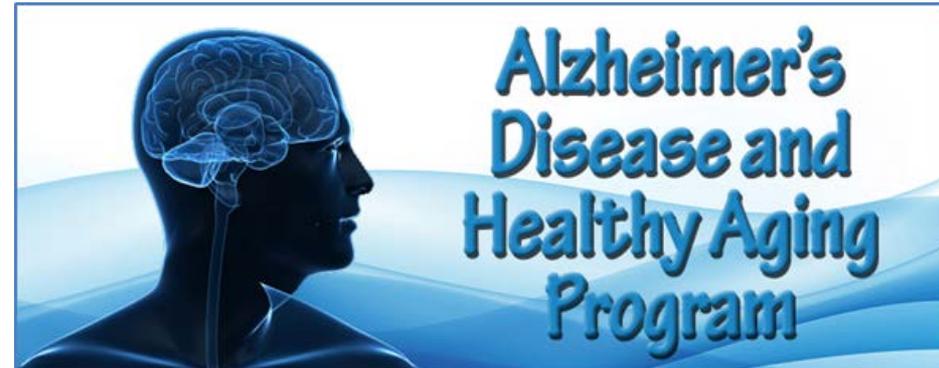


# *Caregiving is a Public Health Issue*

**Lisa C. McGuire, PhD**

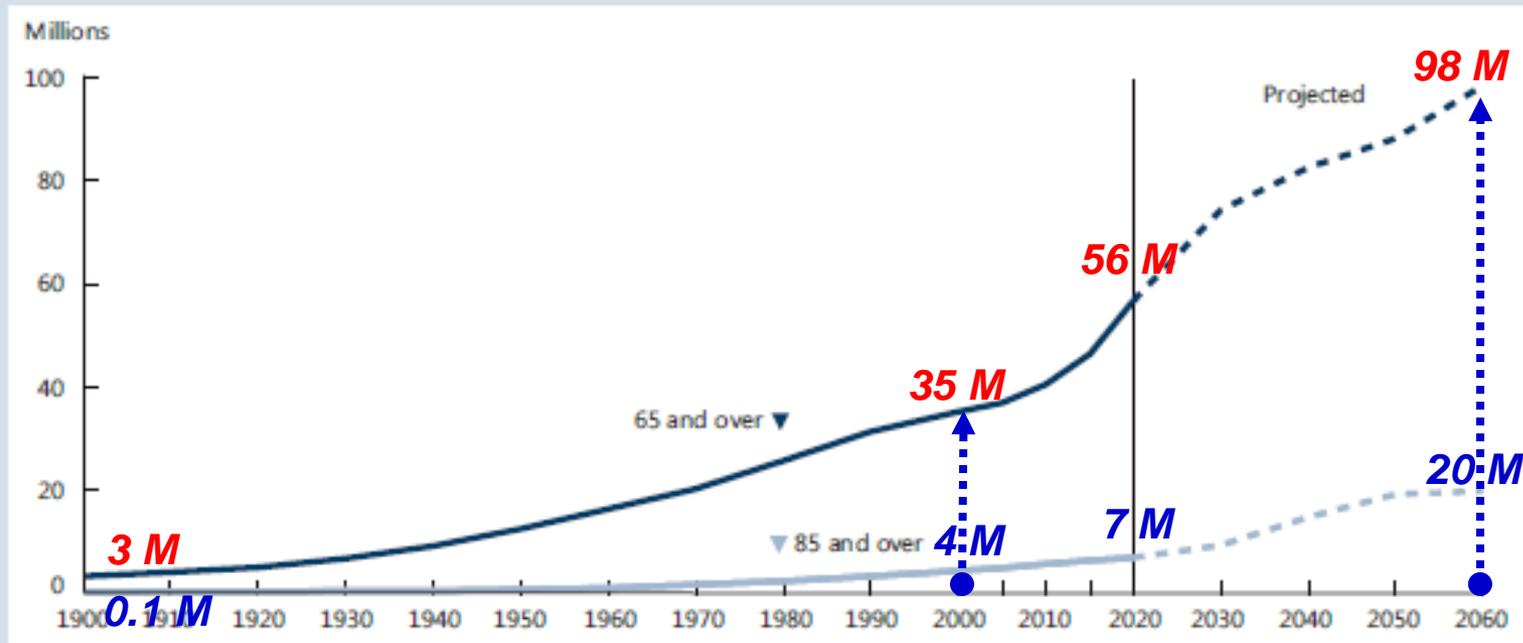


Lead, Alzheimer's Disease and Healthy Aging Program  
Division of Population Health  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention

Presented at ASA: March 21, 2017

# Population $\geq 65$ and $\geq 85$ Years Old United States, 1900–2014 and Projected 2020–2060

Population age 65 and over and age 85 and over, selected years, 1900–2014, and projected years, 2020–2060



NOTE: Some data for 2020–2050 have been revised and differ from previous editions of *Older Americans*.

Reference population: These data refer to the resident population.

SOURCE: U.S. Census Bureau, 1900 to 1940, 1970, and 1980, U.S. Census Bureau, 1983, Table 42; 1950, U.S. Census Bureau, 1953, Table 38; 1960, U.S. Census Bureau, 1964, Table 155; 1990, U.S. Census Bureau, 1991, 1990 Summary Table File; 2000, U.S. Census Bureau, 2001, *Census 2000 Summary File 1*; U.S. Census Bureau, Table 1: Intercensal Estimates of the Resident Population by Sex and Age for the U.S.: April 1, 2000, to July 1, 2010 (US-EST00INT-01); U.S. Census Bureau, 2011, *2010 Census Summary File 1*; U.S. Census Bureau, Annual Estimates of the Resident Population for Selected Age Groups by Sex for the United States, States, Counties, and Puerto Rico Commonwealth and Municipios: April 1, 2010, to July 1, 2014 (PEPAGESEX); U.S. Census Bureau, Table 3: Projections of the Population by Sex and Selected Age Groups for the United States: 2015 to 2060 (NP2014-T3).

# Significance of Caregiving

- 85% of baby boomers desire to “age in place”\*
  - 4.6 years is the average length of time for caregiving in home settings, and for persons living with dementia may range from 4-20 years
- 25% of adults aged 18+ reported providing care or assistance to person with long-term illness or disabilities in past 30 days (2009 BRFSS)\*\*
  - People willingly provide support but caregiving activities put people at increased risk for injury, mental health problems, and economic insecurity

\* Yen, et al. (2014). How Design of Places Promotes or Inhibits Mobility of Older Adults: Realist Synthesis of 20 Years of Research. *Journal of Aging and Health*. published online 30 April 2014doi:10.1177/0898264314527610

\*\* Anderson et al. (2013). Adult Caregivers in the United States: Characteristics and Differences in Well-being, by Caregiver Age and Caregiving Status. *Preventing Chronic Disease*,10:130090. DOI: <http://dx.doi.org/10.5888/pcd10.130090>.

# Population Dynamics Related to Caregiving

- Currently 7 caregivers per patient exist
- This will drop to 4 caregivers per patient
- Number of childless elderly is growing



A photograph of Rosalynn Carter, a woman with short, wavy, reddish-brown hair, wearing glasses, a dark blazer, a white top, and a necklace. She is speaking at a podium, with her right hand raised in a gesture. The background is dark and out of focus.

Rosalynn Carter  
Former First Lady and Chair of the  
Rosalynn Carter Institute on Caregiving

“There are four kinds of people in the world:

Those who have been caregivers;

Those who currently are caregivers;

Those who will be caregivers; and

Those who will need caregivers.”

# Caregivers

- ❑ Play critical role
- ❑ Health care system could not sustain costs of care
- ❑ Caregiving can take a physical and financial toll



# Physical Impact of Caregiving

- ❑ The longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health.
- ❑ 22 percent of caregivers feel their health has gotten worse as a result of caregiving.
- ❑ 19% caregivers reports a high level of physical strain resulting from caregiving and 38% consider their caregiving situation to be emotionally stressful.



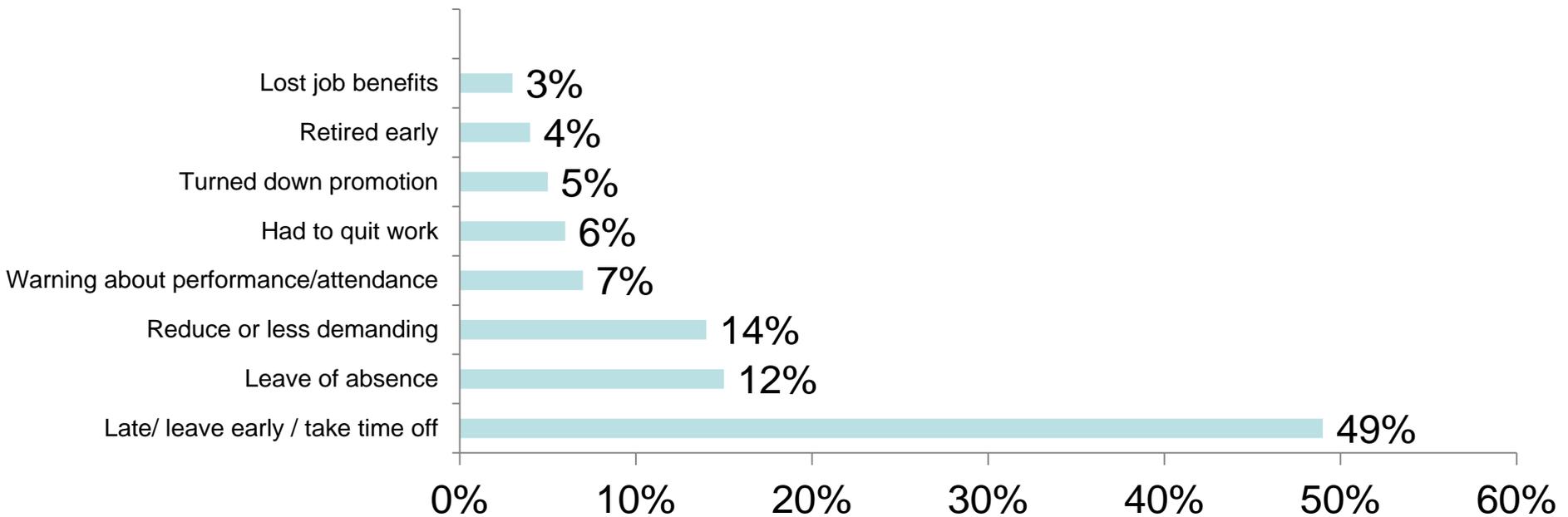
# Financial Impact of Caregiving

- ❑ Caregivers were 28% more likely to eat less or go hungry while caring for someone with Alzheimer's
- ❑ About half cut back on their own expenses to afford dementia-related care for their family member or friend
- ❑ 13% sold personal belongings, such as car, to help pay for costs related to dementia
- ❑ Nearly half tapped into their retirement funds



# Impact on Work

## Caregivers' Work-Related Changes



# Caregiving

- Caregiving is a public health issue



# National Plans and Reports (1)

## Healthy People 2020

- OA-8(Developmental) Reduce the proportion of noninstitutionalized older adults with disabilities who have an unmet need for long-term services and supports





# National Plans and Reports (2)

Assure the needs of caregivers are met and implement caregiver supports. Specific recommendations include:

- ❑ Assure that health systems funded to provide chronic disease management and related services for family caregivers
- ❑ Engage families in care planning and referrals to appropriate community resources to support this planning
- ❑ Expansion of evidence-based caregiver support programs
- ❑ Ensure caregivers of older adults are routinely identified and their needs assessed
- ❑ Support caregivers through respite care, pension credits, financial subsidies, training and home nursing services to reduce their burden



# National Plans and Reports (3)

Strengthen data collection and research. Specific recommendations include:

- ❑ Implementing the Behavioral Risk Factor Surveillance System's cognitive impairment and caregiver modules and inclusion of questions on core rather than as optional module.
- ❑ Expanding data collection on caregivers and cognitive aging
- ❑ Launch a multi-agency research program to evaluate caregiver intervention in real world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes
- ❑ Identify family/unpaid caregivers in EHRs of individuals with AD/ADRD, as well as in the caregiver's own medical records.



# The Healthy Brain Initiative

The Healthy Brain Initiative is designed to spread understanding of and support for healthy cognitive aging as a central part of public health practice.

- creates and supports partnerships,
- collects and reports data,
- increases awareness of cognitive aging, and
- promotes the use of the Roadmap.

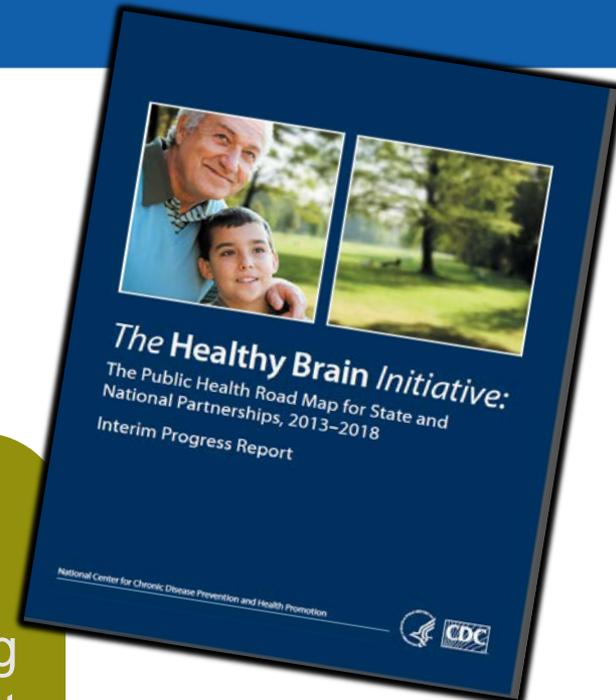
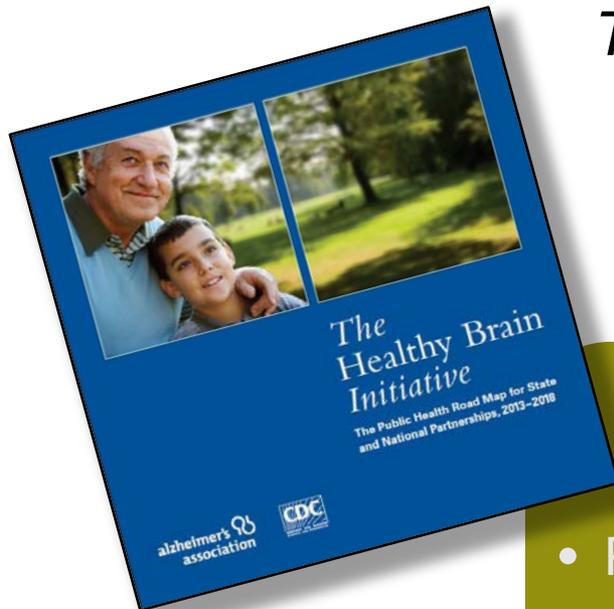
*The  
Healthy Brain  
Initiative*

# CDC's Public Health Road Map

## *The Public Health Road Map for State and National Partnerships 2013-2018*

*35 action items for public health officials to:*

- Promote cognitive functioning
- Address cognitive impairment and Alzheimer's disease
- Meet the needs of caregivers



*The  
Healthy Brain  
Initiative*

<https://www.cdc.gov/aging/healthybrain/roadmap.htm>

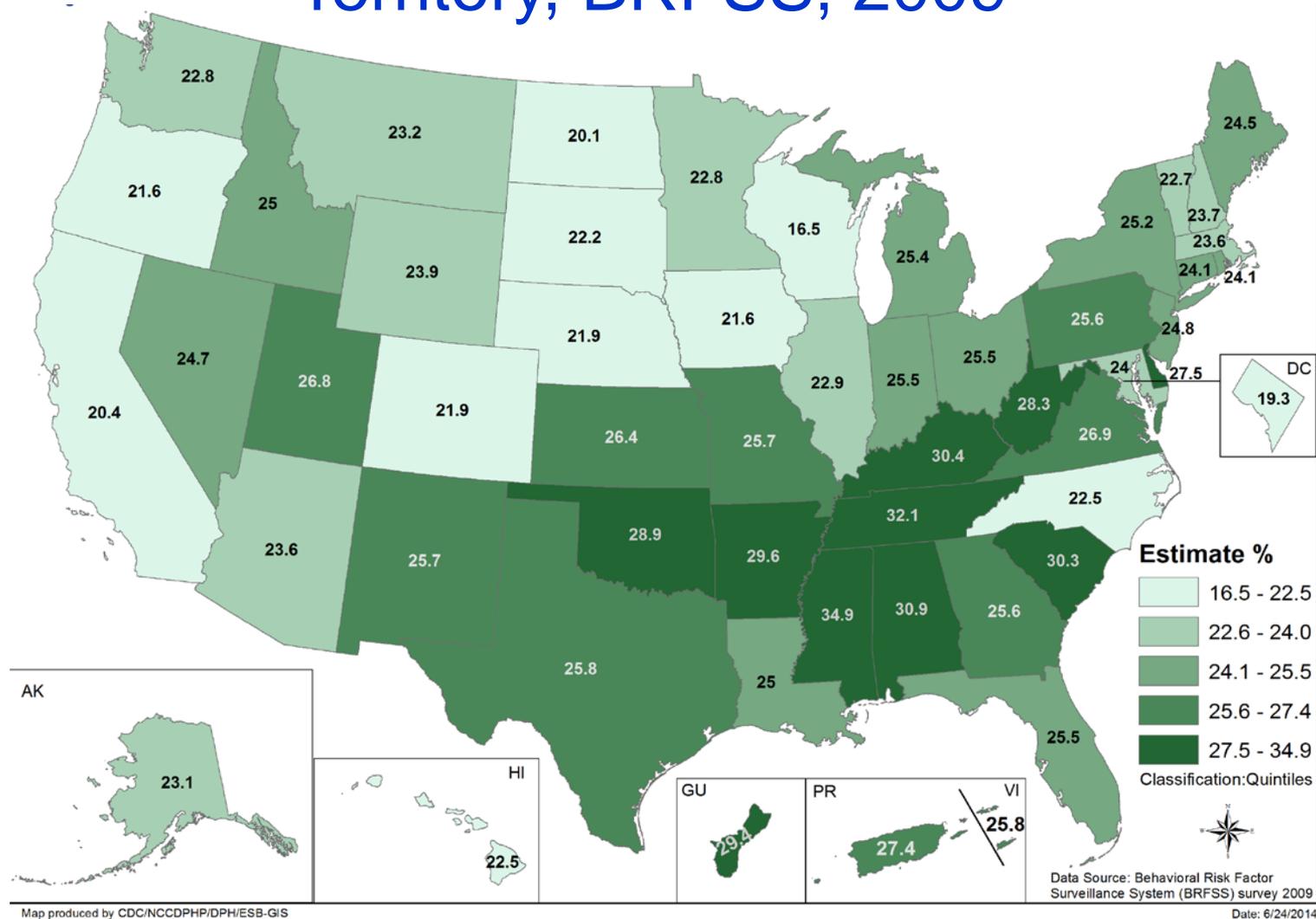
# Five Actions HBI-Related to Caregiving

- M-01 Implement the Behavioral Risk Factor Surveillance System's cognitive impairment and **caregiver** modules.
- M-08 Define the needs of **caregivers** and persons with dementia, including Alzheimer's disease and younger onset, as they relate to employment and employers.
- M-10 Conduct a national-level review of **caregiver programs and policies** consistent with The Guide to Community Preventive Services methodologies.
- M-13 Conduct a national-level literature review on the potential and optimal use of technology for delivering best practices in programs for **caregivers** and persons with dementia, including Alzheimer's disease.
- E-03 Encourage public health entities to provide links on their Web sites to local, state, and national dementia resources, including those specific to Alzheimer's disease and **caregiving**, such as [www.alzheimers.gov](http://www.alzheimers.gov).

# Behavioral Risk Factor Surveillance System (BRFSS)

- ❑ BRFSS is a partnership between CDC and state health departments to produce data that benefits states, territories, localities and public health professionals.
- ❑ Includes 57 state/territorial level telephone surveys on health status, health risk behaviors and chronic conditions.
- ❑ The world's largest continuously conducted telephone health surveillance system.
- ❑ The only source of public health behavior and risk factor data at state/territorial level for most states/territories.
- ❑ Non-institutionalized adults age 18+.
- ❑ Approximately 450,000 respondents in 2014.
- ❑ Data and more information: <http://www.cdc.gov/brfss/>

# Prevalence of Caregiving, by State and Territory, BRFSS, 2009\*



\*BRFSS core question: "People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?"



# Promoting the Health and Well-being of Caregivers for Older Adults

## Caregiving Surveillance

- ❑ In 2009, a question about caregiver status was added to the BRFSS Core.
- ❑ 10-item caregiver module added to BRFSS in 2011-2013
- ❑ Revised 8-item caregiver module added to BRFSS in 2015 with 24 states administering it.

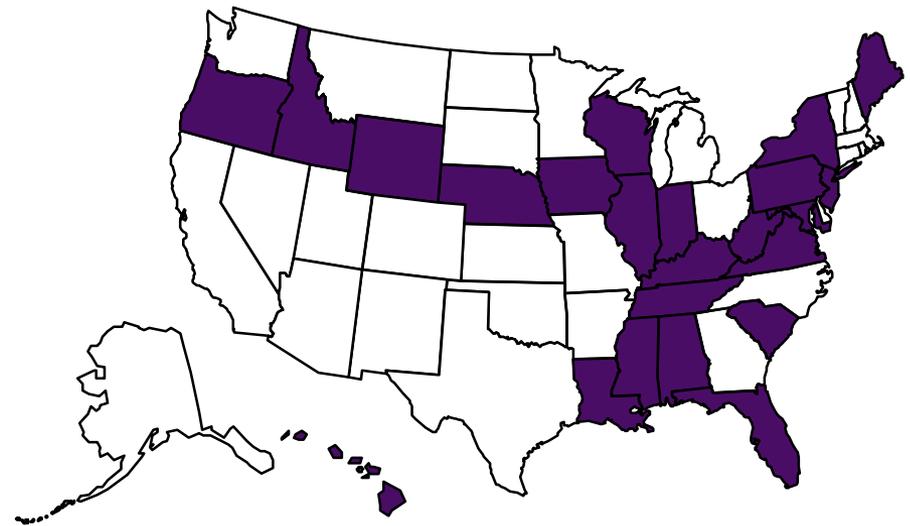
## State-Level Caregiving Information

- ❑ A series of reports and fact sheets were developed with the BRFSS caregiving data from 2011-2013 and products for 2015 data are in development.

# Optional BRFSS Caregiving Module

## Caregiving

- ❑ Characteristics of caregivers
- ❑ Problems they face
- ❑ Greatest care needs
- ❑ 24 states in 2015
- ❑  $N = 141,191$



# Caregiving Screener

During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?

Yes/No



# Forecasting

If not a current caregiver:

In the next 2 years, do you expect to provide care or assistance to a friend or family member who has a health problem or disability?



# Relationship

What is his/her relationship to you? For example is he/she your (mother/daughter or father/son)?



# Length of Care

For how long have you provided care for that person?  
Would you say...

Less than 30 days

1 month to less than 6 months

6 months to less than 2 years

2 years to less than 5 years

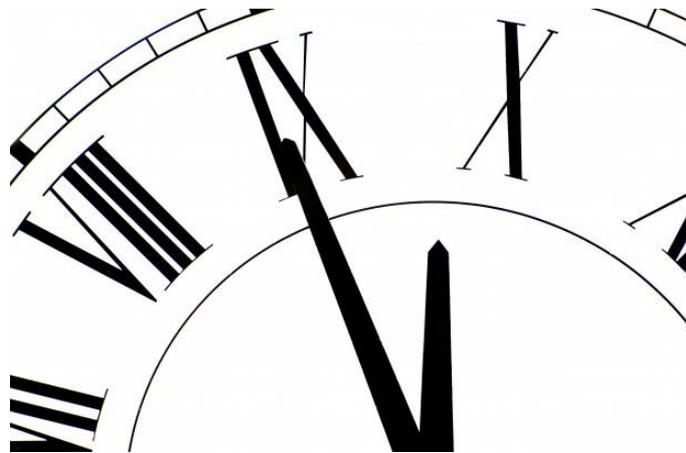
More than 5 years



# Intensity

In an average week, how many hours do you provide care or assistance? Would you say...

- Up to 8 hours per week
- 9 to 19 hours per week
- 20 to 39 hours per week
- 40 hours or more per week



# Cause

What is the main health problem, long-term illness, or disability that the person you care for has?

Broader categories

Match co-occurring chronic conditions



# Caregiving Needs

In the past 30 days, did you provide care for this person by...

...Managing personal care such as giving medications, feeding, dressing, or bathing?

Yes/No

...Managing household tasks such as cleaning, managing money, or preparing meals?

Yes/No

# Support Services Needed

Of the following support services, which ONE you MOST need, that you are not currently getting?

- ❖ Classes about caregiving, such as giving medication
- ❖ Help in getting access to services
- ❖ Caregiver support groups
- ❖ Individual counseling to help cope with caregiving
- ❖ Respite care
- ❖ No caregiver support services needed



# 2015 Highlights

- 22% of respondents aged 18 and older provides regular care or assistance
- Physical and Mental Health
  - More likely to report Fair/poor physical health, depression, frequent mental and physical distress, and obesity
  - No differences on coronary heart disease, stroke, CVD, diabetes, and routine check-up (2 years)
- 17.8% of non-caregivers expect to provide care to someone due to a health problem or disability within the next two years
- 53.7% provided help managing personal care and 79.8% provided help managing household tasks

# Data for Action: 2015 BRFSS

alzheimer's association®

## factsheet

OCTOBER 2016

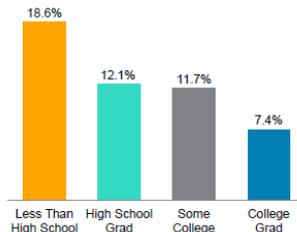
alz.org

### Cognitive Data from the 2015 BRFSS

One in nine people aged 45 and older report facing confusion or memory loss that is happening more often or is getting worse ("subjective cognitive decline").

- Data from 33 states and the District of Columbia show that 11.6 percent of Americans aged 45 and over have subjective cognitive decline.
- African Americans are 21 percent more likely than whites to have subjective cognitive decline.
- Individuals with lower levels of education are more likely to have subjective cognitive decline. Of those who did not graduate from high school, 18.6 percent have subjective cognitive decline compared with 7.4 percent of college graduates.
- Among those with subjective cognitive decline, 29.2 percent live alone, and 24.2 percent have a household income of less than \$15,000.

Subjective Cognitive Decline Among Those Aged 45 and Over By Education Level



People with subjective cognitive decline often have additional health issues beyond their increasing memory problems.

- Eighty percent of those with subjective cognitive decline have at least one other chronic condition (arthritis, asthma, cancer, cardiovascular disease, COPD, and/or diabetes).
- Over half say that, in general, they are in fair or poor health.
- Of those individuals with subjective cognitive decline, 39.4 percent spent at least 14 days in the last month in poor physical health.

#### What is the BRFSS?

The Behavioral Risk Factor Surveillance System (BRFSS) is a public health survey conducted each year by all states, in coordination with the Centers for Disease Control and Prevention (CDC).

The data presented here come from the 2015 BRFSS Cognitive Module – a series of six questions that ask about memory problems, the burden of cognitive decline, and whether memory problems have been discussed with a health care professional. All data were analyzed by the CDC's Healthy Aging Program.

## Subjective Cognitive Decline

Data from the 2015 Behavioral Risk Factor Surveillance System

Aggregates across 34 states:  
Alabama • Arizona • Arkansas • California • Colorado • District of Columbia • Florida • Georgia • Hawaii • Illinois • Iowa • Louisiana • Maryland • Michigan • Minnesota • Mississippi • Nebraska • Nevada • New Jersey • New York • North Dakota • Ohio • Oregon • Rhode Island • South Carolina • South Dakota • Tennessee • Texas • Utah • Virginia • West Virginia • Wisconsin • Wyoming



SCD is self-reported MEMORY PROBLEMS that have been getting worse over the past year.



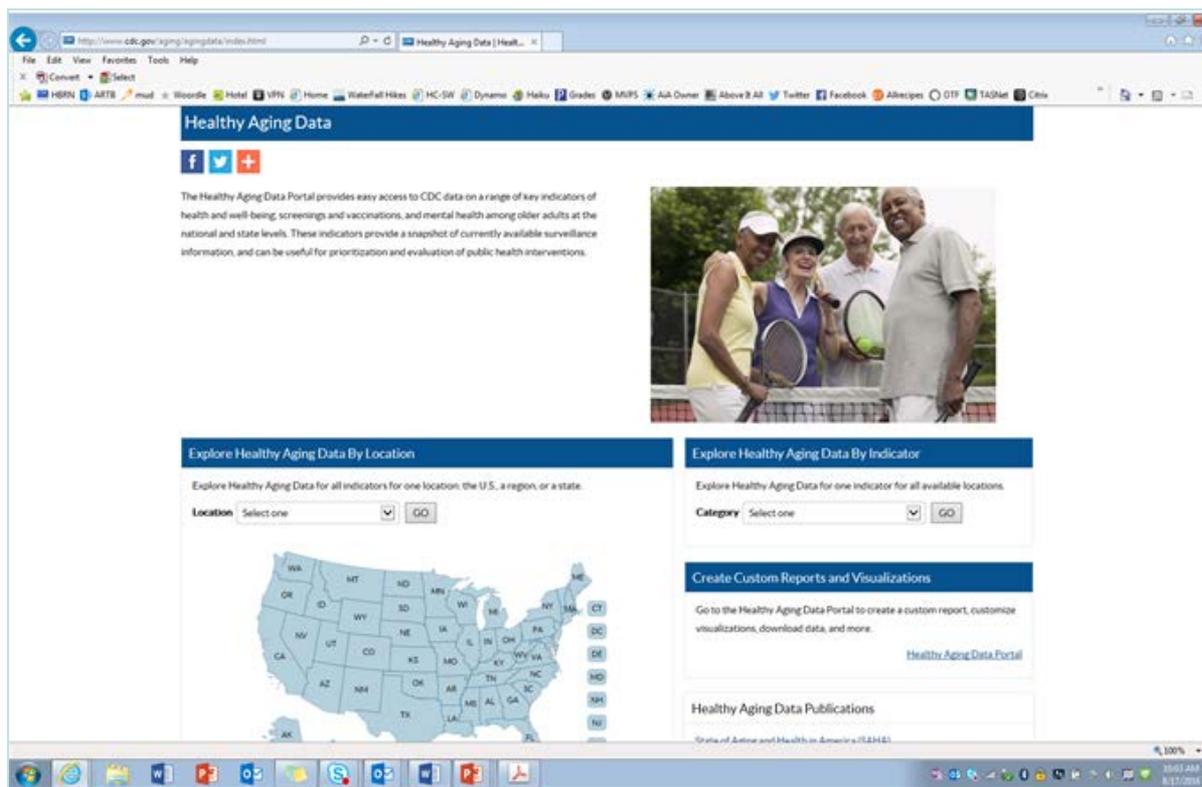
Many with SCD also have other chronic conditions



alzheimer's association  
CDC  
Centers for Disease Control and Prevention

for more information: [www.alz.org/publichealth](http://www.alz.org/publichealth)  
[www.cdc.gov/aging](http://www.cdc.gov/aging)

# Data for Action: Data Portal



<http://www.cdc.gov/aging/agingdata/index.html>

# Planning and Programmatic Information

- Understand the state-level experience & needs of caregivers
  - Wide variation in prevalence of caregiving and impacts of caregiving across states
- Broad age range of caregivers and care recipients (not just older adults)
- Measure burden (time, tasks) for caregivers
- Link to caregiver outcomes, e.g., health, injury

# Promoting the Health and Well-being of Caregivers for Older Adults

## REACH OUT: Moving Programs into Practice

Developed a step-by-step guide to using REACH OUT, an evidence-based intervention for dementia caregivers, in communities of varying size and composition.

## American Indian and Alaska Native (AI/AN) Caregiving

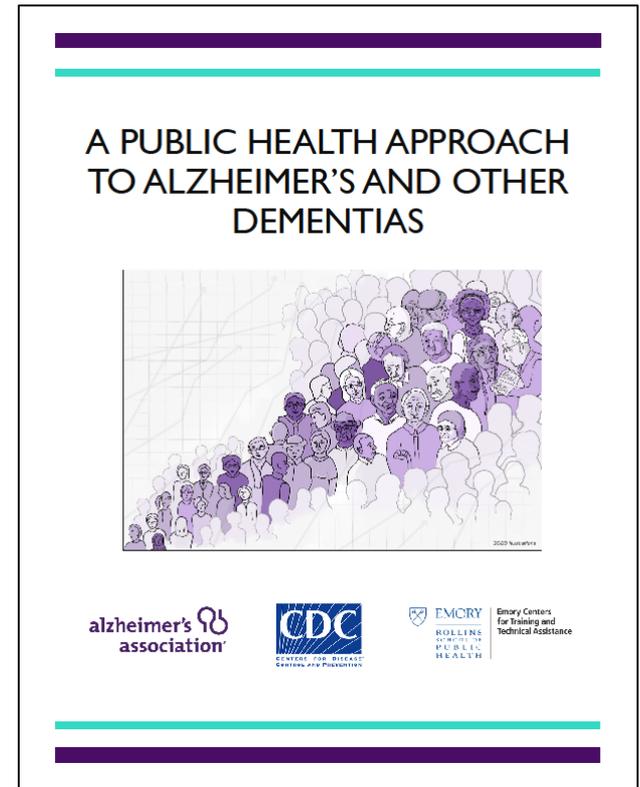
This Critical Issue Brief, [Caregiving in Indian Country: Tribes Supporting Family Traditions](#)[\[PDF-303K\]](#), looks at caregiving issues in Indian country and the support systems that can maintain this traditional family value, while there is outward migration of family caregivers.

Implementing a Community-Based Program for Dementia Caregivers



# A Public Health Approach to Alzheimer's and Related Dementias

- Flexible curriculum linked to public health competencies
- Designed for faculty to use with undergraduate public health courses
- Developed & *evaluated*





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

# For More Information

- Centers for Disease Control and Prevention:
  - <http://www.cdc.gov/aging>
  - <http://www.cdc.gov/aging/caregiving>
  - <http://www.cdc.gov/brfss>
  
- ClinicalTrials.gov, a service of NIH: <http://clinicaltrials.gov>
  
- Community Programs:
  - Contact a local Area Agency on Aging (AAA)
  - Contact a local Aging & Disability Resource Center (ADRC)
  - Or, go to <http://eldercare.gov/>
  
- National Institute on Aging at NIH: <http://nia.nih.gov>
  
- National Prevention Strategy:  
<http://www.surgeongeneral.gov/priorities/prevention/strategy>

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*The*  
Healthy Brain  
*Initiative*

For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 [www.cdc.gov](http://www.cdc.gov)

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.

