

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

Long-Term Services and Supports Federal Update

October 19, 2018

Administration for Community Living

2018 Alzheimer' Disease Programs Initiative (\$16,913,374)

STATE AWARDS

- Alaska Department of Health and Social Services (AK)
- Oregon Department of Health Services (OR)
- Pennsylvania Department of Aging (PA)
- Rhode Island Division of Elderly Affairs (RI)

COMMUNITY AWARDS

- | | |
|---|--|
| <ul style="list-style-type: none">• Alzheimer's and Dementia Care Services of Northwestern Ohio (OH)• Alzheimer's Orange County (CA)• Catholic Charities of Hawaii (HI)• Center for Excellence in Aging and Geriatric Health (VA)• County of Ventura (CA)• Easter Seals New Hampshire, Inc. (NH)• Jewish Family Service Association of Cleveland (OH) | <ul style="list-style-type: none">• Latino Alzheimer's and Memory Disorders Alliance (IL)• LiveWell Alliance, Inc. (CT)• ONEgeneration (CA)• Southeast Tennessee Development District (TN)• United Community Center, Inc. (WI)• University of Wyoming (WY)• WellMed Charitable Foundation (TX)• WISE & Healthy Aging (CA) |
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Administration for Community Living

Additional 2018 Grants

❖ National Alzheimer's Call Center

- Alzheimer's Disease and Related Disorders Association, Inc.
- \$1,233,571

❖ Strengthening the Financial Literacy & Preparedness of Family Caregivers

- Alzheimer's Disease and Related Disorders Association, Inc.
- \$250,000

Contract

❖ National Alzheimer's and Dementia Resource Center (NADRC)

- RTI, International, Inc.
- \$1,699,564

Goal 4 – Enhance public awareness and engagement – educate public, work with state tribal and local governments to improve coordination and identify model initiatives to advance ADRD awareness and readiness

Administration on Aging

National Family Caregiver Support Program (NFCSP)

- 2018 Funding increase of \$30,000,000 to \$180,000,000 ;
- Statutory highest priority of services requirement is “diagnosis of Alzheimer’s Disease or Related Disorder with neurological or organic brain dysfunction”;
- 62% of persons served are caregivers of individuals with a medical diagnosis of ADRD;
- Outreach and awareness programming results in caregivers benefiting from ADRD training in 74.9% of participating providers;
- Offer dementia specific evidence-based caregiver trainings and education interventions (i.e. Resources for Enhancing Alzheimer’s Caregiver’s Health (REACH) and SAVVY Caregiver).

Administration for Community Living

National Alzheimer's and Dementia Resource Center (NADRC) Webinar Series

www.nadrc.acl.gov

Improving Healthcare for People Living with Dementia (9/12/18)

Presenters: Debra Cherry, Lora Connolly, Katie Scott

People Trained – 557

First Responder Training and Programs to Support People with Dementia (8/7/18)

Presenters: Jessica Empeño and Molly Schroeder

People Trained – 626

Addressing Health Disparities in People Living with Dementia (7/31/18)

Presenters: Andrea Garr, Dr. Lisa Barnes

People Trained – 657

Goal 4 – Enhance public awareness and engagement – educate public, work with state tribal and local governments to improve coordination and identify model initiatives to advance ADRD awareness and readiness

Administration for Community Living

Title VI National Conference

(August 2018)

Alzheimer's Disease and Related Dementia Sessions

- Alzheimer's in Indian Country by the International Association for Indigenous Aging
- Supporting Those Living With Dementia (n4a and the WI Dept. of Health)
- Dementia Assistance for Elders by ACL, National Resource Center for Native Hawaiian Elders and the La Courte Oreilles tribe

Administration for Community Living

Long-Term Care Ombudsman Programs (OLTCOP)

Provides 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. Relevant training, provided by ACL's National Ombudsman Resource Center this quarter include:

- *Emergency Preparedness: Ombudsman Program Advocacy and Facility Responsibilities*" (webinar) ACL provides federal perspective on States' LTC Ombudsman programs and their role disaster preparation including case studies on experiences before, during, and after a recent natural disasters. Slides available as a [PDF](#), or view the [webinar recording](#).
- *Nursing Home eviction and discharge*: Technical support for this most common nursing home complaint, including new consumer education materials, [fact sheets](#), [Prezi presentation](#) and on-line training.
- *Sexual Abuse in Nursing Homes: What You Need to Know* (webinar) which reviews (1) prevalence, (2) physical and social signs of sexual abuse, (3) who is most at risk, and (4) who are the perpetrators and (5) strategies to respond and advocate for nursing home residents who are victims of this type of abuse.

Indian Health Service

September 2018

Native Elders National Indian Council on Aging Biennial Meeting

IHS Principal Deputy Director, RADM Michael Weahkee and Dr. Blythe Winchester, IHS Chief Clinical Consultant in Geriatrics and Palliative Care, participated in a panel discussion on Alzheimer's disease and related dementia to over 1000 Native Elders.

Recent Publication on Projections of Alzheimer's Disease

Alzheimer's & Dementia

Featured Article

Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥65 years

Kevin A. Mathews^{1,2}, Wei Xu¹, Anne H. Gaglioti¹, James B. Holt¹, Janet B. Croff¹, Dominic Mack¹, Lisa C. McGuire¹

¹Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, Atlanta, GA, USA
²Department of Geography, University of Wisconsin-Milwaukee, Milwaukee, WI, USA
 National Center for Primary Care, Department of Family Medicine, Marshfield Clinic of Medicine, Marshfield, WI, USA

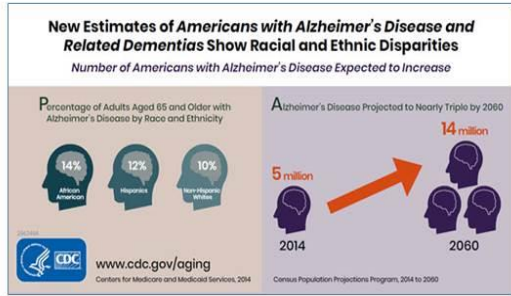
Abstract Introduction: Alzheimer's disease and related dementias (ADRD) cause a high burden of morbidity and mortality in the United States. Age, race, and ethnicity are important risk factors for ADRD. We estimated the future burden of ADRD by age, sex, race, and ethnicity by applying age-specific prevalence estimates from Medicare fee-for-service beneficiaries aged ≥65 years in 2014 to subgroup-specific population estimates for 2014 and population projection data from the US Census Bureau for 2015-2060. Results: The burden of ADRD in 2014 was an estimated 5.8 million adults aged ≥65 years or 14% of the population, and there are significant disparities in ADRD prevalence among populations of different race and ethnicity. ADRD burden will double to 11.9 by 2060 when 17.9 million Americans are projected to be aged ≥65 years. Discussion: These estimates can be used for public planning and interventions related to caring for the ADRD population and supporting caregivers. Published by Elsevier Inc. on behalf of the Alzheimer's Association.

Keywords: Dementia; Alzheimer's disease; Estimates; Prevalence; Projections; Race and ethnicity

1. Introduction

Alzheimer's disease and related dementias (ADRD) are characterized by a decline in memory leading to loss of independence. These diseases have wide-ranging impacts on patients, families, communities, and health-care systems. Alzheimer's disease (AD) is the sixth leading cause of death in the United States (7% population) and the fifth leading cause of death among adults aged ≥65 years [1]. Although the primary risk factor for ADRD is age, race, and ethnicity is also an important demographic risk factor. Estimates of ADRD among these subgroups do not exist. We addressed this gap by estimating ADRD in the population aged ≥65 years by age, sex, and race and ethnicity from 2015

to 2060 using Medicare Fee-for-Service (FFS) beneficiary claims with a clinical diagnosis of ADRD in 2014. Our estimates complement other estimates of the future burden of dementia [2-5]. The most commonly cited estimates for AD state that 47 million Americans had AD in 2010, and 11.8 million will have the disease by 2050 [2]. The most recent estimates in the US show that 6.1 million people had clinical AD or mild cognitive impairment in 2014, and this estimate is projected to grow to 13.0 million by 2060 [3]. We estimate that 5.8 million adults aged ≥65 years in the United States were diagnosed with ADRD in 2014, and 11.9 million Americans aged ≥65 years will be diagnosed with ADRD by 2060. These findings support surveillance activities designed to assess cognitive decline in the population at risk for ADRD as recommended in the Healthy Brain Initiative, a National Public Health Road Map to Maintaining Cognitive Health [6]. These findings will help the public, health-care



[Mathews et al](#)

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

Recent Publication on Older Adults

MMWR | September 21, 2018 | 168(37) | 760-77

CDC Grand Rounds: Promoting Well-Being and Independence in Older Adults

Benjamin S. Chertoff, MPH^{1,2}, Matthew Thompson³, Sarah L. Cook, PhD^{1,2}, Cassi Wong, PhD^{1,2}, Christopher A. Taylor, PhD^{1,2}, John Mankin, MD^{1,2}, Phyllis Thorpe, MD^{1,2}, Lisa C. McGuire, PhD^{1,2}

Healthy aging is not merely the absence of disease or disability but requires physical and mental health and ongoing social engagement (1). As the average U.S. life expectancy increases, recognition that public health can play a vital role in promoting healthy, successful aging even in the face of increased prevalence of chronic diseases, including types of dementia, among older adults (i.e., aged ≥65 years) has grown. Furthermore, actively engaging adults in prevention and wellness along with involving their caregivers (i.e., the family and friends of older adults who provide them with unpaid and informal support and services) can serve to prevent or delay the onset of physical disabilities and cognitive decline. Adults often are reluctant to discuss their concerns about worsening memory with their health care providers although such discussions can lead to earlier diagnosis and better care, planning, and support. As advances in public health and health care have helped increase life expectancy, public health professionals and health care providers have the opportunity to improve the quality of life for older adults and their caregivers and reduce the burdens associated with aging.

Each day, approximately 10,000 Americans reach age 65 years. By 2026, one in five Americans, 72.7 million, will be aged ≥65 years; this number is projected to reach 83.7 million by 2050. Within this group, the fastest growing age group will be persons aged ≥85 years, which is projected to increase from 3.9 million in 2012 to 8.9 million by 2050 (2). Longevity also provides advantages for society: Americans aged ≥50 years generate \$7.6 trillion in economic activity each year (3). Along with benefits of longevity, however, the prevalence of chronic diseases (e.g., hypertension, diabetes, arthritis) and other challenges increase with aging. Among adults aged ≥65 years, 80% have at least one chronic condition (4). Approximately one in three adults aged ≥65 years experience limitations in their activities of daily living (e.g., eating, bathing, and dressing). One third of persons aged ≥65 years live alone, which can compound challenges associated with activities of daily living and increase social isolation risks (5,6).

To help address these challenges, in 2015, the National Prevention Council, chaired by the U.S. Surgeon General, developed the *Healthy Aging in Action*⁷ report to identify recommendations and actions that promote healthy aging and improve health and well-being in later life (6). *Healthy Aging in Action* outlines strategies to eliminate health disparities, encourage safe and healthy communities, promote clinical and community preventive services, and empower older adults to make healthy decisions (6). One example of expanding older Americans' access to clinical preventive services is through Visit & Vax. A community health organization known as National Prevention Action through Regional Collaboration partners with many different collaborators at the federal, state, and local levels to increase the number of Americans who receive influenza vaccines by offering vaccination near polling places (7). In 2012, Visit & Vax served 651 polling locations across the majority of states and the District of Columbia. Approximately half (47.7%) of recipients reported that they had not received a flu shot the previous year or would not otherwise have been vaccinated. As well, 45% of persons receiving influenza vaccine at Visit & Vax clinics identified as African American or Hispanic, providing a potential strategy to reduce racial and ethnic disparities in receipt of influenza vaccination (7,8).

Medicaid, the primary health care payer for Americans aged ≥65 years, has incorporated prevention and screening services into two types of visits: the Welcome to Medicaid visit and the Annual Wellness Visit. During the Welcome to Medicaid visit, providers conduct a prevention-focused physical examination⁸ and review beneficiaries' medical and social history, risk for depression and mental disorders, functional abilities and physical activities, and their history of tobacco use (9). A written plan, similar to a checklist, is created to promote ongoing use of clinical preventive services and the discussion of important health topics, such as advance directives. Annual Wellness Visits⁹ incorporate personalized prevention plan services including a comprehensive health risk assessment.

¹https://www.cdc.gov/od/odj/ohrt/healthy-aging-to-action-0816.pdf.
²https://www.cdc.gov/od/odj/ohrt/healthy-aging-to-action-0816.pdf.
³The population of older adults is becoming increasingly more racially and ethnically diverse. From 2010 to 2050, the percentage of U.S. adults aged ≥65 who identify as non-Hispanic white is projected to decrease from 76.7% to 64.6% (https://www.cdc.gov/od/odj/ohrt/healthy-aging-to-action-0816.pdf).
⁴https://www.cdc.gov/od/odj/ohrt/healthy-aging-to-action-0816.pdf.
⁵https://www.cdc.gov/od/odj/ohrt/healthy-aging-to-action-0816.pdf.
⁶https://www.cdc.gov/od/odj/ohrt/healthy-aging-to-action-0816.pdf.

This is a feature in a series of occasional MMWR reports called **CDC Grand Rounds**. These reports are based on grand round presentations at CDC on high-profile issues in public health science, practice, and policy. Information about CDC Grand Rounds is available at <http://www.cdc.gov/grandround>.

MMWR | @CDCMMWR - Sep 21

Americans are living longer. As the proportion of older adults in the population continues to increase so does the prevalence of chronic diseases, like Alzheimer's. For suggestions to help #OlderAdults improve quality of life, read the latest report: www.cdc.gov/mmwr

ALZHEIMER'S DISEASE

TALK TO YOUR DOCTOR IF YOU EXPERIENCE SYMPTOMS, SUCH AS:

- Memory loss getting worse
- Difficulty completing familiar tasks
- Confusion with time or place

Talking with your doctor helps you and your family develop a plan for your care.

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION
Division of Population Sciences

[Olivari et al](#)

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

Recent Publications on Caregiving

ALJPH OPEN THEMED RESEARCH

The Economic Value of Informal Caregiving for Persons With Dementia: Results From 38 States, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFS5

Rabaron M, Rahman DPHI, JBI, Kim D, Boudin P, MPE, Gove L, BJA, PhD, MPE, Lee C, MG, PhD, Christopher A, Taylor, PhD, and Scott J, Combined, PhD

Objectives: To estimate the economic value from a societal perspective of informal caregiving of persons with dementia in 38 states, the District of Columbia, and Puerto Rico.

Methods: Using a role replacement method and data from the 2015 and 2016 Behavioral Risk Factor Surveillance System caregiver modules, the US Bureau of Labor Statistics May 2016 Occupation Profiles, and the US Department of Labor, we estimated the number and economic direct costs of caregiving hours.

Results: An estimated 3.2 million dementia caregivers provided more than 4.1 billion hours of care, with an average of 120 hours per caregiver. The median hourly value of dementia caregiving was \$15.28. Overall, we valued these caregiving hours at \$41.5 billion, with an average of \$12,600 per caregiver.

Conclusions: Caregivers of persons with dementia provide care that has important economic implications, without those efforts, many people would either not receive needed care or have to pay for that support. Surveillance data can be used to estimate the contributions of informal caregivers and the economic value of the care they provide. *JALN*. (April, 2018) 38(10):1377-1382. DOI:10.2196/2018.03.01

See also Pichon, p. 1383 and Galois and Vaughan, p. 1396.

Dementia is a form of cognitive decline that progresses over time.¹ Alzheimer's disease is the most common form, with an estimated 5.7 million persons in the United States living with Alzheimer's.² In addition, Alzheimer's is the sixth leading cause of death and the leading cause of disability in the United States in 2014.³ By 2025, an estimated 7.1 million people aged 65 years and older will be living with Alzheimer's disease or other dementia.⁴

As a result of the progressive nature of dementia and the required financial and time independence it takes to manage more people with dementia need assistance from formal and informal caregivers. Formal caregivers are paid caregivers, such as home health aides and nurse aides, who provide care at home or in residential facilities.⁵ Informal caregivers

without informal caregivers, people with dementia may not receive some of the services they need to maintain their health and well-being.⁶ Although health insurance and health care costs are paid for by the individual, the need for informal care may increase as Medicare and Medicaid reimbursement for home health services.^{7,8} We estimated the number of informal caregivers from existing data and their economic value as persons with dementia. We also explored the personal effects of providing informal caregiving on the health of these caregivers.

METHODS

The Center of Columbia, Puerto Rico, and 38 states implemented the caregiver module of the 2015 and 2016 Behavioral Risk Factor Surveillance System (BRFSS).⁹ We used data from the BRFSS caregiver module to identify informal caregivers (caregivers) and their characteristics, characteristics of caregiver, demographic and health status, and characteristics of the informal care they provided.

BRFSS is a state-based telephone (landline and cell phone) survey supported by the Centers for Disease Control and

THE JOURNAL OF RURAL HEALTH

ORIGINAL ARTICLE

Financial and Health Barriers and Caregiving-Related Difficulties Among Rural and Urban Caregivers

Scott J, Qualin, MPE, PhD¹; Lynn Shaid, BA²; Elena M. Anderson, PhD²; Valerie L. Edwards, PhD²; Lisa C. McGuire, PhD³

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³Department of Development and Health, School of Public Health, Oregon Health & Science University, Portland, Oregon

Abstract

Objective: To assess whether financial or health-related barriers were more common among rural caregivers and whether rural caregivers experienced more caregiving-related difficulties than their urban peers.

Methods: We used data from 7,616 respondents to the Caregiver Module of the 2015 Behavioral Risk Factor Surveillance System. Respondents were classified as caregivers if they reported providing care to a family member or friend because of a long-term chronic condition. We classified respondents as being in a rural area if they lived outside of a Metropolitan Statistical Area (MSA). We defined a financial barrier as having an annual household income <\$12,000 or not being able to see a doctor when needed in the past year because of cost. We defined a health barrier as having multiple chronic health conditions, a disability, or not or poor self-rated health.

Findings: Rural caregivers more frequently had financial barriers than urban caregivers (44.1% vs 31.6%, $P = .001$), but the prevalence of health barriers was similar (43.1% vs 40.4%, $P = .18$). After adjusting for demographic differences, financial barriers remained more common among rural caregivers. Rural caregivers were less likely than their urban peers to report that caregiving increased their difficulty in both emotional and behavioral aspects of self-rated health (0.30 vs 0.10, $P = .001$).

Conclusions: Informal caregivers, particularly in rural areas, face financial barriers. Rural caregivers were less likely than urban caregivers to report caregiving-related difficulties. Rural caregivers' coping strategies or skills in identifying informal supports may explain this difference, but additional research is needed to explore this hypothesis.

Key words: caregiving, geography, genetics, long-term care, observational data.


Informal care provided by friends and family members of people with chronic health conditions or disability is a vital component of the United States long-term care system.¹ These caregivers provide a variety of types of support, including helping care recipients to maintain independence, helping them manage diet and medications



Rabaron et al

Boudin et al

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

Healthy Brain Initiative Road Map, 2018-2023



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


Making Alzheimer's Our Next Public Health Success Story

Are communities ready to respond to a large population of older people with dementia? Current practices reduce the burden of people living with Alzheimer's and other dementias by supporting the family boom generation and older caregivers who need care, remain in the community system.¹ These caregivers provide a variety of types of support, including helping care recipients to maintain independence, helping them manage diet and medications

SELECT FACTS

- Today, nearly 6 million Americans are living with Alzheimer's dementia, with annual costs topping \$277 billion. In 2050, 10 million will be affected, with an annual cost to the U.S. of \$1.1 trillion.
- African Americans, Hispanics, and women are particularly at risk of developing Alzheimer's and other dementias.
- More than 90% of people with dementia live at or near their homes.
- In 2015, there were 1,471 emergency department visits for every 1,000 Medicaid beneficiaries with dementia.
- More than 1 in 3 Alzheimer's caregivers report their health has become worse due to care responsibilities.

Conceptual Framework for the Healthy Brain Initiative Road Map



The Action Agenda of the Hill Road Map aligns across four domains of public health: Policy, Practice, Research, and Education. Each domain has associated action items to address dementia.

The common Healthy Brain Initiative, The Road Map for Indian Country is specifically designed for public health systems serving American Indians and Alaska Natives.

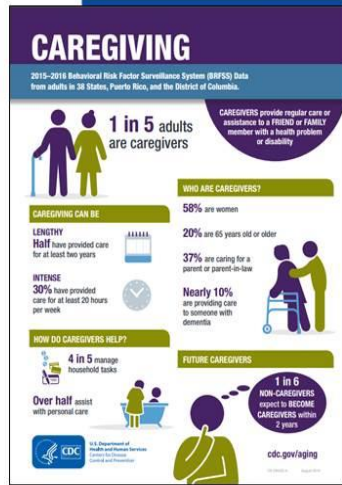
NEW: Road Map

Road Map Executive Summary

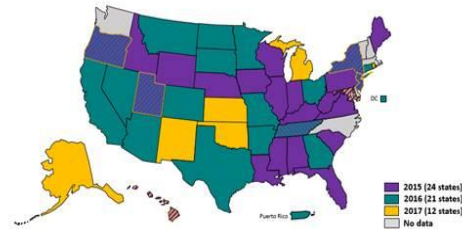
HEALTHY BRAIN INITIATIVE State and Local Partnerships to Address Dementia: The 2018-2023 Road Map

Data for Action

National Caregiving Infographic



Caregiving Surveillance

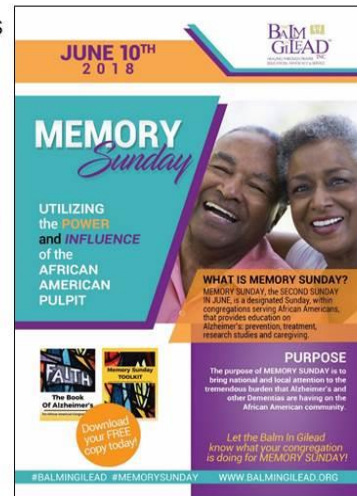


Caregiving Infographic

HEALTHY BRAIN INITIATIVE State and Local Partnerships to Address Dementia: The 2016-2023 Road Map

2018 Memory Sunday Highlights

- 246 Congregations participated – reaching approximately 75,000 congregational members
- 6 in-person Memory Sunday events across the country reaching over 500 participants in Atlanta, Boston, Chattanooga, Seattle, Jacksonville, and Baltimore.
- 650,000 media impressions across radio, print, and social media
- 600+ downloads of *Memory Sunday Toolkits* and *The Book of Alzheimer's*
- 95% of participating churches distributed materials
- 43% hosted a special event or service for caregivers
- 38% partnered with agencies to provide information on Alzheimer's and dementia



HEALTHY BRAIN INITIATIVE State and Local Partnerships to Address Dementia: The 2016-2023 Road Map



THANK YOU!