



State Policies on Caregiving: Opportunities for Supporting Dementia Caregivers

October 1st, 2024



Welcome from...



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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.

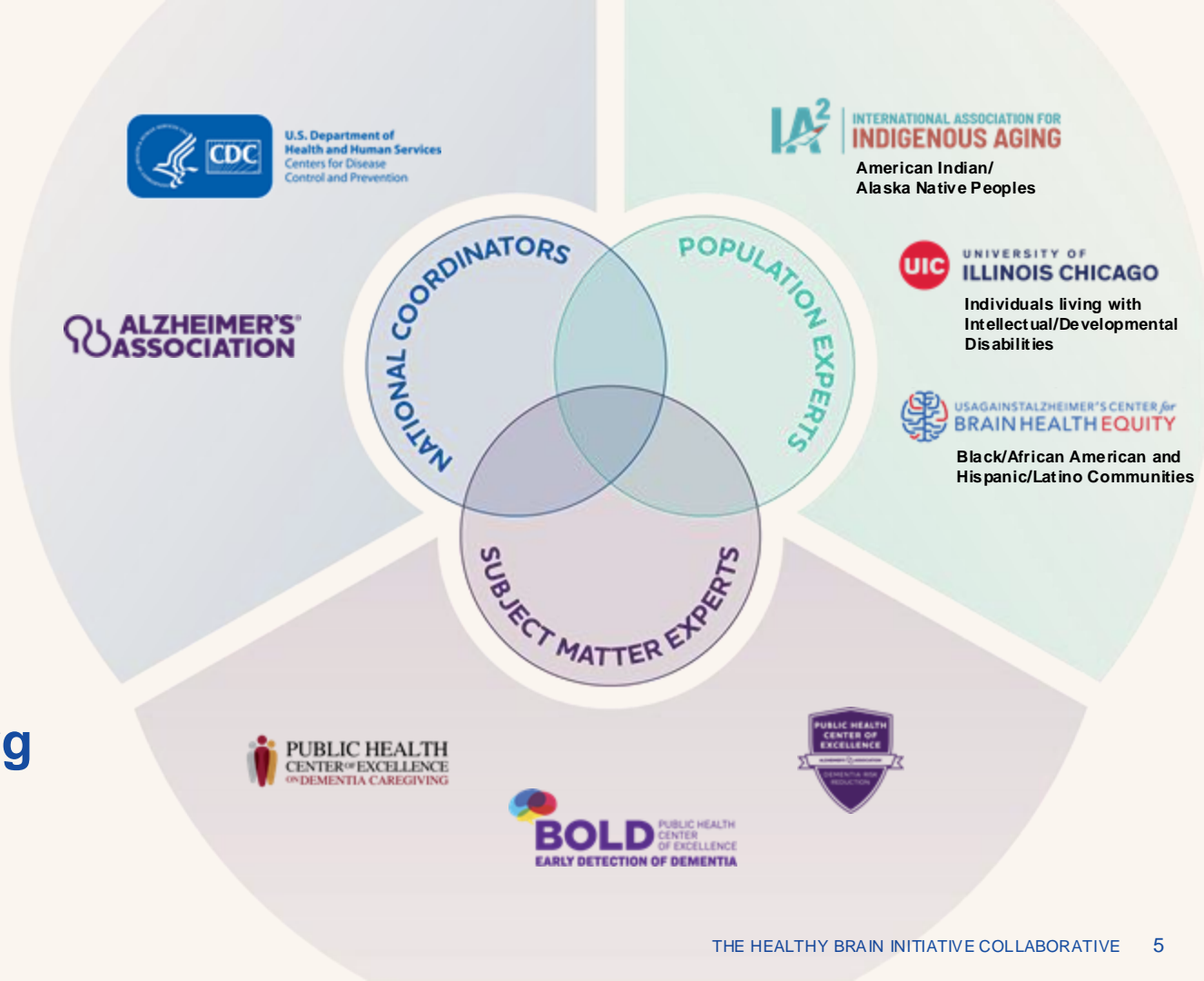
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Reminders for the Presentation Session

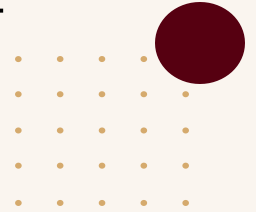
- **Submit your questions for the speakers into the Q&A feature.**
- Use the **CHAT** to share comments, resources, links, and ideas.
- The recording, slides and resources will be shared after the event.
- **Please complete the survey at the end of this event.** *An invitation will pop up in Zoom when you leave this webinar, or you can scan this QR code. Thank you!*



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 speakers!



Jennifer Belkov

Vice President, Public Policy,
Alzheimer's Association,
Illinois Chapter



Bill Gustafson

Director of Government Affairs,
New York State,
Alzheimer's Association



Carter Harrison

Director,
State Regulatory & Legislative Affairs,
Alzheimer's Association,
Alzheimer's Impact Movement



Katie Mahar

Director,
Bureau of Alzheimer's Disease Center for
Home and Community Based Services
New York State Department of Health



Jessica Link

Dementia Coordinator,
Illinois Department of Public Health



State Policies on Caregiving: Opportunities for Supporting Dementia Caregivers



Alzheimer's Caregiver Background



Current Impact of Alzheimer's Caregiving

IN 2024, ALZHEIMER'S
AND OTHER DEMENTIAS WILL
COST THE NATION
\$360 BILLION
————— \$\$\$\$\$ —————

BY 2050, THESE COSTS
COULD RISE TO NEARLY
\$1 TRILLION

70% OF DEMENTIA
CAREGIVERS
FEEL STRESSED WHEN
COORDINATING CARE

**AND MORE
THAN HALF**
OF CAREGIVERS
SAID NAVIGATING
HEALTH CARE IS
DIFFICULT



OVER **11 MILLION**
AMERICANS PROVIDE
UNPAID CARE

FOR PEOPLE WITH ALZHEIMER'S
OR OTHER DEMENTIAS



THESE CAREGIVERS
PROVIDED MORE THAN
18 BILLION HOURS
VALUED AT NEARLY
\$347 BILLION



Source: Alzheimer's Facts and Figures 2024

Needs of Persons Living with Dementia

- Assistance with instrumental activities of daily living (IADLs) care.
- Medication management.
- Assistance with personal activities of daily living (ADLs).
- Managing behavioral symptoms.
- Finding and using support services.
- Making arrangements for care.
- Managing other health conditions.
- Emotional support and a sense of security.
- Others person-centered supports to remain in the community.

Source: Alzheimer's Facts and Figures 2024

Needs of Alzheimer's Caregivers

- Becoming educated about the disease.
- Maintaining a sense of self and relationships with others.
 - Identifying and participating in activities that are meaningful and bring purpose to one's life.
 - Identifying opportunities to connect with others living with dementia and their caregivers and participating in related activities.
- Planning for the future, including future health care needs, changes in employment and financial changes.



Source: Alzheimer's Facts and Figures 2024

Alzheimer's Caregiver Policy Response

Alzheimer's Caregivers Policy Response: Example

- ACL Lifespan Respite Care Program
 - Since 2009, ACL has awarded competitive grants to eligible agencies in 38 states and the District of Columbia.
 - Comprehensive dementia education and trainings: Offering "Dementia 101 Training", Dementia Caregiver Resource Guide, and specific meetings to share caring strategies linked with Alzheimer's Disease and Alzheimer's Disease Related Dementia (AD/ADRD).
 - "Nine Steps to Respite Care for Family Caregivers of Persons with Dementia, including Alzheimer's Disease."
 - Initiatives should include offering respite services, building partnerships, promoting volunteerism, providing adequate training, identifying and reducing service gaps, and prioritizing all unserved and underserved populations across the lifespan.

Alzheimer's Caregivers Policy Response: Example

- Dementia Specific Respite Care Programs
 - These programs exist in 18 states;
 - In 2023, about \$108,000,000 was appropriated to these programs;
 - The programs provide services similar to that of the ACL Lifespan Respite Care Program, but some have been more creative with the services provided;
 - Many use traditional partners like Area Agencies on Aging and Aging and Disability Resource Centers;
 - The financial criteria vary across the states;
 - Benefit levels also vary with many providing less than \$1000 in respite coverage.

Alzheimer's Caregivers Policy Response: Example

- Respite in Medicaid Programs
 - Provided via waivers or state plan amendments;
 - Generally a part of a larger waiver that services those over a certain age and persons with disabilities;
 - However, some state use 1915(i), 1915(j), 1915(k), (PACE) or other Medicaid State Plan Options
- Missouri Structured Family Caregiving Waiver (SFCW)
 - Provides a comprehensive and cost-effective Home and Community-Based Service (HCBS) option for individuals ages 21 and older diagnosed with Alzheimer's or a related disorder who wish to live at home in the community and would otherwise require institutionalization in a nursing facility.



ILLINOIS CAREGIVER SUPPORT PROGRAMS

COMMUNITY CARE PROGRAM (CCP)	\$1.46 BILLION ANNUALLY
DEDICATED FAMILY CAREGIVER FUNDING AT THE AAAs	\$5 MILLION ANNUALLY
DEMENTIA EARLY PLANNING WORKSHOP SERIES	~\$250,000 ANNUALLY
DEMENTIA CAREGIVER PROGRAM FOR UNDERSERVED POPULATIONS	\$475,000 ANNUALLY
CAREGIVER PORTAL	\$3 MILLION ONE TIME

COMMUNITY CARE PROGRAM (CCP)

OBJECTIVE: Assist older adults in maintaining their independence by providing cost-effective alternatives to delay/avoid nursing home placement.

Alzheimer's is the only disease listed in statute.



**ADMINISTERED
BY THE ILLINOIS
DEPARTMENT
ON AGING**



**131,153 RESIDENTS
CURRENTLY ENROLLED**

SERVICES OFFERED

- Comprehensive care coordination
- Adult day services
- In-home service
- Emergency home response services
- Automated medication dispenser service



**1915(c)
WAIVER**

ELIGIBILITY

- 60 years or older
- Either U.S. citizens or eligible non-citizens
- Residents of Illinois
- Have non-exempt assets of \$17,500 or less (home, car, or personal furnishings are classified as exempt assets.)
- Have an assessed need for long-term care

Note: Medicaid eligibility is NOT required

FAMILY CAREGIVER FUNDING

Dedicated funding for family caregiver at the Area Agencies on Aging (AAAs)



SERVICES PROVIDED

- *Evidence-based assessments that tailor interventions to caregivers' unique needs*
- *Support services and respite care*
- *Hands-on caregiver training, education and stress relief programs*



DEMENTIA EARLY PLANNING WORKSHOP SERIES

High-quality advanced care planning workshops that are culturally tailored for individuals living with dementia and their caregivers



HANUL FAMILY ALLIANCE

- *Provide access to Advance Directives and legal education to members of the Korean American population*
- *Educate the population about complicated healthcare and legal systems that create barriers to accessing care for Asian American communities*
- *Provide links to culturally and linguistically appropriate resources in the community*
- *Create safe and culturally responsive space for caregivers to discuss their concerns about racial/health equity and stress management*



CENTER FOR DISABILITY & ELDER LAW

- *Power of Planning Program provides Power of Attorney Documents and Advanced Directives for people living with early ADRD*
- *Workshop core curriculum content is tailored for Black American, LGBTQ+, and Hispanic/Latinx communities*
- *Pilot clinics are provided in target communities with partner organizations*
- *Content will be adjusted based on target community feedback and will then expand throughout the state within 3 years*
- *Expansion will include online access through IL Legal Aid Online*

FUNDED THROUGH IDPH

COMPETITIVE BIDDING PROCESS, 3-YEAR CYCLE

2 GRANTEES SELECTED

DEMENTIA CAREGIVER PROGRAM FOR UNDERSERVED POPULATIONS

MULTIPRONGED PURPOSE: *Education, support, and community connection for caregivers of people living with ADRD.*

Culturally Tailored for: Black, Latino/Hispanic, Asian, & Rural communities

**FUNDED
THROUGH IDPH**

**COMPETITIVE
BIDDING PROCESS,
3-YEAR CYCLE**

5 GRANTEES SELECTED

1. Illinois Public Health Association
2. Chinese American Service League
3. University of Illinois at Chicago
4. Shawnee Health Service & Development Corporation
5. Moultrie County Health Department





ILLINOIS PUBLIC HEALTH ASSOCIATION

- *Community Health Workers trained to support ADRD caregivers and lead ADRD Caregiver Support Groups to serve the Black American, Hispanic/Latinx, and Asian American communities*
- *Increase caregiver's knowledge of available resources as well as willingness to ask for help*
- *Increase ADRD caregiver's stress management tools*





CHINESE AMERICAN SERVICE LEAGUE



- *Educate 150 caregivers and community members annually*
- *Provide options counseling to 30 individuals/families*
- *Provide healthy behaviors and occupational therapy evaluation to staff serving clients in home with ADRD*
- *Complete training and become certified in Skills2Care and Stress-busting Program for caregivers (EBP)*
- *Develop & deliver culturally appropriate Memory Café for caregivers and persons with ADRD*



UNIVERSITY OF ILLINOIS AT CHICAGO

- *Develop one core workshop curriculum and three culturally adapted versions for the Black American, South Asian American, and Southeast Asian Americans including culturally-relevant activities/social gatherings*
- *Deliver educational workshops and social gatherings to 50 ADRD caregivers from target communities*





SHAWNEE HEALTH SERVICES & DEVELOPMENT CORP.



- *Provide culturally tailored dementia care education and create culturally appropriate, accessible educational program for caregivers in rural areas*
- *Provide accessible caregiver support via monthly support groups*
- *Create community connection via culturally appropriate in-person memory care cafes within rural communities for caregivers and persons with ADRD*



MOULTRIE COUNTY HEALTH DEPARTMENT

- *Increase public awareness of education and support for persons living with ADRD and their caregivers among Moultrie County residents via public education and presentation in every community*
- *Develop enhanced network of professional providers and services to increase the availability of services*
- *Improve provider knowledge and awareness and create a provider service and referral network*
- *Develop and implement a comprehensive caregiver wellness program that addresses physical, mental, social, emotional, and other needs of caregivers*



CAREGIVER PORTAL



PORTAL FEATURES

- *Portal will serve as a “one-stop shop” for caregivers, providing easy user-friendly access to a broad spectrum of resources, including state, federal, nonprofit, and professional caregiving information*
- *Nursing home care, home and community-based services, veteran resources will be highlighted*
- *Illinois Dept. on Aging managing the program, coordinating with disability, and veteran state agencies*



**Department
of Health**

New York State Department of Health Alzheimer's Disease Program

State Policies on Caregiving: Opportunities for Supporting Dementia Caregivers

October 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.

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

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

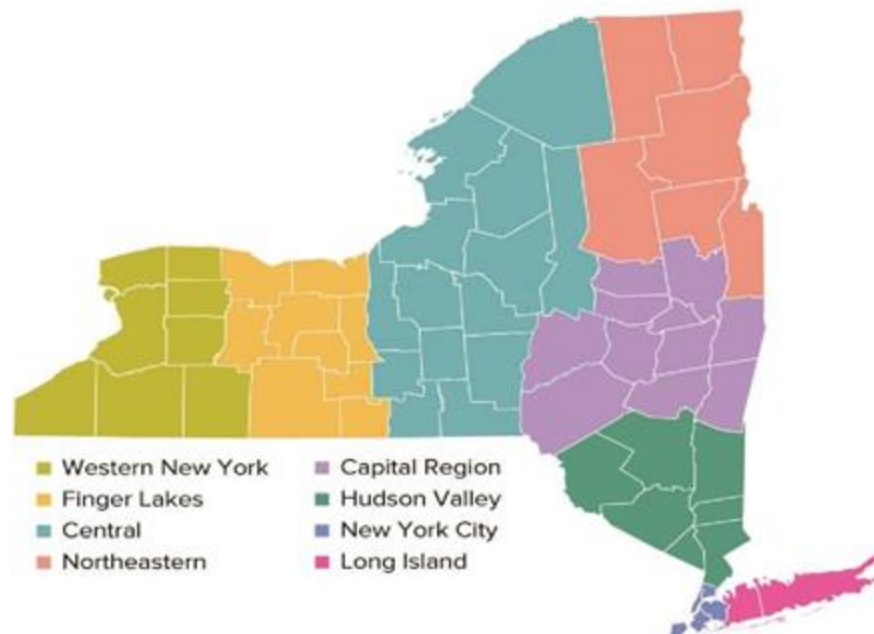
Organizational Infrastructure for the NYS Alzheimer's Disease Program

- 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”

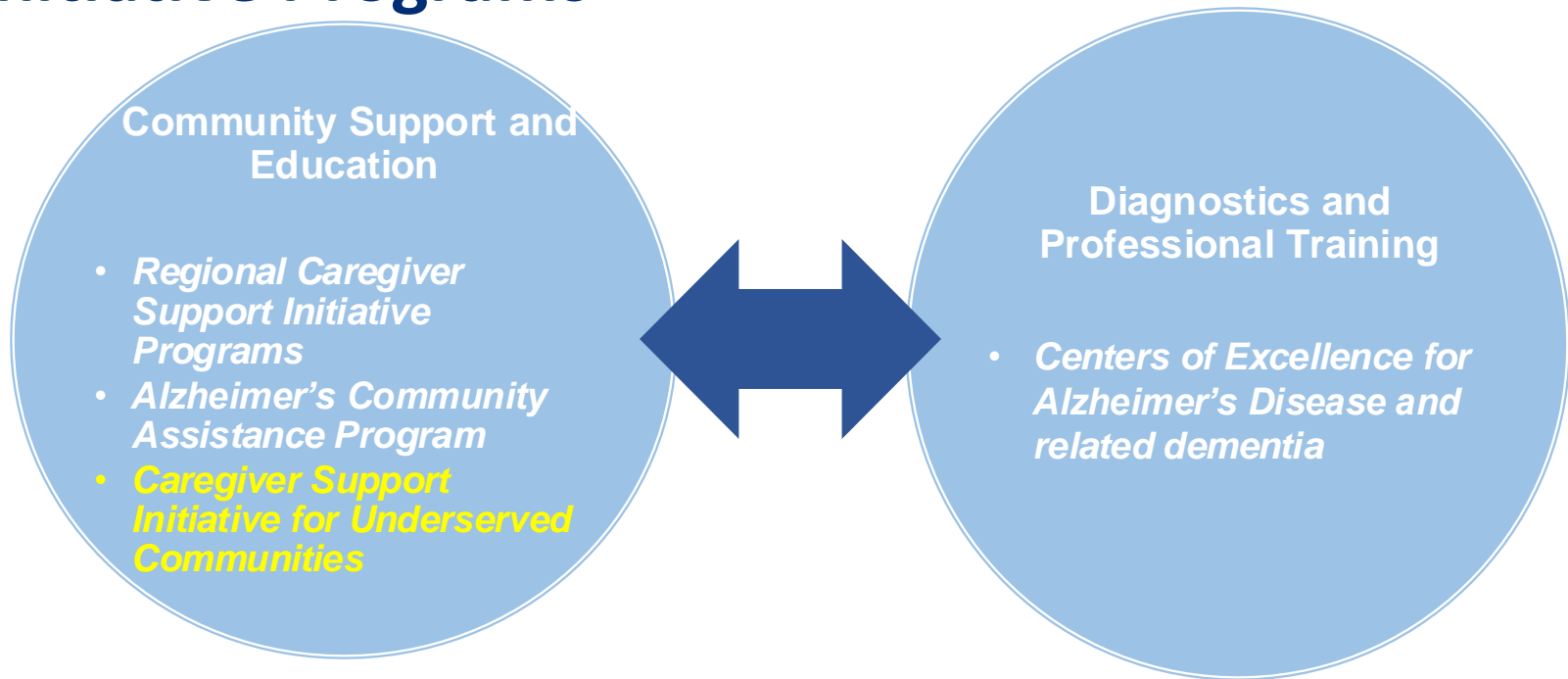
Alzheimer's Disease Caregiver Support Initiative

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

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



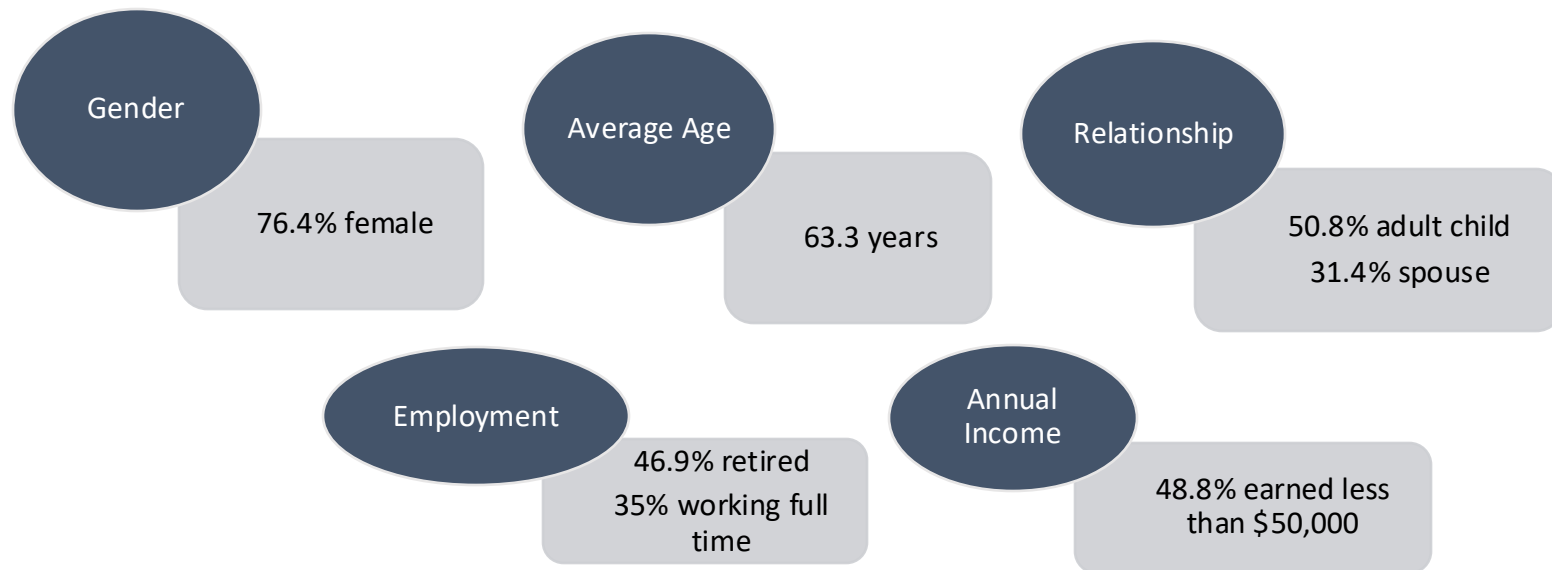
Services provided 2016-2022:

- 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 Catalina's population ages further.

Alzheimer's Disease Caregiver Support Initiative: *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

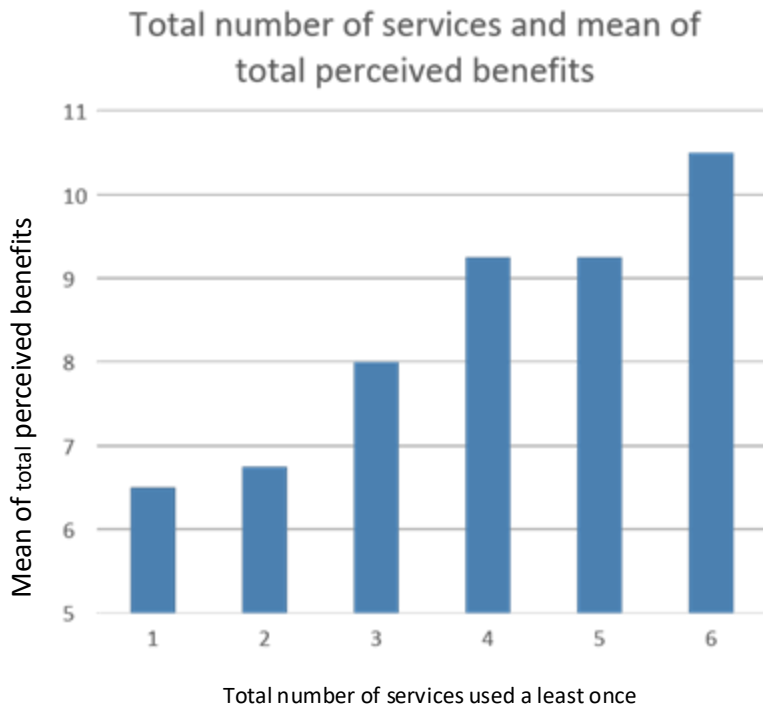
What Benefits did caregivers perceive from participating in services?

- 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 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

- ▶ 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 ⁺	627	.55	447	.21
Education*	642	.56	428	.17
Joint enrichment	400	.59	675	.30

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

NYS DOH Alzheimer's Disease Program Website

<https://www.health.ny.gov/diseases/conditions/dementia/help.htm>

You are here: [Home Page](#) > [Alzheimer's Disease and Other Dementias](#) > [Where Can I Get Help?](#)

Where Can I Get Help?

Select a county from the map below, or from [a list of counties in New York State](#) to view Caregiver Support Programs and Centers of Excellence for Alzheimer's Disease in that county.



THANK YOU!

- Contact Information:
 - Katie Mahar, Director - Alzheimer's Disease Program, katie.mahar@health.ny.gov
 - NYS Alzheimer's Disease Program, alz@health.ny.gov

Q&A

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



Thank you for joining us today!

Please take a moment to
complete a brief survey.

We appreciate your feedback!



<https://bit.ly/StatePoliciesEval>

