



# **Successful Public Health Approaches in Dementia Caregiving: *New York State***

*A Virtual Roundtable Series*

*August 14th, 2024*



# Welcome from...

**Elma Johnson, MPH, *Coordinator***

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

Center for Healthy Aging and Innovation (CHAI)

University of Minnesota



# 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.

Visit our  
website!





# HEALTHY BRAIN INITIATIVE

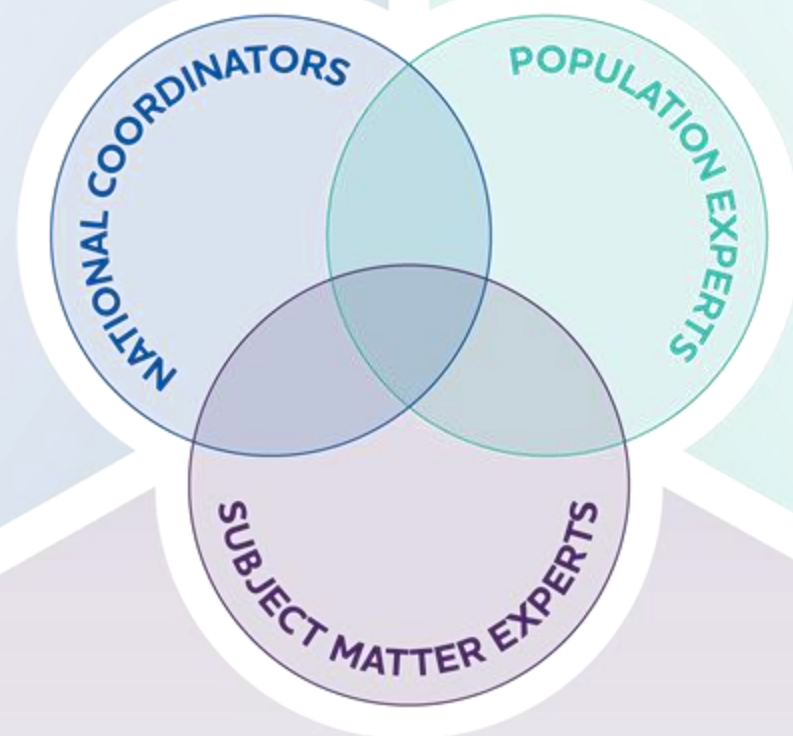
Collaborative



[hbicollaborative.org](http://hbicollaborative.org)



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



INTERNATIONAL ASSOCIATION FOR  
**INDIGENOUS AGING**

American Indian/  
Alaska Native Peoples



UNIVERSITY OF  
**ILLINOIS CHICAGO**

Individuals living with  
Intellectual/Developmental  
Disabilities



US AGAINST ALZHEIMER'S CENTER for  
**BRAIN HEALTH EQUITY**

Black/African American and  
Hispanic/Latino Communities



PUBLIC HEALTH  
CENTER OF EXCELLENCE  
ON DEMENTIA CAREGIVING



**BOLD** PUBLIC HEALTH  
CENTER OF EXCELLENCE  
EARLY DETECTION OF DEMENTIA

# We value your feedback!

*\*Please give us your feedback before you leave today's meeting!\**

**Scan the QR code**

*OR visit*

**[https://bit.ly/PublicHealthRoundtable\\_NewYorkState](https://bit.ly/PublicHealthRoundtable_NewYorkState)**



# Successful Public Health Approaches in Dementia Caregiving: *A Virtual Roundtable Series*

- ✓ **Bi-monthly**, roundtable series for **public health**.
- ✓ We will highlight **the story of one state**.
- ✓ Opportunity for **networking, peer-learning and idea generation**.
- ✓ A **community of practice**, where agencies can share their successes and learnings, and get ideas for action.



# Reminders for the Presentation Session

- Please, **MUTE yourself** and **turn your VIDEO ON** while the panelists are presenting.
- Display **your name and organization in Zoom**.
- **Submit your questions for the speakers into the Q&A feature.**
- During the Q&A time, please raise your hand if you wish to speak and **only unmute if you are prompted.**
- Use the **CHAT to share comments, resources, links, and ideas.**
- Feel free to use your reaction buttons!
- The recording, slides and resources will be shared after the event.
- **Please complete the survey at the end of this event** (linked in chat). We greatly appreciate your feedback!

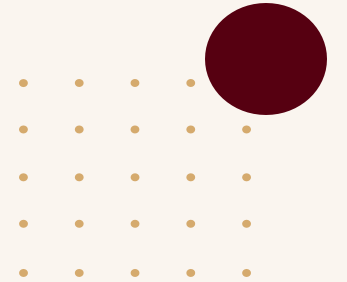




# Poll Question

## In what capacity are you attending this event?

- BOLD Public Health Agency
- Non-BOLD Public Health Agency
- Community organization/service provider
- Person living with dementia
- Interested caregiver and/or community member
- Care/clinical professional
- Other



# Welcome to our presenters!



**Kimberly LaBarge, LMSW**

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



**Lynn Young, PT, MS**

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



**Cassandra Tsyn, MSW**

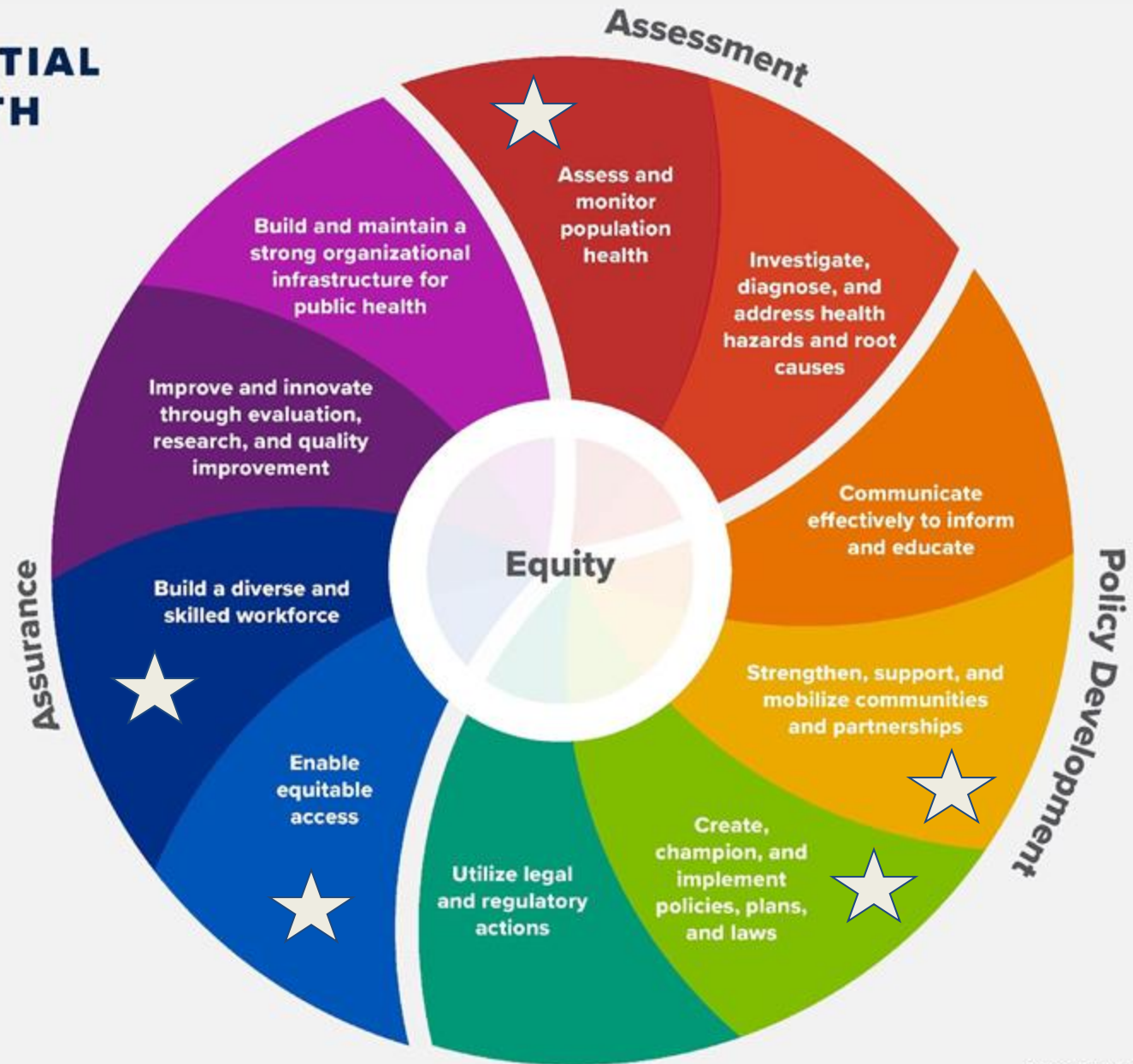
Program Manager,  
Alzheimer's Community Service Program  
Alzheimer's Disease Program, New York State Department of Health



# THE 10 ESSENTIAL PUBLIC HEALTH SERVICES

*To protect and promote the health of all people in all communities*

The 10 Essential Public Health Services provide a framework for public health to protect and promote the health of all people in all communities. To achieve optimal health for all, the Essential Public Health Services actively promote policies, systems, and services that enable good health and seek to remove obstacles and systemic and structural barriers, such as poverty, racism, gender discrimination, and other forms of oppression, that have resulted in health inequities. Everyone should have a fair and just opportunity to achieve good health and well-being.



Created 2020





**Department  
of Health**

# **New York State Department of Health Alzheimer's Disease Program**

**Successful Public Health Approaches in Dementia Caregiving: New York**

**August 2024**

# This discussion will....

- Provide an overview of the services and supports that are available to New Yorkers through a comprehensive *Alzheimer's Disease Caregiver Support Initiative*.
- Explain the infrastructure that has enabled New York to build Alzheimer's Disease and Related Dementia supports and services since 1988.
- Discuss efforts to evaluate the impact of services and supports on New York caregivers and on systems of care.

# Alzheimer's Disease and Related Dementia in New York State



- 426,500 New Yorkers are 65+ and living with Alzheimer's Disease, 12.7% of the total population in that age group.
- Bronx, New York City, has been identified as one of ten counties in the United States with highest prevalence, 16.6% of the population given its density, of residents who are African American and Hispanic.
- In 2020, the cost of Medicaid to care for individuals with Alzheimer's Disease was \$5.453 billion and that number is projected to increase by 15.6% by 2025.

# Caregiving

- 543,000 New Yorkers are in a caregiving role
  - Almost 60% report having chronic health conditions
  - A quarter, or 24.7%, have depression
  - 12% consider themselves in poor physical health
- These caregivers provide more than 879 million hours of unpaid care, equivalent to just under \$19 billion in unpaid care

# Racial Disparities and Prevalence

- According to the 2020 Census, 55% of New Yorkers are White; reduced from 68% in 2010.
- Individuals who are Hispanic account for 20% of New York's population, while individuals who are African American account for 17.5% of New York's population.
- New York State is projected to be a “majority minority state” by 2035.



# New York State Department of Health Alzheimer's Disease Program

# New York State Alzheimer's Disease Program History

- 1985 - Governor Mario Cuomo appoints Blue Ribbon Panel
- 1988 – Legislation created Alzheimer's Disease Assistance Centers, currently rebranded as Centers of Excellence for Alzheimer's Disease
- 1990 – Established funding for Alzheimer's Disease Community Service Programs
- 2007 – Created the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia
- 2008 – Alzheimer's Community Assistance Program modified to ensure statewide effort
- 2009 – First report released by the New York State Coordinating Council, establishing a strategic plan for Alzheimer's Disease and Related Dementia services and supports in New York
- 2015 – New York State \$25 Million Public Health Response to Alzheimer's Disease

# Organizational Infrastructure for the NYS Alzheimer's Disease Program

- Currently positioned within the New York State Department of Health, Office of Aging and Long-Term Care, Center for Home and Community Based Services
- Strategic guidance provided by the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia – “The Council”

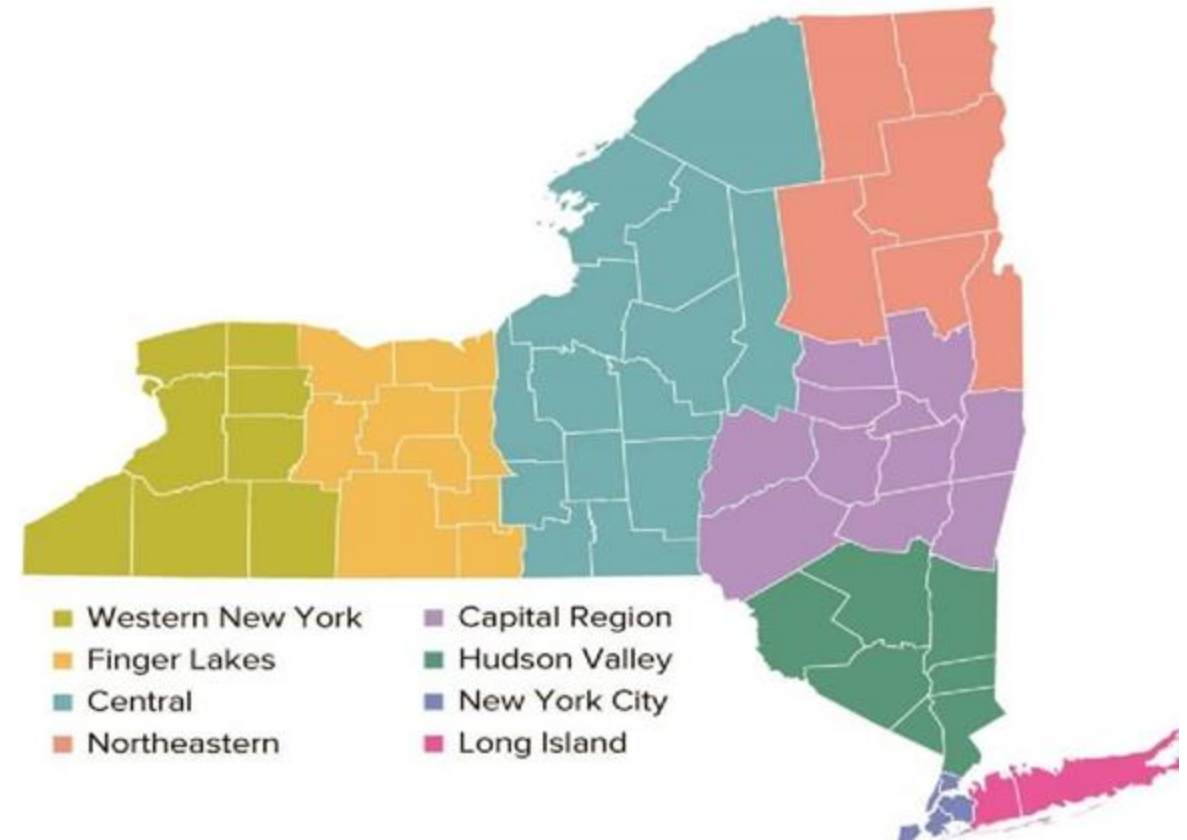
# New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia

- Established in statute in 2007.
- Facilitates interagency planning and policy, reviews specific initiatives for their impact on services related to the care of persons living with Alzheimer's Disease and Related Dementia and their caregivers and provides a forum for the formulation of a comprehensive state policy.
- Membership of 21.
- Meets quarterly and produces a biannual report with recommendations to the Governor and Legislature.
- Shared leadership by the New York State Department of Health and New York State Office for the Aging.

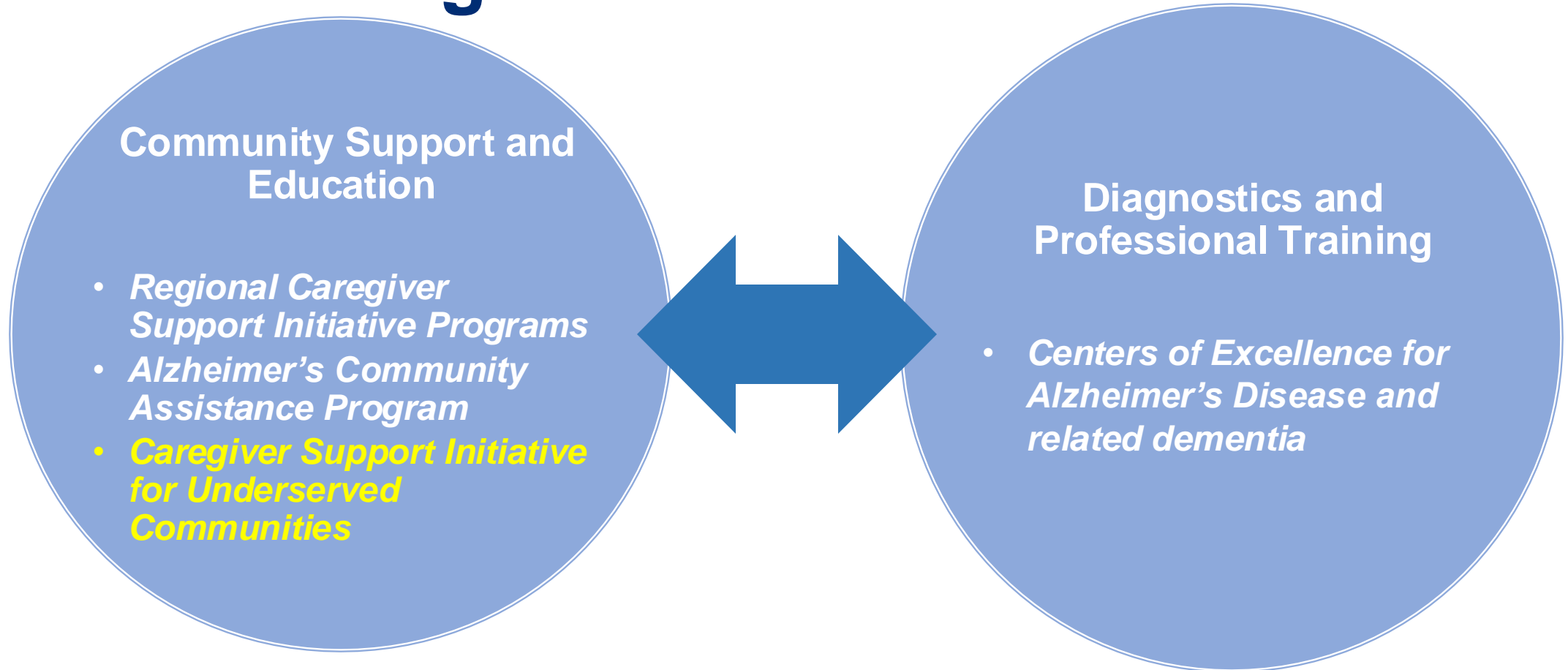
# Alzheimer's Disease Caregiver Support Initiative

# New York State Alzheimer's Disease Caregiver Support Initiative

A landmark \$25 million annual investment in community support and health services for people living with dementia and their caregivers that began in 2015



# Alzheimer's Disease Caregiver Support Initiative Programs



# Goals of the Alzheimer's Disease Caregiver Support Initiative

Expand and enhance access to evidence-based support services

Improve health and well-being of caregivers and people with dementia

Reduce avoidable emergency department visits and hospitalizations

Continue community residence and reduce institutionalization of people with dementia



# Priorities of the Initiatives

- Promoting the Importance of Early Detection and Diagnosis
- Person-Centered Care Planning
- Creating Linkages to Community Based Services



# Alzheimer's Disease Caregiver Support Initiative: Program Components

# Centers of Excellence for Alzheimer's Disease

- Regional experts in the detection, diagnosis and treatment of Alzheimer's Disease and Related Dementia.
- Positioned to offer comprehensive, interdisciplinary diagnostic assessments.
- Expand workforce capacity by training medical and health professionals, and students, regarding early detection, diagnosis and treatment.
- Educate the community on the importance of early detection, annual wellness visits and addressing cognitive changes with their provider.

# Alzheimer's Disease Community Assistance Program

This is a statewide effort that is contracted through the Coalition of New York State Alzheimer's Association Chapters.

## Services Include:

- Care consultations
- Caregiver education and training
- Support groups
- 24-hour Helpline available in more than 200 languages
- Community education, awareness, and outreach
- Training for important constituencies, such as professional caregivers, faith leaders, and gatekeepers

# Regional Caregiver Support Initiative

The Regional Caregiver Support Initiative contractors provide evidence-based, evidence-informed and proven strategies in the implementation of these core caregiving support services within every county in New York State.

- Caregiver Assessments
- Outreach to & Engagement with Underserved Communities
- Caregiver Education
- Caregiver Support & Engagement Activities
- Support Groups
- Joint Enrichment Activities and/or Caregiver Wellness Programs
- Respite
- Optional Innovative, Access and/or Other services



# Program Monitoring and Evaluation

# Monitoring and Evaluation

## Evaluation Goals:

- Track implementation
- Demonstrate impact and achievement
- Support continuous improvement
- Contribute to knowledge of best practices
- Demonstrate the translatability of evidence-based interventions to different populations and contexts

# Behavioral Risk Factor Surveillance System

The Alzheimer's Disease Program analyzed and supported dissemination of caregiver and cognitive decline data from this annual survey of New York State community-dwelling residents.

The data brief from the 2018 survey on cognitive decline can be found here:

[https://www.health.ny.gov/statistics/brfss/reports/docs/2021-02\\_brfss\\_cognitive\\_decline.pdf](https://www.health.ny.gov/statistics/brfss/reports/docs/2021-02_brfss_cognitive_decline.pdf)



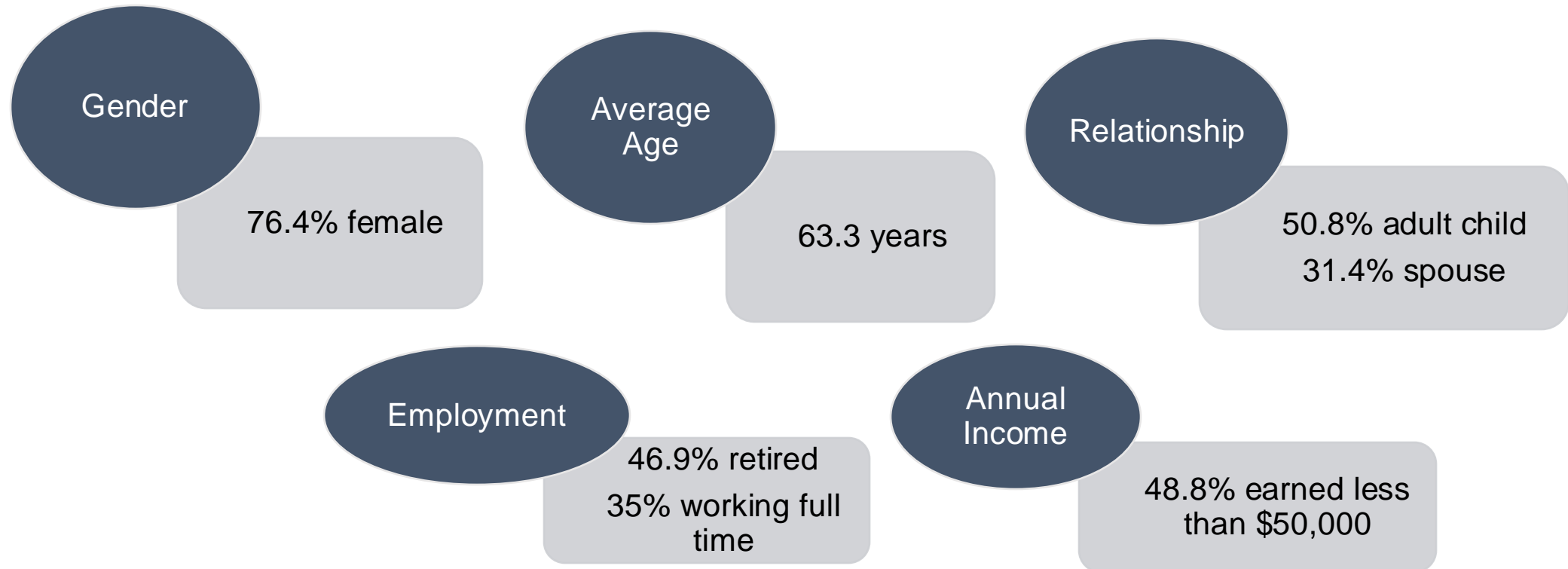
# Services provided 2016-2022:

- 61,000+ diagnostic assessments
- Nearly 200,000 referrals to community providers
- Training sessions that reached more than 100,000 physicians, healthcare providers & students
- 292,000 consultations
- Almost 21,000 support group sessions
- More than 12,500 education opportunities
- Over 752,000 hours of respite care



Home and community care services will become increasingly important as Canada's population ages further.

# Alzheimer's Disease Caregiver Support Initiative: *Caregivers*





Department  
of Health

# Serving Rural Caregivers?

**What patterns have other states seen with providing services to rural caregivers?**

# Targeted Survey - Caregiver Outcomes

- Online survey conducted among participating caregivers in Fall 2019
- Emailed to ~22,500 caregivers who received services
- 1,866 caregivers responded

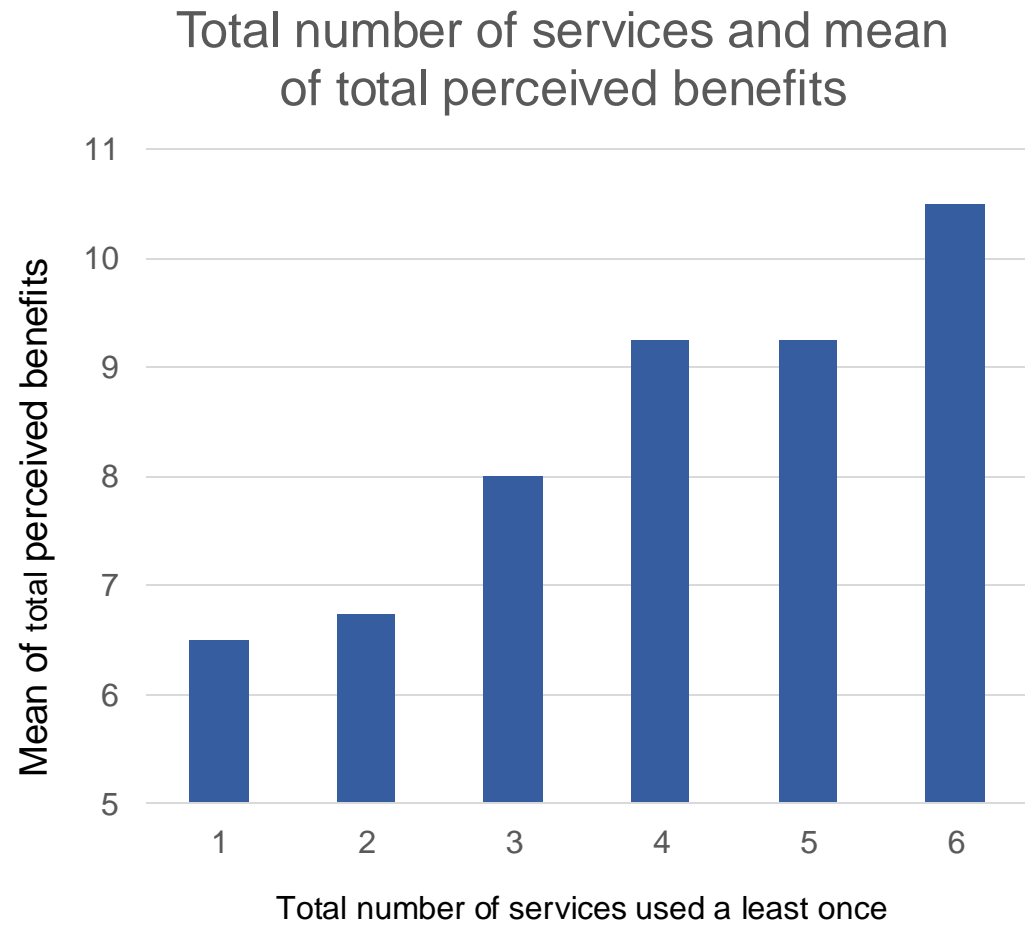
## What Benefits did caregivers perceive from participating in services?

- More than half of respondents reported at least eight different benefits
- The most common benefits relate to increased knowledge

| Perceived Benefits   | Agree or strongly agree<br>N=1507-1539 |
|--|--|
| Increased my knowledge of Alzheimer's disease and/or other dementias           | 84%                                    |
| Improved my knowledge of caregiver and dementia-related resources and supports | 82%                                    |
| Increased my knowledge & understanding of the caregiving role                  | 82%                                    |
| Improved my ability to provide care  | 73%                                    |
| Improved the quality of life of the person I care for                          | 71%                                    |
| Made me feel more confident about being a caregiver                            | 69%                                    |
| Helped me feel less isolated and alone   | 69%                                    |
| Improved specific skills I need as a caregiver                                 | 67%                                    |
| Helped me feel less stressed   | 62%                                    |
| Improved my quality of life as a caregiver                                     | 55%                                    |
| Helped me feel less depressed  | 51%                                    |
| Helped me improve my general health  | 41%                                    |
| Helped me access health care   | 41%                                    |

# Benefits

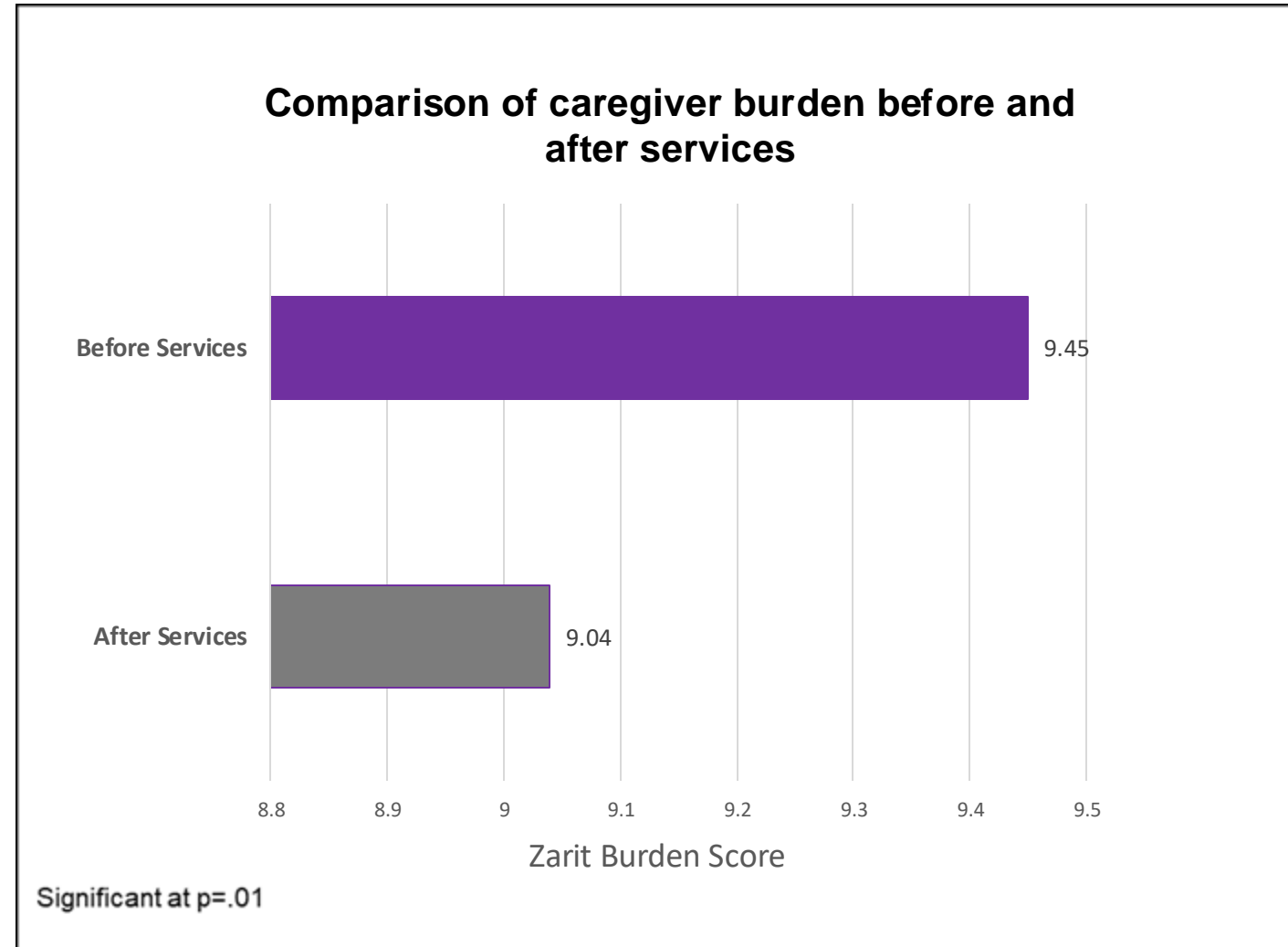
- As caregivers used more and different services, the number of benefits they identified increased



# Caregiver Burden:

## Is the service use related to caregiver burden?

- On average, caregivers reported less burden after using services as compared to thinking back to before using services



# Caregiver Burden

- ▶ Respondents who participated in each core service also reported greater average decreases in burden than caregivers who did not use that service

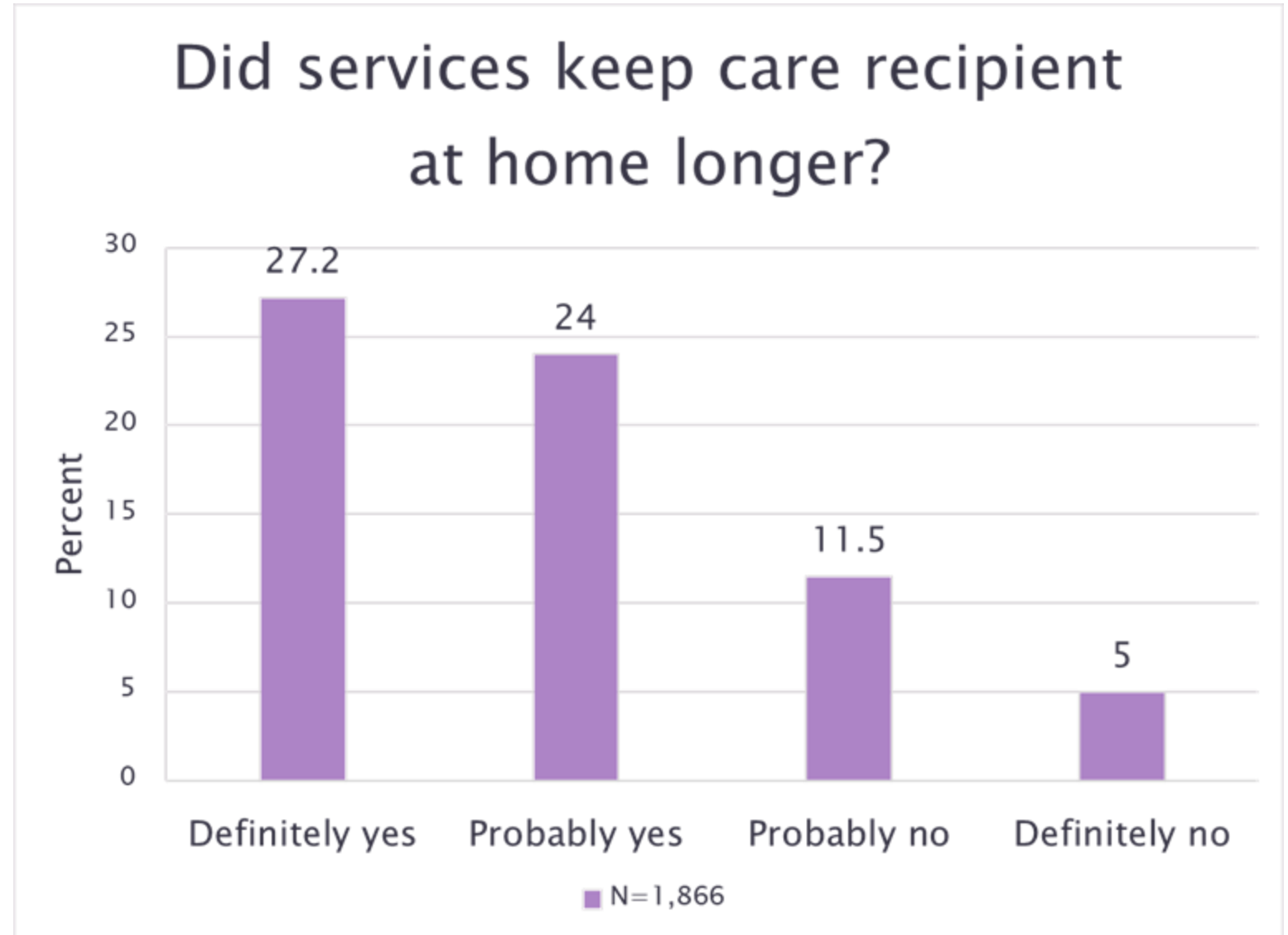
| Caregiver Services Used and Change in Zarit Burden Score |              |                       |                     |                       |
|--|--------------|-----------------------|---------------------|-----------------------|
| Service  | Used Service | Used Service          | Did not Use Service | Did not Use Service   |
|  | N            | Average Burden Change | N                   | Average Burden Change |
| Care consultation  | 652          | .53                   | 420                 | .23                   |
| Respite**  | 387          | .75                   | 683                 | .21                   |
| Wellness*  | 304          | .73                   | 767                 | .28                   |
| Support Group <sup>+</sup>                               | 627          | .55                   | 447                 | .21                   |
| Education*   | 642          | .56                   | 428                 | .17                   |
| Joint enrichment   | 400          | .59                   | 675                 | .30                   |

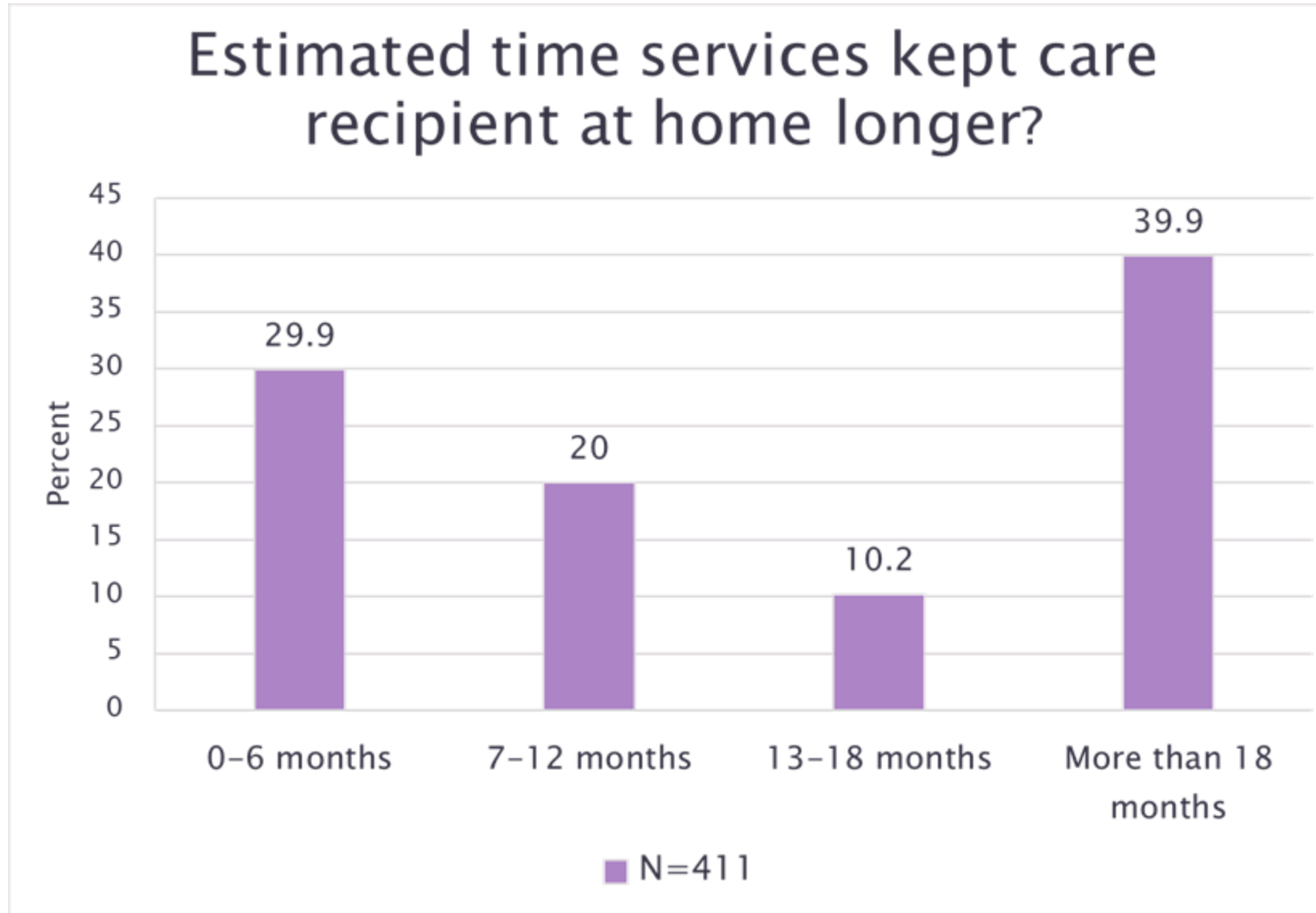
\*\* p<.01, \* p<.05



## Nursing Home Placement Delay

- ▶ Half of respondents felt that services kept their loved one at home longer





# Estimated Nursing Home Cost Savings

- Survey respondents who used 3+ different services or 8+ total service sessions were most likely to indicate that services delayed nursing home placement.
  - 14.3% of ADCSI participants
  - Average annual cost for nursing home of \$140,000
  - Average one-year delay in nursing home placement
- Projected \$2.05 billion savings in nursing home costs to NYS
- Translates to \$18 of savings for each dollar invested in the initiative

# Final Evaluation Reports (2016-2022)

- Final evaluation reports can be found on the NYS DOH Website
- [Alzheimer's Disease Reports and Data \(ny.gov\)](https://www.health.ny.gov/statistics/diseases/conditions/dementia/alzheimer/)
  - <https://www.health.ny.gov/statistics/diseases/conditions/dementia/alzheimer/>

## Alzheimer's Disease Program Evaluation

- [Evaluation Report - Year 1 \(PDF\)](#)
- [Executive Summary - Year 1 \(PDF\)](#)
- [Final Evaluation Report 1: Growth of Dementia Workforce Capacity in NYS \(PDF\)](#)
- [Final Evaluation Report 2 for the Period 2015-2020: Effects on Caregiver Health and Well-Being \(PDF\)](#)
- [Final Evaluation Report 3 for the Period 2015-2020: Estimates of Economic Impact on NYS \(PDF\)](#)



# THANK YOU!

- Contact Information:
  - Kimberly LaBarge, BOLD Program Coordinator, [kimberly.labarge@health.ny.gov](mailto:kimberly.labarge@health.ny.gov)
  - NYS Alzheimer's Disease Program, [alz@health.ny.gov](mailto:alz@health.ny.gov)

# Questions?

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



# 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.
- ✓ Stay up to date with PHCOE-DC activities.



Follow us on X @PHCOE\_DC





# Thank you for joining us today!

Please take a moment to complete a brief survey. Scan the QR code or click the link in the chat.

We appreciate your feedback!

