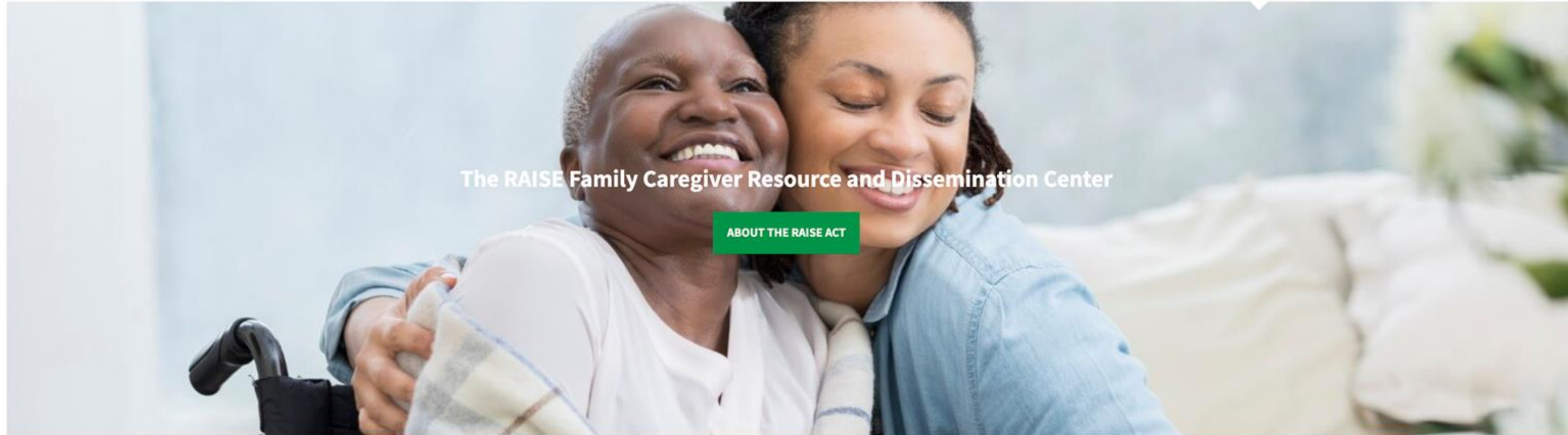


RAISE Family Caregiver Resource and Dissemination Center

<https://www.nashp.org/the-raise-family-caregiver-resource-and-dissemination-center/>



HOME ABOUT US PUBLICATIONS **POLICY** EVENTS CAREERS CONTACT



THE FAMILY CAREGIVING ADVISORY COUNCIL AND FACULTY

COUNCIL MEETING MATERIALS AND RESOURCES

STATE RESOURCES

RESPITE CARE



nashp.org

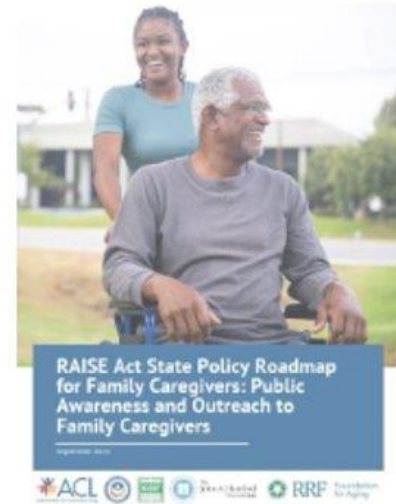
2022 National Strategy to Support Family Caregivers

acl.gov/CaregiverStrategy

- The Strategy includes about 350 federal actions and 150 state, community, and private partner actions to achieve the goals
- Five goals provide the framework for the Strategy
 - Goal 1: Increase awareness of and outreach
 - Goal 2: Advance partnership and engagement
 - Goal 3: Strengthen services and supports
 - Goal 4: Ensure financial and workplace security
 - Goal 5: Expand data, research, and evidence-based practices

RAISE Act State Policy Roadmap

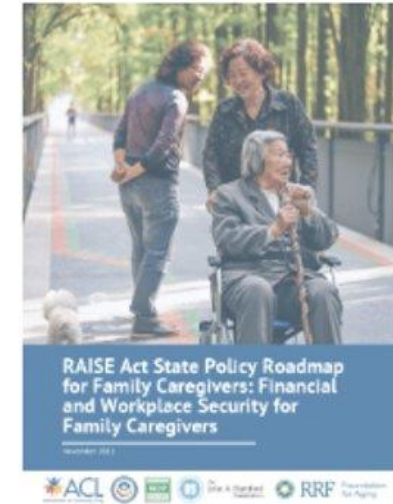
- Six papers highlighting state strategies and promising practices
- <https://www.nashp.org/roadmap-for-family-caregivers/>



Public Awareness and Outreach



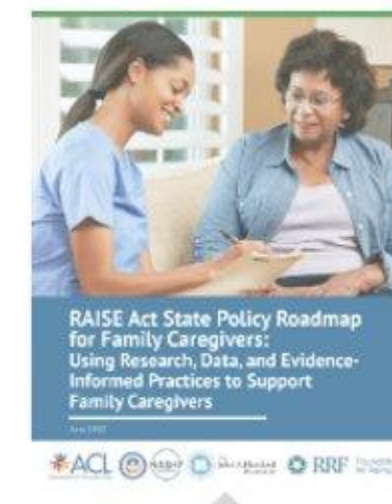
The Direct Care Workforce



Financial and Workplace Security



Family Caregiver Services and Supports



Using Research, Data, and Evidence-Informed Practices to Support Family Caregivers



Engagement of Family Caregivers in Health Care Systems

State Actions: Services and Supports for Family Caregivers

- To help caregivers receive services that enable them to provide care in their homes, states can address funding by:
 - Blending and braiding federal and state funding for services like respite care
 - Leveraging new Medicaid funding and flexibilities
 - Rebalancing toward more home and community-based services
 - Paying family caregivers through Medicaid self-direction options



State Actions: Services and Supports for Family Caregivers

- Examples:

- Connecticut plans to incorporate caregiver assessment, training, respite, care coordination, and the Care of Persons with Dementia in their Environments (COPE) evidence-based support model into permanent initiatives for caregivers of those with Alzheimer's and related dementias
- Montana trains Aging Disability Resource Center/Area Agency on Aging personnel to be Dementia Care Navigators, who utilize an evidence-informed tool, the Alzheimer's Navigator®, to assess care needs, provide care consultation, and disseminate service referrals for individuals with AD/ADRD and their caregivers



State Actions: Using Research, Data, and Evidence-Informed Practices

- To promote data and research on family caregivers, states can:
 - Use broader definitions of family caregiver that go beyond blood relatives
 - Collect family caregiver data and outcomes
 - Compile state inventories of family caregiver services
 - Develop state evaluations of family caregiver programs
 - Implement evidence-supported programs for family caregivers



State Actions: Using Research, Data, and Evidence-Informed Practices

- Examples:
 - New York administers the Behavioral Risk Factor Surveillance System's (BRFSS) Caregiver Module through its Alzheimer's Disease Assistance Fund and uses that data for its Alzheimer's Disease Caregiver Support Initiative evaluation
 - Massachusetts funds access to evidence-based programs, including the Savvy Caregiver (English and Spanish) and Powerful Tools for Caregivers through the Home Care Program, the Family Caregiver Support Program, and the Medicaid 1915(c) Frail Elder waiver



Next Steps

- Call to Action: Read and speak up about the National Strategy at acl.gov/CaregiverStrategy
- New RAISE Advisory Council to be announced in Spring, will focus on an update and implementation
- Public comments are being analyzed
- Full Council meetings are live-streamed and open to the public at acl.gov/raise
- The plan: to update the National Strategy every two years

Thank you!



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Health Policy

A PUBLIC HEALTH APPROACH TO DEMENTIA CAREGIVING

JOHN D. OMURA, MD, MPH
ALZHEIMER'S DISEASE TEAM, HEALTHY AGING BRANCH



Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion

Division of Population Health

Presented on January 12, 2023 for a BOLD Public Health Center of Excellence on Dementia Caregiving webinar



OVERVIEW

- Caregiving
- A Public Health Approach
- CDC Initiatives
- Policy Initiatives
- National Initiatives
- Resources

CAREGIVING

- In 2020, an estimated **21% of adults** were **family/friend caregivers**.
- Can have **benefits** including enhancing the bond between caregiver and care recipient.
- Can place emotional and physical **strain** on caregiver.
- As number of older adults in U.S. is **projected to increase** so will the need for caregivers



CAREGIVING AND COGNITIVE DECLINE

Centers for Disease Control and Prevention

MMWR

Weekly / Vol. 70 / No. 46

Morbidity and Mortality Weekly Report

November 19, 2021

Prevalence and Characteristics of Subjective Cognitive Decline Among Unpaid Caregivers Aged ≥ 45 Years — 22 States, 2015–2019

Eva M. Jeffers, MPH^{1,2}; Erin D. Bouldin, PhD^{1,3}; Lisa C. McGuire, PhD¹; Kenneth A. Knapp, PhD⁴; Roshni Patel, MPH⁵; Dana Guglielmo, MPH^{1,2}; Christopher A. Taylor, PhD¹; Janet B. Croft, PhD¹

- **1 in 8 unpaid adult caregivers aged ≥ 45 years reported subjective cognitive decline (SCD)** (i.e., the self-reported experience of worsening confusion or memory loss over the past year)
- **SCD was higher among caregivers (12.6%) than among non-caregivers (10.2%)**
- **Caregivers with SCD were more likely than those without SCD to report chronic health conditions, a history of depression, and frequent activity limitations.**

CDC'S NATIONAL PUBLIC HEALTH APPROACH



WHAT IS THE PUBLIC HEALTH APPROACH?



**One at a time
time**



Many at a



Bridging
the

Public
Health

CDC

Community Services

Biomedical Research

GAP



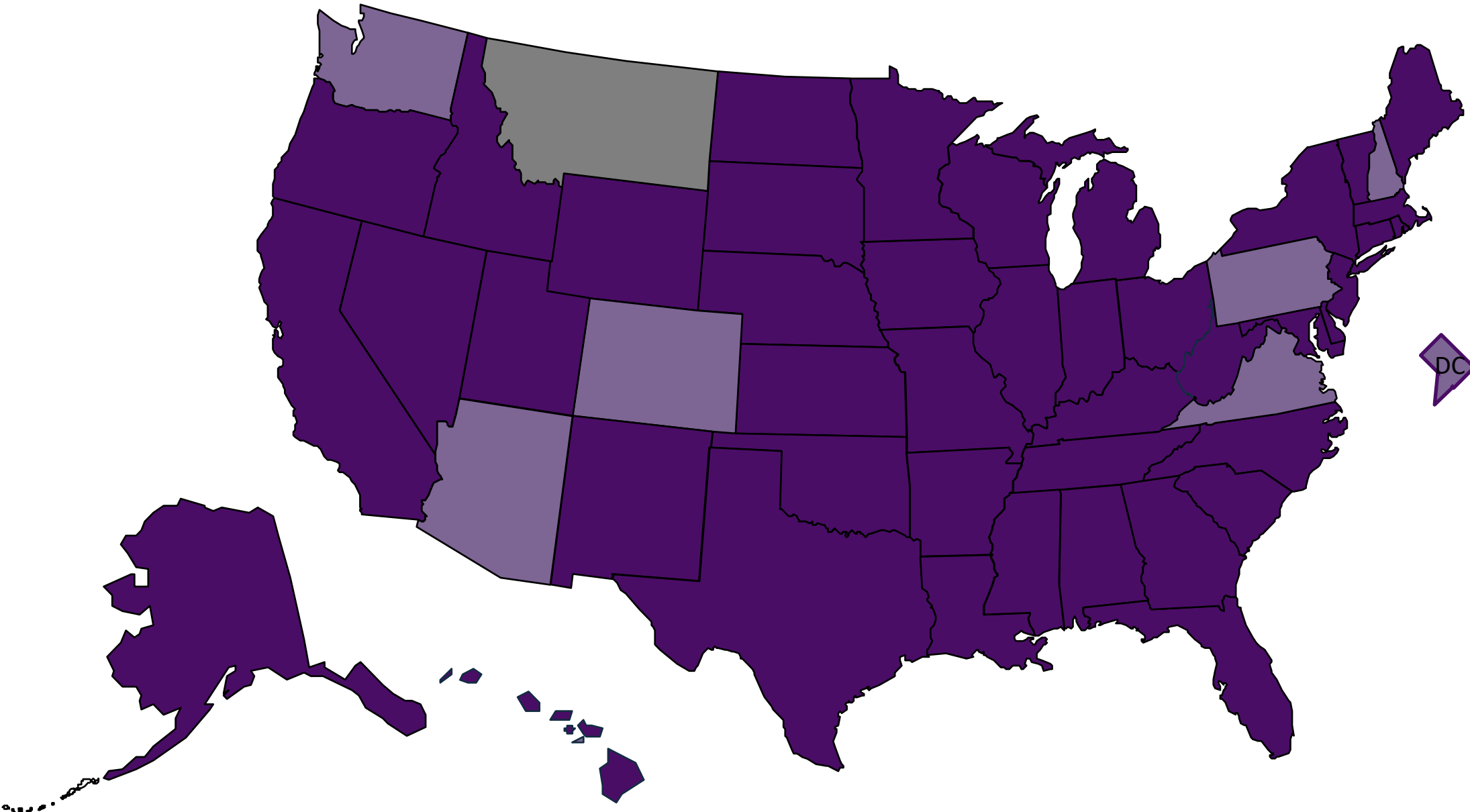
DATA FOR ACTION



<https://www.cdc.gov/aging>



BRFSS Caregiver Module Administration



- 2021
- 2022
- Did not use module



CAREGIVING

2015-2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from adults in 44 States, Puerto Rico, and the District of Columbia.

1 in 5 adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

CAREGIVING CAN BE

LENGTHY
Half have provided care for at least two years



INTENSE
Almost 1/3 have provided care for at least 20 hours per week



WHO ARE CAREGIVERS?

58% are women

19% are 65 years old or older

37% are caring for a parent or parent-in-law

9% are providing care to someone with dementia



HOW DO CAREGIVERS HELP?

Nearly 80% manage household tasks

Over 50% assist with personal care



FUTURE CAREGIVERS

1 in 6 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

cdc.gov/aging

CS 294205.A April 2020

GEORGIA CAREGIVING



2018 Behavioral Risk Factor Surveillance System (BRFSS) Data

1 in 5 adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

CAREGIVING CAN BE

LENGTHY
Nearly 50% have provided care for at least two years



INTENSE
A third have provided care for at least 20 hours per week



WHO ARE CAREGIVERS?

59% are women

26% are 65 years old or older

36% are caring for a parent or parent-in-law

9% of caregivers are providing care to someone with dementia



HOW DO CAREGIVERS HELP?

Over 75% manage household tasks

Over 50% assist with personal care



FUTURE CAREGIVERS

1 in 7 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

cdc.gov/aging

CS 294205.A March 2020

PRESTACIÓN DE CUIDADOS ENTRE ADULTOS HISPANOS

Datos del Sistema de Vigilancia de Factores de Riesgo del Comportamiento (BRFSS), del 2015 al 2018, correspondientes a adultos hispanos en 44 estados, Puerto Rico y el Distrito de Columbia

1 de cada 6 adultos hispanos se encarga de prestar cuidados

Los ENCARGADOS DE CUIDADOS se ocupan de atender o asistir en forma habitual a un AMIGO o FAMILIAR con problemas de salud o una discapacidad

PRESTAR CUIDADOS PUEDE SER

UN PROCESO LARGO
Casi la mitad ha prestado cuidados por al menos dos años



UN PROCESO INTENSO
Una tercera parte ha prestado cuidados por un mínimo de 20 horas semanales



¿QUIÉNES SON LOS ENCARGADOS DE CUIDADOS?

El 58 % son mujeres

El 9 % tiene 65 años o más

El 39 % está cuidando a sus padres o padres políticos

El 8 % cuida a alguien con demencia



¿CÓMO AYUDAN LOS ENCARGADOS DE CUIDADOS?

Casi el 80 % se ocupa de las tareas del hogar

Más del 50 % asiste con el cuidado personal



FUTUROS ENCARGADOS DE CUIDADOS

Casi 1 de cada 5 PERSONAS QUE NO ESTÁN ENCARGADAS DE PRESTAR CUIDADOS en la actualidad espera HACERLO dentro de 2 años



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

cdc.gov/aging

CS 294205-C Julio 2019

INFOGRAPHICS

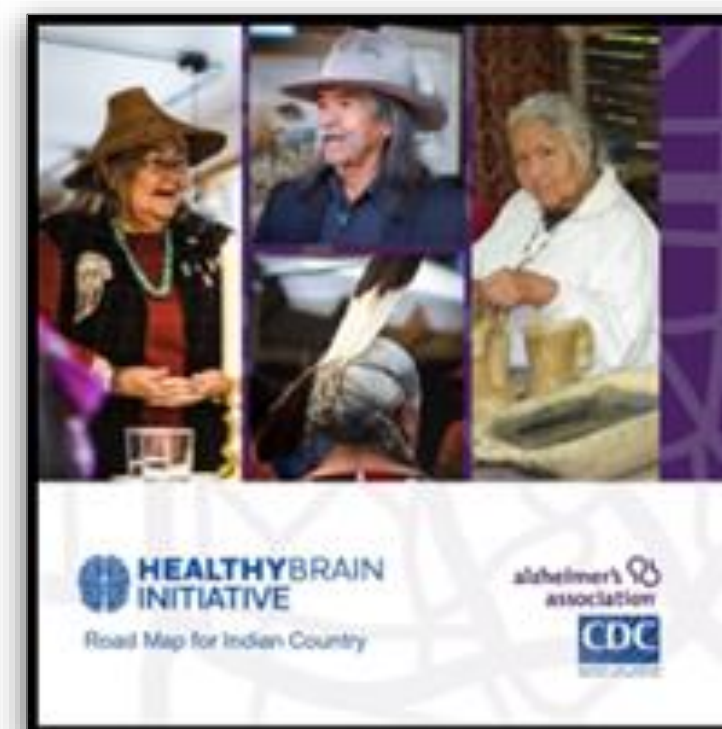
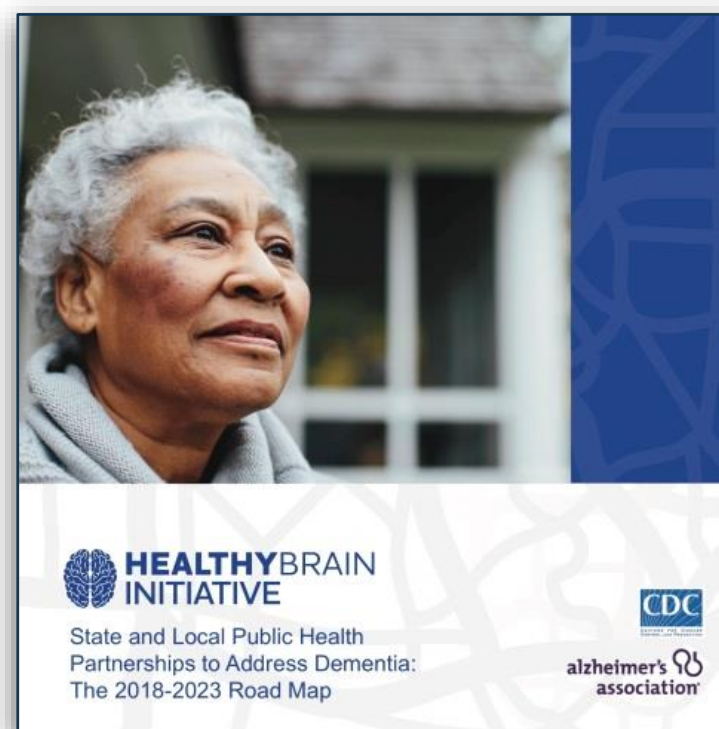
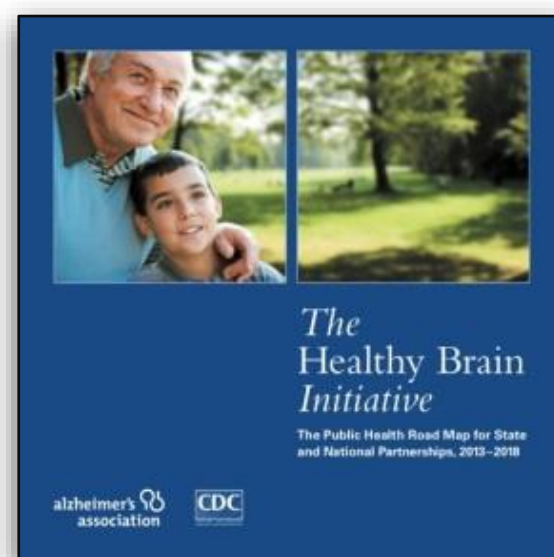
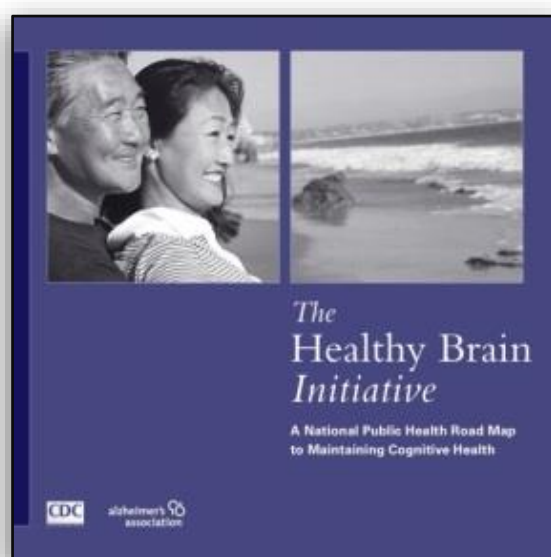
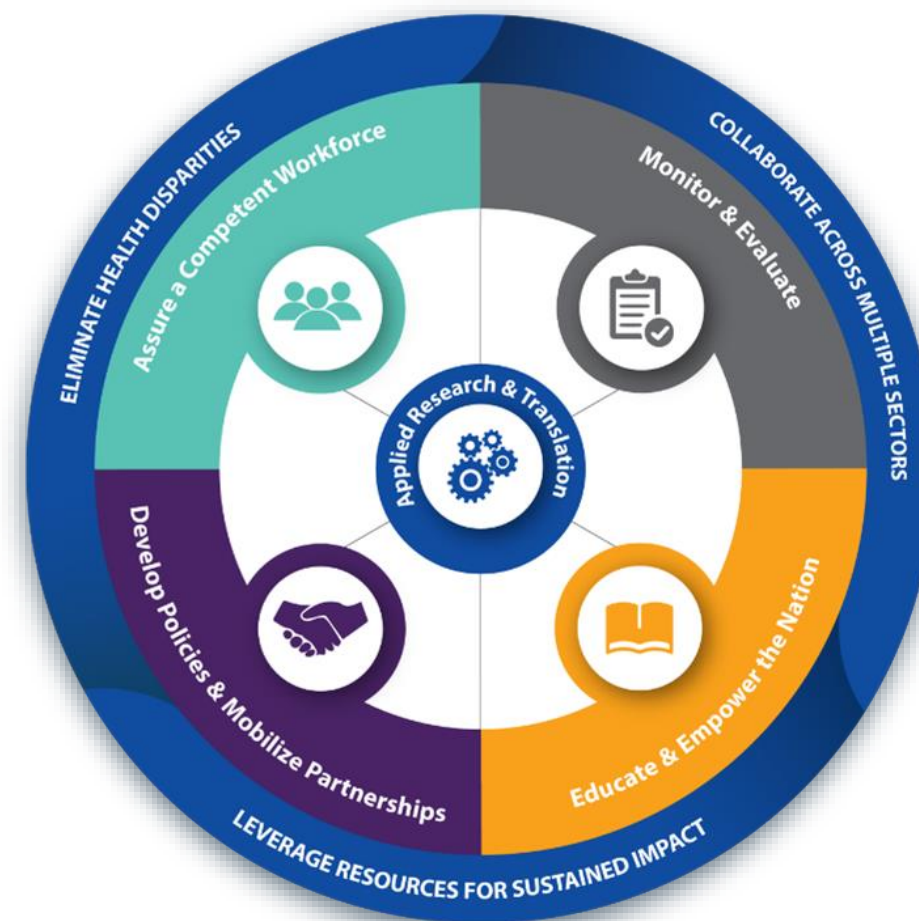
BRFSS™



HEALTHYBRAIN INITIATIVE

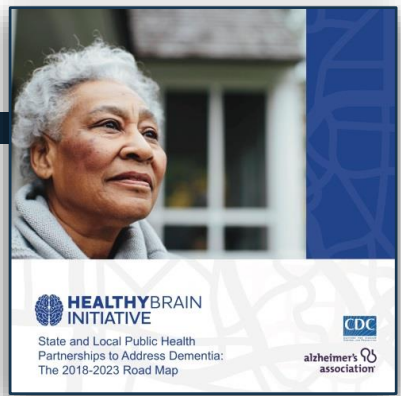
Road Map Series

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



www.cdc.gov/aging

EXAMPLE CAREGIVING-RELATED ACTIONS



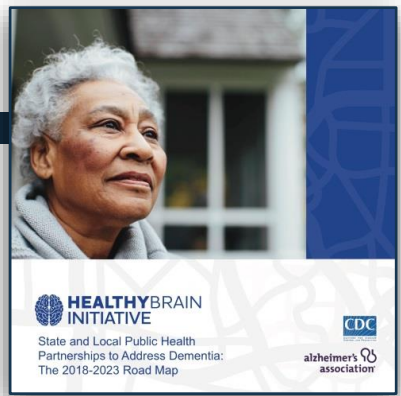
EDUCATE & EMPOWER

- E-3: Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and wellbeing.
- E-7: Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, wellbeing, and independence.

DEVELOP POLICIES & MOBILIZE PARTNERSHIPS

- P-5: Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.

EXAMPLE CAREGIVING-RELATED ACTIONS



ASSURE A COMPETENT WORKFORCE

- W-7: Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.



MONITOR & EVALUATE

- M-2: Support national data collection on dementia and caregiving.
- M-3: Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.



Building Our Largest Dementia Infrastructure (BOLD) is designed to create a **strong public health infrastructure** for dementia and dementia caregiving



Establishes
Alzheimer's Centers
of Excellence



Provides funding for
public health departments
across the country



Increases data
analysis and
timely reporting

<https://www.cdc.gov/aging/bold/index.html>

HIGHLIGHTS



- ✓ Resource to nation on caregiving
- ✓ Mapping dementia caregiving in the US (RTI collaboration)
- ✓ Role of public health in disseminating evidence-based interventions (webinar)
- ✓ Public health education module on dementia caregiving
- ✓ Elevating *caregiving* as a social determinant of health
- ✓ National Conference

POLICY INITIATIVES



TIMELINE OF NATIONAL POLICY INITIATIVES

2005-2007

- Healthy Brain Initiative Established with Congressional Support (2005)
- The first HBI Road Map Released (2007)

2011-2017

- National Alzheimer's Project Act (NAPA; 2011) and 1st National Plan to Address Alzheimer's Released (2012)
- Caregiving questions added to BRFSS (2015)
- HBI Road Map (2nd edition--2013 and 3rd edition--2018)

2018

- RAISE Family Caregivers Act (2018)
- The Supporting Grandparents Raising Children Act (2018)

2019

- Building our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (2019)
- Road Map for Indian Country Released

2020

- Healthy People expands to 3 dementia objectives
- *First* BOLD recipients awarded including BOLD PHCoE on Caregiving
- Caregiving in US (2020)

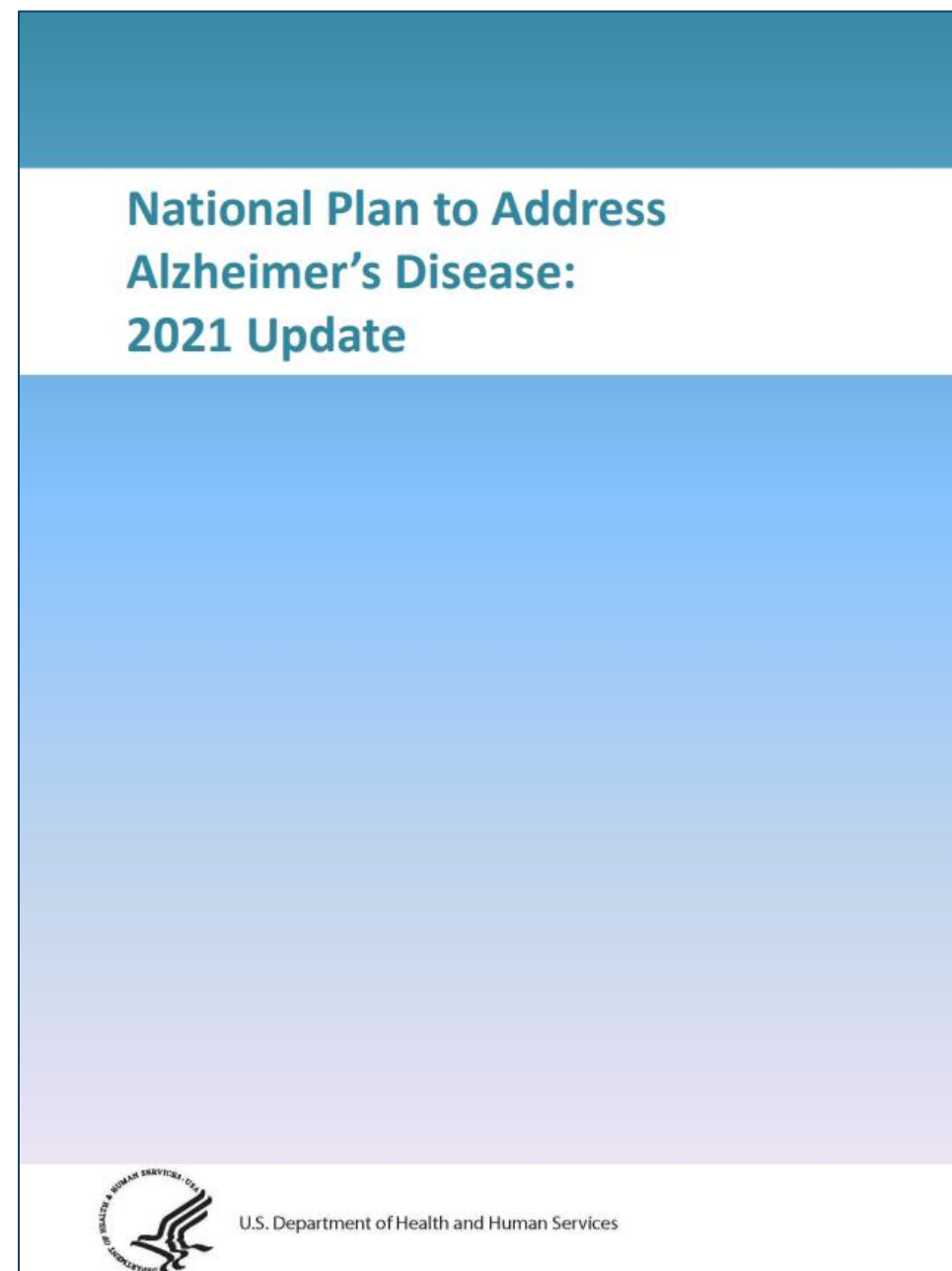
2021-2023

- RAISE report to Congress (2021)
- NAPA adds goal on Risk Reduction (2021)
- RAISE National Family Caregiver Strategy (2022)
- HBI Road Map for State and Local Public Health (4th edition -2023)

NATIONAL INITIATIVES



NATIONAL ALZHEIMER'S PLAN



1. Prevent and Effectively Treat Alzheimer's Disease and Related Dementia by 2025
2. Enhance Care Quality and Efficiency
- 3. Expand Supports for People with Alzheimer's and Related Dementias and Their Families**
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress
6. Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias

2022 NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

2022 National Strategy to Support Family Caregivers



Developed by:

The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren



Technical assistance provided by the Administration for Community Living | September 21, 2022

Proposes 5 main goals:



Increase awareness and outreach



Build partnerships and engagement with family caregivers



Strengthen services and supports

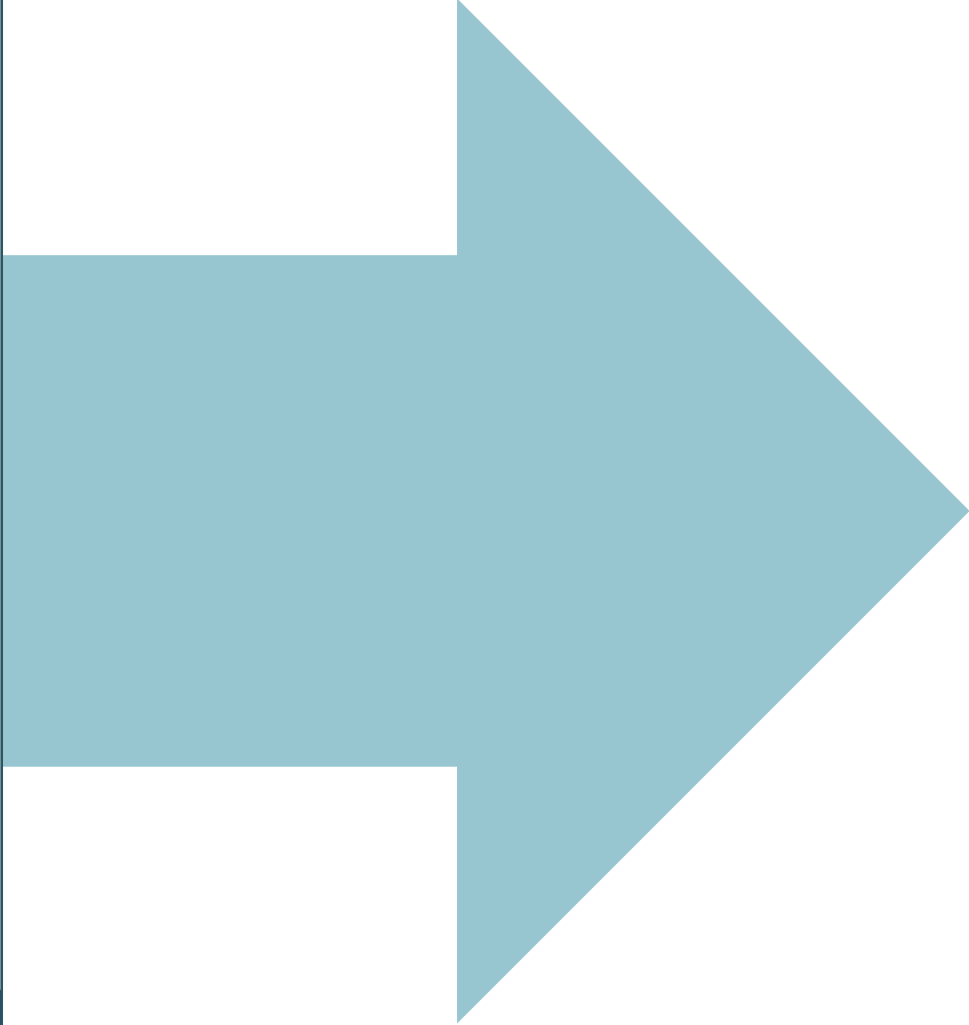
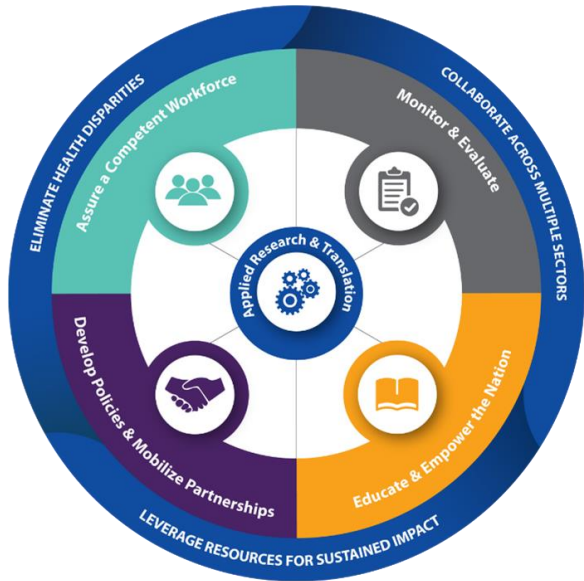
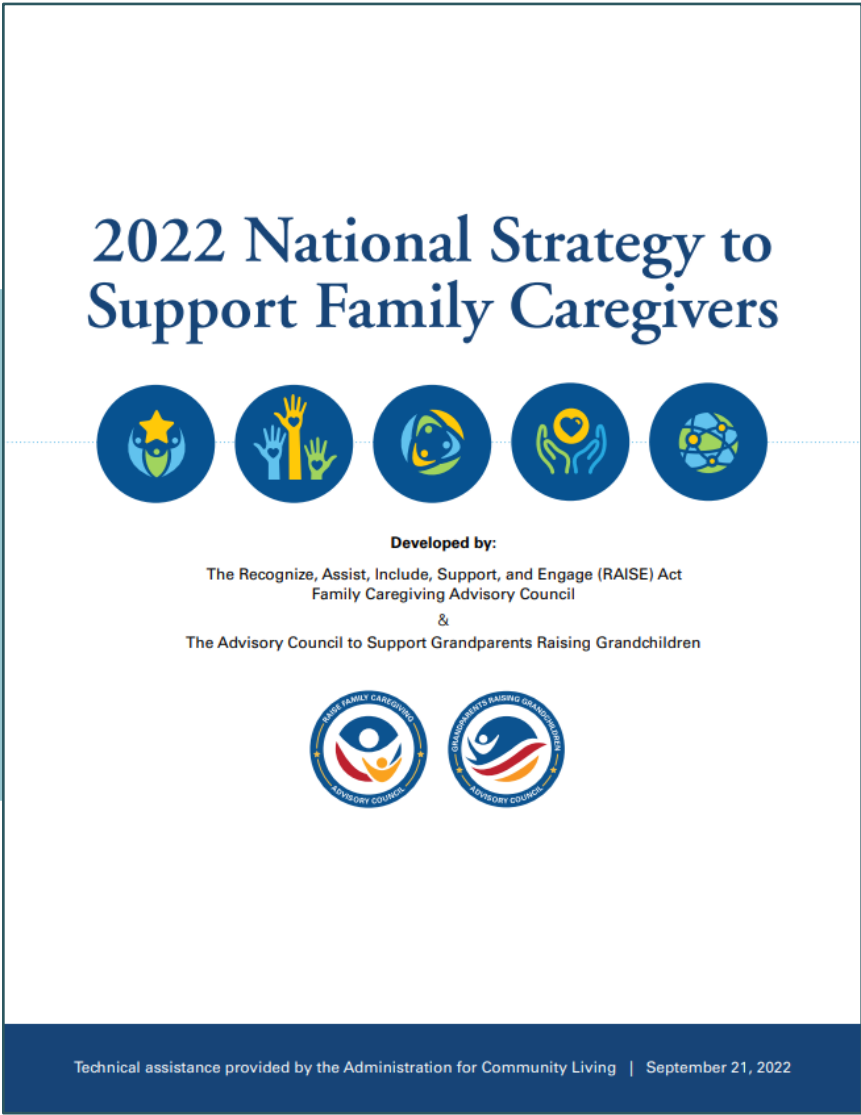
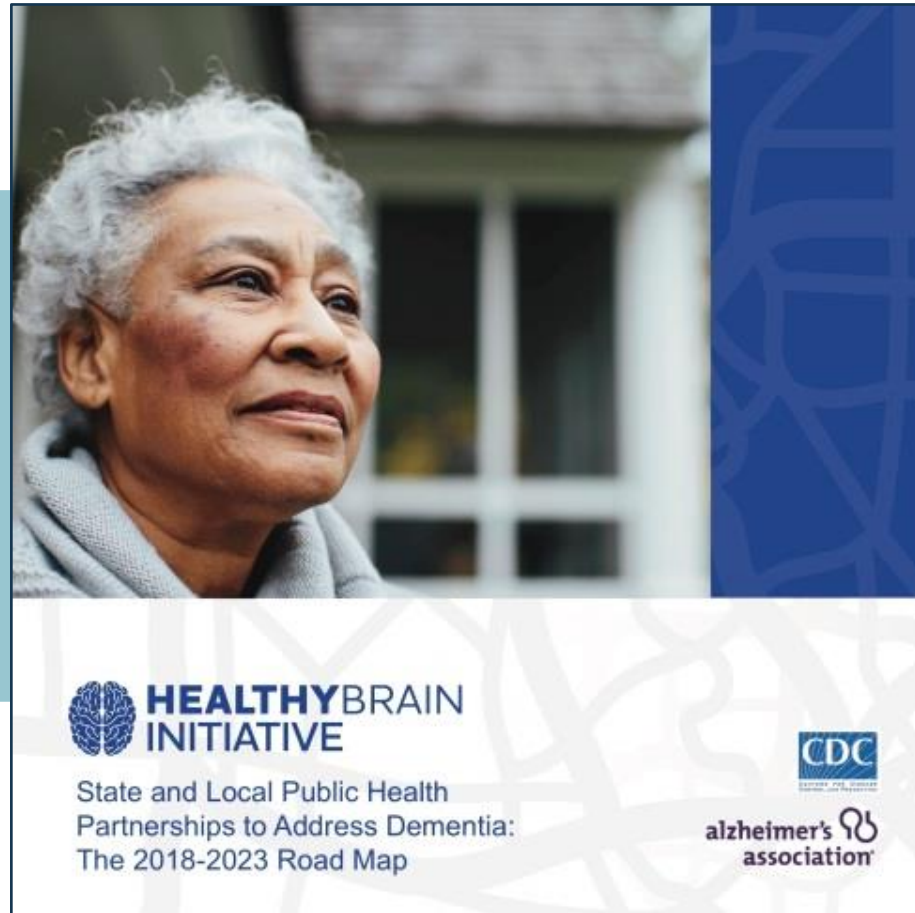


Ensure financial and workplace security



Expand data, research, and evidence-based practices

<https://acl.gov/CaregiverStrategy>



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Newsletter Subscription

The screenshot shows the CDC website for Alzheimer's Disease and Healthy Aging. At the top, there is a search bar and a navigation menu. The main content area features a large image of an elderly woman with a text overlay: "Evidence-based, scientific information to educate, inform, and assist translating research into public health practice." Below this is a "What's New" section with several article links. A "What is Alzheimer's Disease?" section provides a brief overview. The bottom of the page has a grid of six resource boxes: "Alzheimer's Disease", "Caregiving", "Healthy Brain Road Maps", "Communications Center", "Awardees", "Emergency Preparedness for Older Adults", "Healthy Brain Resource Center", "Resources & Publications", and "Training for Public Health Professionals".

Homepage

THANK YOU

YKD8@CDC.GOV



www.cdc.gov/aging



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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.



Panel Discussion

Liz Head, MPH

Kina White, DrPH, MHSA, FACHE

Erin Fay, LMSW



Five Goals from the RAISE Strategy

Goal 1: Increase awareness of and outreach

Goal 2: Advance partnership and engagement

Goal 3: Strengthen services and supports

Goal 4: Ensure financial and workplace security

Goal 5: Expand data, research, and evidence-based practices



Q&A

Please, submit your questions in the Q&A Zoom feature!



Future Events

January

- Successful Public Health Approaches in Dementia Caregiving: California - A Virtual Roundtable Series
 - Tuesday, 1/31 from 12:00-1:30pm ET

February/April

- Dementia Caregiving Topics in Public Health: A Virtual Roundtable Series
- And more topics...



Connect with us!

Visit us online at <https://bolddementiacaregiving.org> to....

- ✓ Find today's slides and recording.
- ✓ Request Technical Assistance to support your public health work in dementia caregiving.
- ✓ Access resources and materials.
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Thank you for joining us today!

Please, take a moment to complete our evaluation form at the end of this presentation.

