

From Data to Action

Using the Behavioral Risk Factor Surveillance System (BRFSS) to Advance the Public Health Agenda of Dementia Caregiving



Presented by:



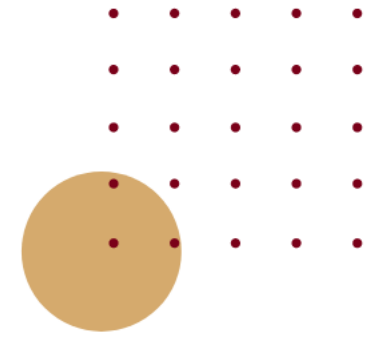
BOLD
PUBLIC HEALTH
CENTER OF EXCELLENCE
ON DEMENTIA
CAREGIVING



In collaboration with:



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.



Welcoming our presenters...



John Beilenson

President, Strategic
Communications and Planning



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Director, Division of Health
Promotion, North Dakota
Department of Health



Phil Echevarria

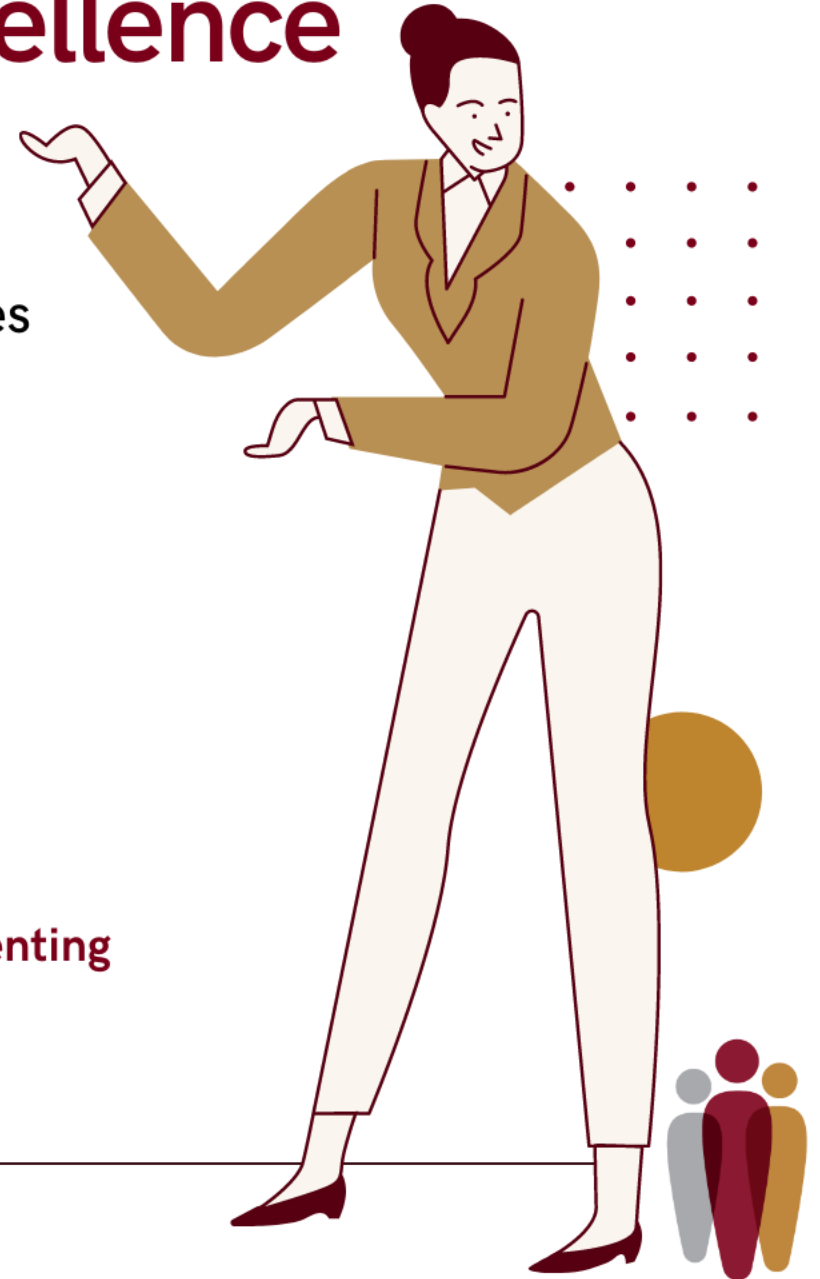
Director of Government Affairs,
Alzheimer's Association



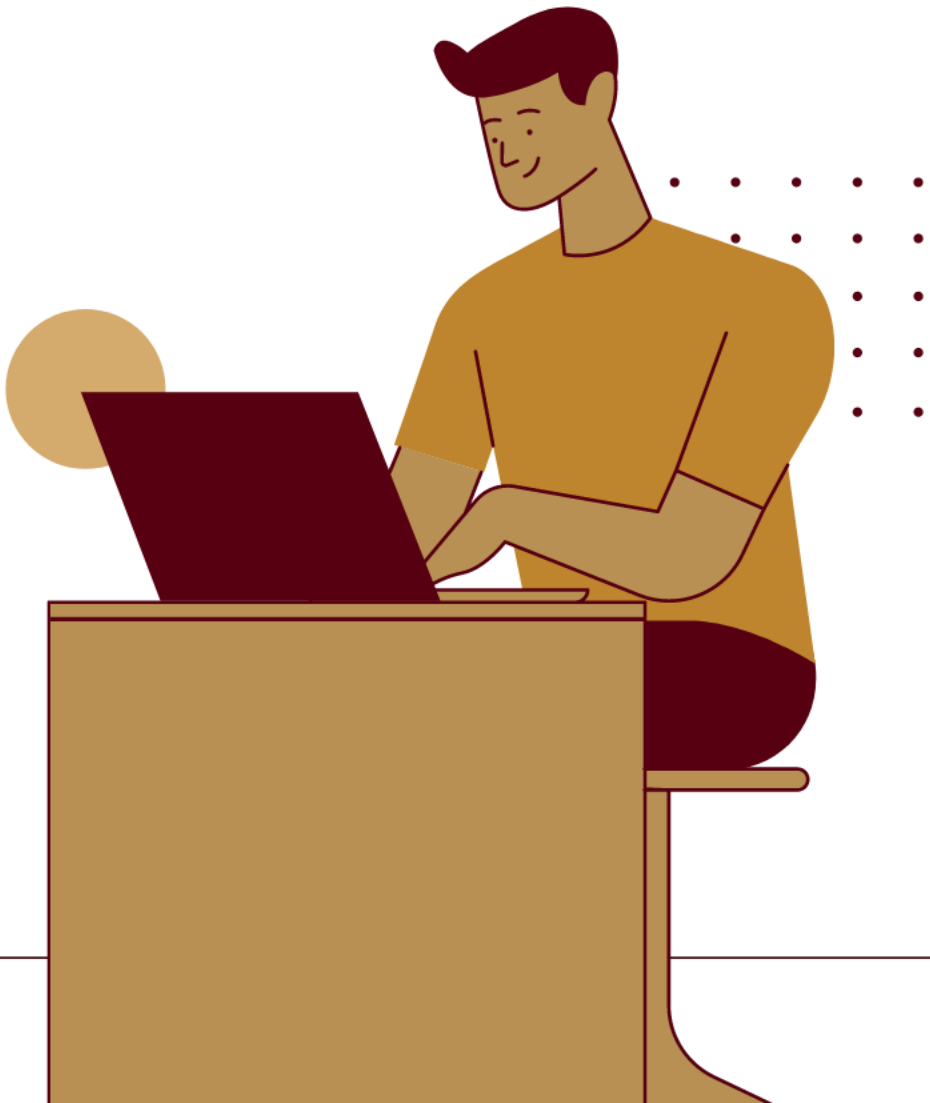
The Public Health Center of Excellence on Dementia Caregiving

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



The BRFSS Caregiver Module



Overview....

- Optional, along with the Cognitive Decline Module
- 9 Questions
- Administered Intermittently
- Identifies the relationship to the care recipient
- Caregiving can be linked to socio-economic and health data in BRFSS

The Questions Identify...

- ✓ Caregivers
- ✓ Length and intensity of Caregiving
- ✓ Caregiving Duties
- ✓ Health condition that requires care
- ✓ Whether a person needing care has AD/ADRD or Cognitive Impairment



BRFSS Data in Action: State Examples



In testimony to the Aging Committee as it heard evidence on proposed respite care program bill.



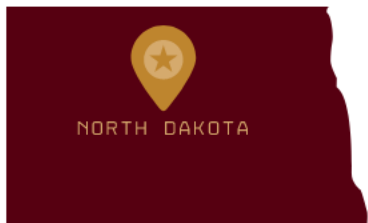
Educated state legislators about Alzheimer's and caregiving issues



Developed training for supervisors at LA Health Department to support employees who are caregivers



Set the ground for long-term legislative infrastructure for dementia caregiving and more...



Cognitive Decline and Caregiver Module data to support the needs for State Alzheimer's plan and more...



Subjective Cognitive Decline measures are included in Master Plan for Aging dashboard.





TOGETHER, WE CAN END ALZHEIMER'S.

BRFSS Impact on New Jersey

alzheimer's  association®

**WALK TO
END
ALZHEIMER'S** 
alzheimer's  association®

Introduction

The Alzheimer's Association® is the leading voluntary health organization in Alzheimer's care, support and research.

Our Vision: A world without Alzheimer's and all other dementia®

Our Mission: The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.



Impact of Alzheimer's in New Jersey

- **190,000 New Jersey Residents are living with the disease.**
- **347,000 caregivers providing care.**
- **658,000,000 hours of care provided by caregivers.**
- **Over \$12 billion in unpaid care provided.**
- **The burden of Alzheimer's is large, the impact is major, and there are ways public health can intervene.**



New Jersey 2016 Alzheimer's State Plan

Goal 1: *Increase public awareness of the difference between “normal” cognitive aging.*

Goal 2: *Expand support for unpaid caregivers of persons with Alzheimer's disease.*

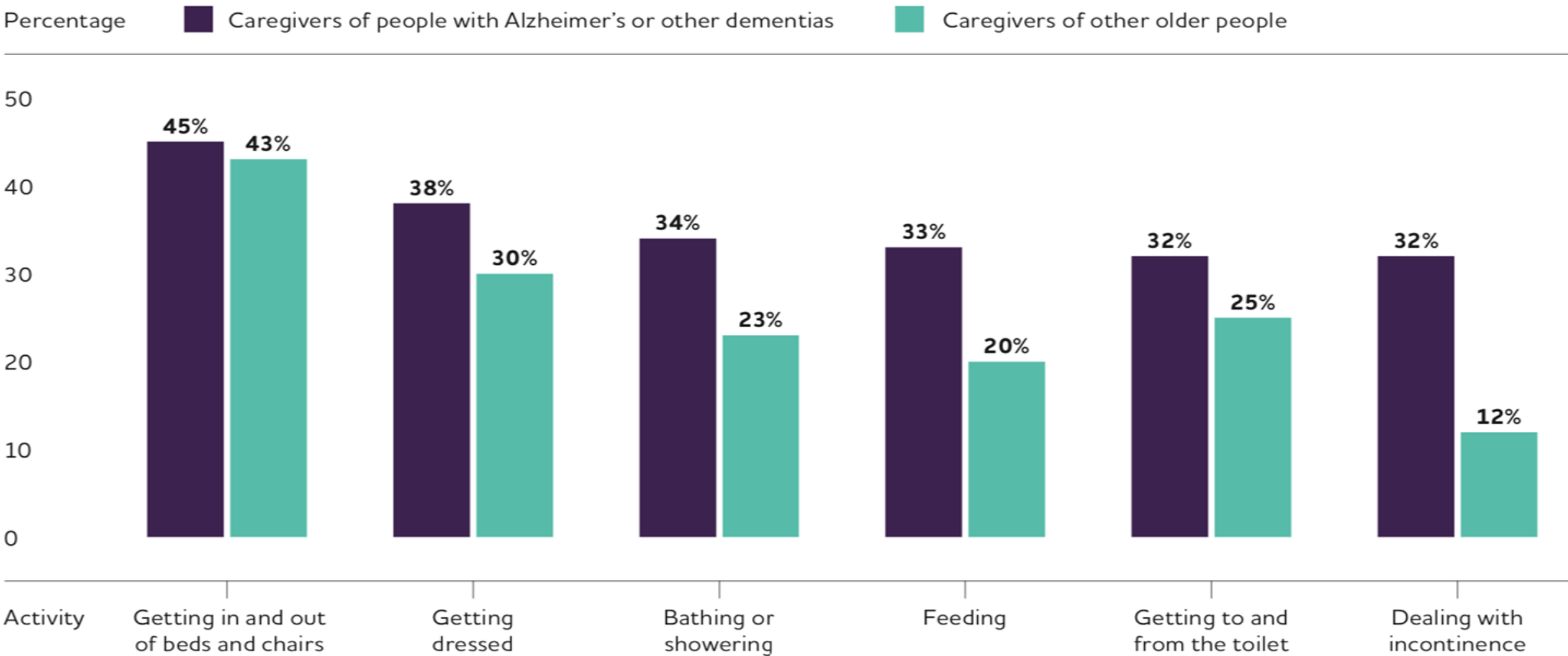
Goal 3: *Promote the infrastructure for enhanced quality of services within the healthcare system.*

Goal 4: *Improve public safety and address the safety-related needs of those with Alzheimer's disease.*

Goal 5: *Support legal protections for, and legal issues faced by, individuals with Alzheimer's disease.*

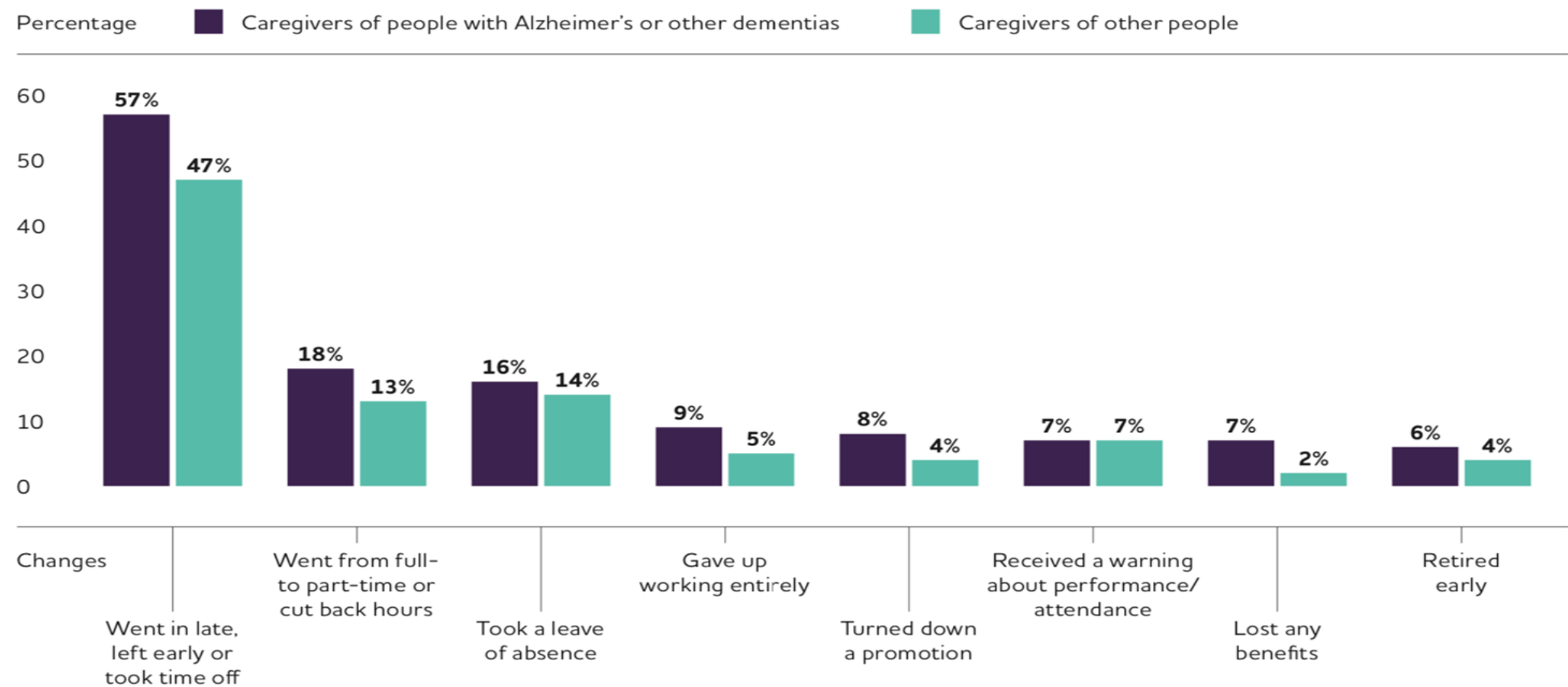


Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



Created from data from the National Alliance for Caregiving and AARP.³⁷⁴

Work-Related Changes Among Caregivers of People with Alzheimer's or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Created from data from the National Alliance for Caregiving and AARP.³⁷⁴

NEW JERSEY CAREGIVING

2017 Behavioral Risk Factor Surveillance System (BRFSS) Data



dementia caregiving in new jersey

alzheimer's association®

DATA FROM THE 2017 BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM



1 in 6 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 half have provided care for at least two years



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



WHO ARE CAREGIVERS?

59% are women

22% are 65 years old or older

39% are caring for a parent or parent-in-law

12% of caregivers are providing care to someone with dementia



HOW DO CAREGIVERS HELP?



80% manage household tasks

Over 50% assist with personal care



FUTURE CAREGIVERS

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



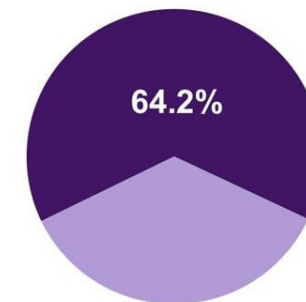
cdc.gov/aging

In New Jersey, nearly two-thirds of all adults providing unpaid care to loved ones with Alzheimer's or another dementia have been doing so for at least two years.

More than one in three Alzheimer's and dementia caregivers provide 20 or more hours of care per week.

Almost 60 percent of Alzheimer's and dementia caregivers provide care to their parent or parent-in-law.

Percent of dementia caregivers providing care for at least 2 years



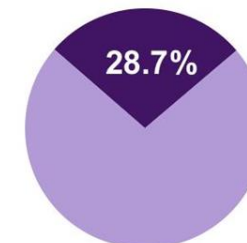
Characteristics of Alzheimer's and Other Dementias Caregivers							
Gender		Age		Hours of Care per Week		Caring for Parent or Parent-in-law	Also Caring for Minor
Women	Men	45-64	65+	20+	40+		
59.8%	40.2%	45.8%	40.7%	34.6%	28.2%	57.4%	15.5%

Percent of dementia caregivers providing help with specific tasks



Manage household care, such as cleaning or cooking
Manage personal care, such as feeding or bathing

Percent of dementia caregivers with a history of depression



This Fact Sheet is supported by Cooperative Agreement #NU58DP006115 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the Alzheimer's Association and do not necessarily represent the official views of the CDC.



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

BRFSS and New Jersey's Caregiver Task Force

- Community Advocates saw the need for a deeper understanding about the need of caregivers.
- New Jersey in 2018, using our BRFSS information, passed legislation to create a caregiver task force.
- The purpose of the Task Force is to determine the availability of caregiver support services in the State, and provide recommendations for the improvement and expansion of such services.



Additional Outcomes

- **Legislation drafted to address public awareness of Alzheimer's and the creation of a Alzheimer's and Dementia Long-Term Planning Commission.**
- **Newark Classic Car Show To Help Teach Older Men About Brain Health, Avoiding Alzheimer's Disease, and Participating in Aging Research at RU-Newark.**



What's Next?

- **Pandemic's impact on caregivers and cognitive decline.**
- **Increased awareness and access to community based services.**
- **Continued advocating for inclusion of the caregiver module on the BRFSS.**



Thank you

Phil Echevarria / Director of Government Affairs / pmechevarria@alz.org / 908-812-0435



North Dakota Chronic Disease and BRFSS Data Driven Programming

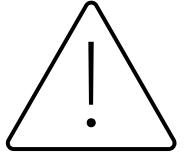
*Janna Pastir, MPH
Director of Health Promotion
June 9, 2021*

Making the Case for Data Use

Leveraging project priorities

- BRFSS data related to caregivers and cognitive decline provide support for chronic disease program inclusion of these populations

NOTE



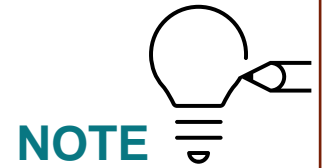
Caregivers:
60.2% are overweight
or obese

Cognitive decline:
70.7% are overweight
or obese

Data For Programming

Defining populations

- Including caregivers and those with cognitive decline as a priority population in chronic disease programs



North Dakota does not
receive federal funding
for
Alzheimer's
Programming

Cross-cutting Examples

Strategy integration

- Virtual and asynchronous community-based program delivery grew exponentially during 2020, including converting long-time, in-person programs

NOTE



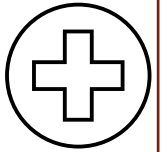
A majority of caregivers responded as having not seen their own PCP in the previous 12 months in 2016

Improving Program Participation

Cross-recruiting example

- The North Dakota DPP begins with “Session 0” as a chance to share all resources available from tobacco cessation to caregiver support

NOTE



Powerful tools for
caregivers
and the national
Diabetes Prevention
Program
partnerships

Service Delivery Improvement

Understanding needs of people with cognitive decline

- Medication therapy management to improve compliance, and
- Addressing barriers such as driving, food dependence and access, and ability to ambulate



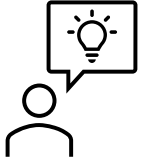
Educating all of the health care and related providers on the additional needs of patients with cognitive decline to improve outcomes

ND Alzheimer's Strategic Plan

Comprehensive approach

- Using BRFSS and other data together, we are able to create a comprehensive plan to improve outcomes for both patients and caregivers through sustainable policy, system, and environmental approaches

NOTE



Examples include:

- health care workflows
- workforce enhancement & capacity building
- medication compliance
- community design
- alternate delivery modes of services
- planning for the future

THANK YOU

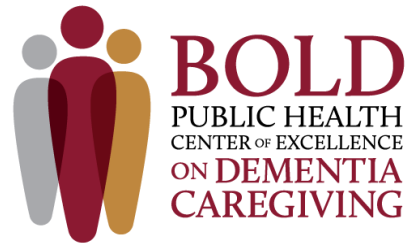
*Janna Pastir, MPH | Director, Division of Health Promotion |
jlpastir@nd.gov | 701- 328-2315*

Data, Messaging, and Dementia Caregiving

From Data to Action

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to Advance the Public Health Agenda of Dementia Caregiving

June 2021



What are we talking about?

A **message** is a clear, concise statement or set of statements that describes a position, opinion or point of view.

Just a few words...

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“If you were to boil your book down to a few words, what would be its message?”

Data as a Key Building Block for Caregiving Messages

- Still, you need to do the social math
- What does the data mean?

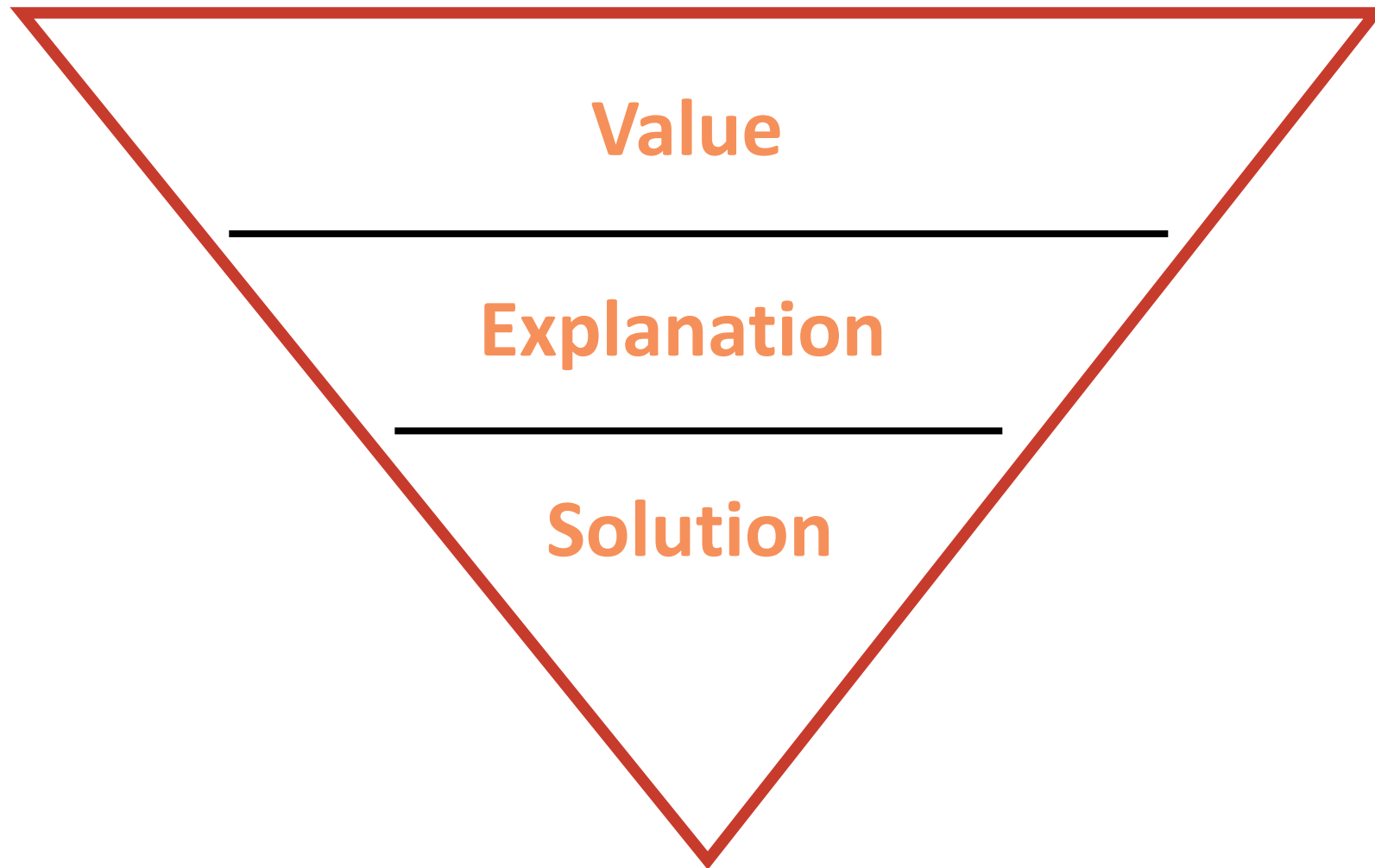


Too Much of a Good Thing?

- One or two strong data points per issue/ communication are better than a raft of data.
- Dangers:
 - “Data numbing”
 - Fatalism – how will we ever solve this?



Strong Messages = More than Data



Messaging in Practice: An Example

My target audience is: State legislators

Value: Importance of family and community

All of us in [state] want the best care possible for our family and neighbors suffering from serious disease.

Problem

According to CDC data, **XXX** people are living with Alzheimer's and dementia in our state. That number is expected to grow to **XXX** by 2030. Programs and supports are already inadequate, as caregivers may spend years looking after a spouse, parent, family member or friend. As Wanda Johnson of Fayetteville said recently, "Our family would do anything for my mother. That's what we do, but basically my husband and I have been on our own."

Cause

Quality long term services and supports exist, but are underfunded and inaccessible to many people due to location or cost. Families and caregivers – the lynchpins of our care system -- are left to fend for themselves.

Answer/Action/Solution

Our new state Alzheimer's plan will complement the often heroic efforts of caregivers of people living with dementia, providing better access to programs that deliver support and respite and enable them to continue to work jobs, care for their children and maintain their health.

Four Kinds of Appeals

Ethos
Based on credibility of
the speaker

Logos
Based on logic

Pathos
Based on emotion

Mythos
Based on broadly
held cultural
values

Different Kinds of Evidence

Statistical
Quantitative, even qualitative

Anecdotal

- A story (best when connected to statistical data)
- Examples that support a general statement

Testimonial

- My story (spokesperson, eye-witness account)
- An expert's account

Pictorial/schematic

Worth a thousand words

Analogical

- Similes (It's like...)
- Scenarios (What if)

Data Can Start and Drive the Conversation around Dementia Caregiving

- North Dakota – Informed state AD Plan
- New Jersey – Supported legislative agenda
- CA – Included in the Master Plan for Aging





Cultural Considerations

- Messengers matter
 - Community partners can be more effective
- Language matters
 - Check the reading level – low English proficiency in some communities
 - Translation/translators
 - Don't blame the victims
 - Acknowledge structural barriers

Resources

- Phrases (from DeBeaumont Foundation)
<https://www.phrases.org>
Public Health, Collaboration and Storytelling Toolkits
- Frameworks Institute
<https://www.frameworksinstitute.org/>
Search “public health,” “aging”
- Diverse Elders Coalition
<https://www.diverseelders.org/wp-content/uploads/2021/03/DEC-Toolkit-Final-R2.pdf>
“Caring for Whose Who Care: Meeting the Needs of Diverse Caregivers”
- CDC Style Guide to Health Equity for the COVID-19 Response
https://ehe.jhu.edu/DEI/Health_Equity_Style_Guide_CDC_Reducing_Stigma.pdf

Thank You!



**Connect
Communicate
Change**

Web: aboutSCP.com

Twitter: [@aboutscp](https://twitter.com/aboutscp)

Coming Soon!

<https://bolddementiacaregiving.org>

Visit us online to...

- ✓ Find today's slides and recording
- ✓ Request Technical Assistance to support your public health work in dementia caregiving
- ✓ Access resources and materials
- ✓ Stay up to date with PHCOE-DC activities!



Join us on June 30th!



The first of a 3-part series!

"Considerations and Models for Cultural Adaptions in Dementia Caregiving"

June 30th, 2021 | 12:30 PM EST

Follow us on Twitter to learn more!

 @PHCOE_DC



Learn more about BRFSS

CDC BRFSS Webinar Series (hosted by GSA)

“Introduction to the Behavioral Risk Factor Surveillance System (BRFSS) Data for Cognitive Decline and Caregiving”, McGuire, L. (2021)

- [Webinar recording](#)
- [Webinar slides](#)

“Analyzing and Interpreting Cognitive Decline Data in the BRFSS”, Taylor, C. A., & Olivari, B. S. (2021)

- [Webinar recording](#)
- [Webinar slides](#)

“Analyzing and Interpreting Caregiving Data in the BRFSS”, Bouldin, E. D., & Olivari, B. S. (2021).

- [Webinar recording](#)
- [Webinar slides](#)

“Using BRFSS Data for Action and Impact”, Baumgart, M., & Shean, J. (2021).

- [Webinar recording](#)
- [Webinar slides](#)



Additional Resources

Centers for Disease Control and Prevention

- <https://www.cdc.gov/aging/data/index.htm>
- <https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm>

Alzheimer's Association

- [State Overview](#) for state specific information and links to state BRFSS fact sheets
- [Fact sheet about the BRFSS](#)
- [Use Data and Evidence for Action](#)
- [Tools for public health leaders to address Alzheimer disease and dementia](#)



Thank you for joining us today!

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

