Linking Cognitive Health Data to Effective Policy

Lynda A. Anderson, PhD
Director, Healthy Aging Program
Division of Adult and Community Health
National Center for Chronic Disease Prevention and Health Promotion
Overview

- Aging trends
- Stories of dementia
- Public health perspective
- CDC’s Healthy Brain Initiative
  - Healthy People 2020
  - Surveillance
2006, Life expectancy at birth – 78.1 yrs

1900, Life expectancy at birth – 47 years

Reference population: These data refer to the resident population.
Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System.
### Leading Causes of Death in the United States

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause</th>
<th>Age Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Heart Disease</td>
<td>616,403</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Heart Disease</td>
</tr>
<tr>
<td>2</td>
<td>Malignant Neoplasms</td>
<td>565,390</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Malignant Neoplasms</td>
</tr>
<tr>
<td>3</td>
<td>Chronic Low Respiratory</td>
<td>141,057</td>
</tr>
<tr>
<td></td>
<td>Disease</td>
<td>Chronic Low Respiratory Disease</td>
</tr>
<tr>
<td>4</td>
<td>Cerebrovascular</td>
<td>134,002</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cerebrovascular</td>
</tr>
<tr>
<td>5</td>
<td>Unintentional Injury</td>
<td>120,565</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alzheimer's Disease</td>
</tr>
<tr>
<td>6</td>
<td>Alzheimer's Disease</td>
<td>82,434</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diabetes Mellitus</td>
</tr>
<tr>
<td>7</td>
<td>Diabetes Mellitus</td>
<td>70,548</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Influenza &amp; Pneumonia</td>
</tr>
<tr>
<td>8</td>
<td>Influenza &amp; Pneumonia</td>
<td>56,057</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nephritis</td>
</tr>
</tbody>
</table>
Alzheimer’s Touches All of Us

Cognitive Impairment & Alzheimer’s Disease

Alzheimer’s Legislative Champion Applies Experience with her Father

Former Missouri Rep. Lana Baker’s life has been altered by Alzheimer’s disease since she was in college. That is when her father first showed signs of the disease. Since her mother was deceased, Lana became her father’s primary caregiver, even as she was starting a career and family.

For several years after his diagnosis, Baker’s father was able to live in his own home with some assistance. But as symptoms progressed, his health deteriorated. Baker was forced to consider alternatives. Because of her father’s violent outbursts, Baker was hesitant to allow him to move into a house where Baker lived with her small children. Finally, in 1996, six years after his diagnosis, Baker made the tough choice to have him placed in a nursing home.

“It was the most difficult thing I ever did,” she recalled. “It was like completely taking away his independence.”

Baker’s father died in 1996, just months before she was elected to the Missouri House. Baker was already a volunteer with the Alzheimer’s Association, and her new role as a legislator gave her an opportunity to become a key player in continued research funding and to become a champion for issues related to Alzheimer’s and nursing home quality. “It became the focus of my goals of what I wanted to accomplish when I was in office,” she said.

During her eight years in office, Baker won passage of special care unit disclosure requirements mandating facilities and programs tell the state and families what they are doing that merits that designation. She also pushed legislation to protect a couple’s financial assets when one is receiving Medicaid home- and community-based services. She was unable to win approval for that measure, however, before Missouri’s term limits forced her out of office. It still has not become law.

“I wish I had been able to do more,” Baker recalled. Today, she works as a lobbyist in Missouri. Although the Alzheimer’s Association is not one of her clients, Baker said she never hesitates to lobby informally for legislation that will help Alzheimer’s patients and their families.
American Public’s Views about Alzheimer’s Disease*

- 73% of Americans report they know or have known someone with Alzheimer’s disease
- 43% of those report that the person is/was a family member

* The Value of Knowing Survey was designed and analyzed by the Harvard School of Public Health and Alzheimer Europe, in collaboration with national Alzheimer associations. www.alzheimer-europe.org/EN/Research/Value-of-knowing
Losing Mental Capacity is Greatest Fear

When you think about aging, what do you fear more: diminished physical ability or losing mental capacity?

- Losing mental capacity: 62%
- Diminished physical ability: 29%
- Don't know: 9%

Taking Our Pulse: The PARADE/Research!America Health Poll
Charlton Research Company, 2005
Proportion of U.S. Adults Reporting Alzheimer’s Disease as the Disease They are Most Afraid of Getting, by Age*

<table>
<thead>
<tr>
<th>Age</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-34</td>
<td>15%</td>
</tr>
<tr>
<td>35-59</td>
<td>22%</td>
</tr>
<tr>
<td>60+</td>
<td>32%</td>
</tr>
<tr>
<td>Total</td>
<td>22%</td>
</tr>
</tbody>
</table>

* The Value of Knowing Survey was designed and analyzed by the Harvard School of Public Health and Alzheimer Europe, in collaboration with national Alzheimer associations. [www.alzheimer-europe.org/EN/Research/Value-of-knowing](http://www.alzheimer-europe.org/EN/Research/Value-of-knowing)
Exchanging the Public’s Perceptions - Select Findings*

Most adults reported being aware of Alzheimer’s disease

Concerns:
- Developing Alzheimer’s disease (3 surveys)
  - 26% to 49% reported being concerned
- Caring for others with the disease (2 surveys)
  - 49% reported being equally afraid of getting the disease as caring for someone with it
  - 63% reported they were concerned about having to provide care for someone

Public Health

- Focuses on population health
- Policy development and planning to align resources and protect health
- Identification and monitoring of health

[Diagram showing the components of public health with sections for research, management, policy development, assurance, and assessment.]
The Healthy Brain Initiative: National Public Health Road Map to Maintaining Cognitive Health

A guide for moving cognitive health into public health practice

For national and state level agencies and organizations

Progress report released August 2011
“Include cognitive health in Healthy People 2020, a set of health objectives for the nation that will serve as the foundation for state and community public health plans.”

“Develop a population-based surveillance system with longitudinal follow-up that is dedicated to measuring the public health burden of cognitive impairment in the United States.”
Healthy People 2020

Dementias, Including Alzheimer's Disease

Overview

Objectives

Download all Dementias, Including Alzheimer's Disease Objectives [PDF – 10 KB]

DIA-1  (Developmental) Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis

DIA-2  (Developmental) Reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer's disease and other dementias

Download all Dementias, Including Alzheimer's Disease Objectives [PDF – 10 KB]
Behavioral Risk Factor Surveillance System

- Largest continuously conducted telephone health survey in the world
- Conducted by health departments in all states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam
- Survey of adults aged 18 years and older
- Over 350,000 interviews conducted each year
Behavioral Risk Factor Surveillance System

- Allows monitoring of health status and risk behaviors
- Establish and track health objectives
- Support health policies and legislation
- Informs the development and evaluation of public health programs

www.cdc.gov/brfss/maps/gis_data.htm
Obesity Trends* Among U.S. Adults

BRFSS, 1985

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults

BRFSS, 1986

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1987

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1988
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1989
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1990
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1991

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1992
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1993

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1995
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1996
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1997
(*BMI ≥30, or ~30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1998
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults

BRFSS, 1999

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 2000
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults

BRFSS, 2001

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)

No Data          <10%           10%–14%           15%–19%           20%–24%           ≥25%

[Map showing obesity trends across the United States, with states colored to represent different percentage ranges.]
Obesity Trends* Among U.S. Adults
BRFSS, 2002
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 2003
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4’’ person)
Obesity Trends* Among U.S. Adults

BRFSS, 2005

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 2006
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults

BRFSS, 2007

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 2008

(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 2009
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 2010
(*BMI ≥30, or ~ 30 lbs. overweight for 5’ 4” person)
Obesity Trends* Among U.S. Adults
BRFSS, 1990, 2000, 2010
(*BMI ≥30, or about 30 lbs. overweight for 5’4” person)
The Impact of Cognitive Impairment
BRFSS Module

Purposes:

- To advance the understanding about the impact of cognitive impairment among American adults
- Provide a window into current and future needs of states and communities related to cognitive impairment
- To assist states, policy makers, researchers, CDC and other organizations with “data for action”
What is Cognition?

Cognition is a combination of mental processes, including:

– The ability to learn new things
– Intuition
– Judgment
– Language, and
– Memory

The CDC Healthy Aging Program, in consultation with an expert panel of methodologists and subject matter experts, developed the Cognitive Impairment Module.

What you can learn about your state:

- Individuals’ perceptions about cognitive impairment
- Perceptions about the need assistance and impact on everyday activities
- Number of individuals living alone with cognitive impairment
- If more than one person is living in the household, the total number of people in the household who experience impairment
Assessing the Impact of Cognitive Impairment

States Using the BRFSS Cognitive Impairment Module in 2009–2011

2009

Added in 2011
Percentage of Adults with Perceived Cognitive Impairment, by select state and age, 2009*

- **California** (n=7,327): 11.4% aged 50+ / 7.8% aged 18-49
- **Florida** (n=7,371): 11.4% aged 50+ / 6.0% aged 18-49
- **Iowa** (n=4,181): 9.2% aged 50+ / 3.8% aged 18-49
- **Louisiana** (n=6,263): 9.3% aged 50+ / 4.5% aged 18-49
- **Michigan** (n=2,477): 14.9% aged 50+ / 7.7% aged 18-49

*Cognitive impairment: a call for action, Now! is available at www.cdc.gov/aging/healthybrain/index.htm
Respondent & Proxy Responses
Adults with Perceived Cognitive Impairment, 2009 BRFSS*
(Un-weighted)

* 2009 BRFSS Pilot States CA, FL, IA, LA, MI
FMD, FPD, FAL: 14 or more days of poor mental health, poor physical health and activity limitation days in the past 30 days, respectively.
Chronic Conditions and PCI Status, Adults Age 60+
2009 BRFSS, CA, FL, IA, LA, MI

Number of chronic conditions: Cardiovascular disease, diabetes, high blood pressure, high cholesterol, asthma, and arthritis.
Model Reports

General Audiences

More than 16 million adults aged 18 years and older in the United States are living with cognitive impairment.

Most adults in the United States live vital and productive lives, but an estimated 15 million are living with some form of cognitive impairment. Some are younger adults who may have cognitive impairment as a result of a head injury, as from a car crash or a fall. Most people with cognitive impairment are older adults, and they are the primary focus of this fact sheet. Cognitive impairment is not an inevitable part of aging, although age is the greatest risk factor. As the baby boomers turn 65 over the next two decades, the number of people living with cognitive impairment will likely double.

You can be a Champion
Individuals and communities need to prepare to meet the challenges associated with cognitive impairment. You can help make a difference by becoming a community champion. Community champions, like you, are needed to help promote brain health in your community. Tips included in this fact sheet provide valuable information about brain health and cognitive impairment. It also includes actions you can take to become a community champion and help make a difference.

Essentials of Brain Health
To protect your brain health, research suggests it is essential to:
- Be physically active.
- Eat a healthy diet.
- Keep your mind active (e.g., learn new things, be engaged socially).
- Maintain good health (e.g., quit smoking, decrease cholesterol levels, reduce sodium (salt) intake, and decrease alcohol consumption).
- Protect your head from injury (e.g., wear a helmet when riding a bike, buckle your seat belt, remove objects that could lead to a fall in or around your home).

Know the Signs
You can take action if you know the signs of cognitive impairment. Some causes of cognitive impairment are treatable, so it is important that individuals showing possible signs of cognitive impairment be evaluated by a health care provider for appropriate care and treatment.

The number of people living with cognitive impairment in the United States is equal to twice the population of New York City.

Cognitive impairment is costly. People with cognitive impairment report more than three times as many hospital stays in individuals who are hospitalized for some other condition. Alzheimer’s disease and related dementias alone are estimated to be the third most expensive disease to treat in the United States. The average Medicaid nursing facility expenditure per state in 2010 was estimated to have Alzheimer’s disease is estimated at $401 billion, not including homes and community-based care or prescription drug costs.

“The average Medicaid payment for a person aged 65 or older with Alzheimer’s or other dementias is nine times higher than that for other beneficiaries in the same age group.”

—Alzheimer’s Disease Facts and Figures 2010

Policy Makers
State-Specific Model Reports

COGNITIVE IMPAIRMENT: The Impact on Health in Iowa

Although cognitive impairment is an inevitable sign of aging, age is not the greatest risk factor. As a study from the University of Iowa notes, the number of people with cognitive impairment in Iowa has increased dramatically in recent years. In 2018, the number of people aged 65 or older with Alzheimer’s disease in Iowa is estimated to be over 40,000.

Estimates vary, but experts suggest that 5.1 million Americans aged 65 or older may have Alzheimer’s disease, the most well-known form of cognitive impairment. These numbers are projected to increase to over 13.2 million by 2050.

What is Cognitive Impairment?
Cognitive impairment is a condition that affects memory, thinking, and judgment. The severity of cognitive impairment can range from mild to severe, and it can affect an individual’s ability to perform everyday tasks. Questions that are frequently asked include:

- How much does cognitive impairment affect daily life?
- How can one manage cognitive impairment?
- What is the best way to treat cognitive impairment?

With the rapidly increasing number of older Americans, cognitive impairment is a growing public health concern in Iowa and other states. Cognitive impairment will place unprecedented demands on our existing health system and, if not properly addressed, this condition will pose tremendous economic hurdles. Every state needs to prepare for the cognitive health challenges required, and new public health professionals need to be trained in this area. As every other public health issue, this one can be solved through a coordinated approach, that will help provide the best services and solutions, while addressing the needs of community, dealing with cognitive impairment, while improving the health and well-being of those affected by Alzheimer’s disease. Public health efforts are critical to prevent healthy behavior and mental independence in the community.
<table>
<thead>
<tr>
<th>Year</th>
<th>States</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>Iowa, Kentucky</td>
</tr>
<tr>
<td>2009</td>
<td>Illinois, Louisiana, Michigan, Mississippi, New York, North Dakota, Oklahoma, South Carolina, Tennessee, Vermont</td>
</tr>
<tr>
<td>2010</td>
<td>Colorado, Maryland, Missouri, Texas</td>
</tr>
<tr>
<td>2011</td>
<td>Arkansas, California, Minnesota</td>
</tr>
</tbody>
</table>

* [www.alz.org](http://www.alz.org)
“There are only 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 need caregivers.”

—Rosalynn Carter
BRFSS Caregiving Module

2009
Illinois
Louisiana
New York
Ohio
Washington, DC

2010
Connecticut
New Hampshire
New York
North Carolina
Tennessee
Virginia
Amount of Caregiving*

Duration of Caregiving*

Greatest Difficulties Resulting from Caregiving*

## Functional Limitations for which Caregiver Provided the Most Help*

<table>
<thead>
<tr>
<th>Functional Limitation</th>
<th>Caregivers of Persons with Alzheimer's or Dementia</th>
<th>Caregivers of Persons without Alzheimer's or Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care</td>
<td>32.6</td>
<td>12.6</td>
</tr>
<tr>
<td>LRC**</td>
<td>18.8</td>
<td>2.5</td>
</tr>
<tr>
<td>Transportation</td>
<td>12.6</td>
<td>11.3</td>
</tr>
<tr>
<td>Anxious or Depressed</td>
<td>25.6</td>
<td>9</td>
</tr>
</tbody>
</table>

**LRC = Learning, remembering, confusion

Assessing the Impact of Cognitive Impairment

States Using the BRFSS Cognitive Impairment Module in 2009–2011
Applications

- Assist states and communities to prepare for and track current and future needs
- Support program development and service delivery
- Create a state-level report on the burden of cognitive impairment
- Provide data for grants and to guide state and local plans and policies
Contact Information

CDC’s Healthy Brain Initiative

Lynda Anderson, PhD
Director, Healthy Aging Program
laa0@cdc.gov

Angie Deokar, MPH
Public Health Advisor, Healthy Aging Program
ftm4@cdc.gov

The findings and conclusions in this presentation are those of the author and do not necessarily represent the official position of CDC or ATSDR