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New York State’s Public Health Approach to Alzheimer’s Disease

February 21, 2019

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Featured Speakers

**Mary Gallant, PhD, MPH**
Senior Associate Dean for Academic Affairs
Professor of Health Policy, Management & Behavior
University at Albany School of Public Health

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Director of Evaluation and Collaborative Projects
Bureau of Community Integration and Alzheimer’s Disease
New York State Department of Health
Learning Objectives

- Describe the New York State Department of Health (NYSDOH) Caregiver Support Initiative
- List emerging findings from the evaluation of the NYSDOH Caregiver Support Initiative
- Discuss policies relevant to Alzheimer’s disease and caregiving in New York State

A Public Health Issue

Alzheimer’s Disease in the US

Alzheimer’s Association 2018 Facts and Figures Report
Alzheimer’s Disease in NY State

400,000 New Yorkers have Alzheimer’s Disease or another dementia

53.4% Percent of New Yorkers with memory problems who have not talked to a health care provider

Caregivers in New York State

Over 1 million caregivers provide 1.1 billion hours of unpaid assistance for people with dementia in New York, valued at $14 billion

History of Public Health Action in NYS

- 1984: Blue Ribbon Panel
- 1987: Alzheimer’s Disease Assistance Centers
- 1988: Alzheimer’s Disease Community Service Program
- 2007: NYS Coordinating Council for Services Related to Alzheimer’s Disease & Other Dementias
- 2015: NYS Caregiver Support Initiative
Caregivers in New York State

“I love my mother and want to keep her with me, and now I’m realizing that if I want to continue, I need help in order to stay healthy myself.”

- New York State Caregiver

Evidence-Based Interventions

NYSDOH Alzheimer’s Disease Caregiver Support Initiative

Community Support and Education
- Regional Caregiver Support
- Alzheimer’s Community Assistance
- Caregiver Support for Underserved Communities

Diagnostics and Professional Training
- Centers of Excellence for Alzheimer’s Disease
Community Support and Education

- Care consultation
- Education
- Support groups
- Respite
- 24-hour helpline

Diagnostics and Professional Training

- Assessment and diagnosis
- Care management
- Medical and healthcare provider training
- Promotion of clinical trials

Support in Your Region

New York State Department of Health Alzheimer’s Disease Program

https://www.health.ny.gov/diseases/conditions/dementia/help.htm
Key Evaluation Questions

- What services are being delivered?
- Who is being reached?
- How is this impacting people with dementia and their caregivers?
  - Caregiver health/wellbeing, unnecessary hospitalizations, delaying nursing home placement
- How is this initiative changing the dementia support infrastructure in NYS?

Initial Results

- Service availability
- Service utilization
- Statewide coverage in every county

Community Support and Education

- 60,161 care consultations serving 25,930 individuals
- 47,837 hotline calls serving 26,648 individuals
- 183,218 respite hours for 4,190 individuals
- 7,777 support group sessions serving 12,889 individuals
- 6,759 education sessions serving 19,192 individuals
Diagnostic and Professional Training

- 12,284 diagnostic assessments
- 36,245 medical and healthcare professionals trained
- 44,785 referrals to community providers

Issues of Service Delivery

Challenges
- Caregiver self-identification
- Understanding of service
- Caregiver competing priorities
- Staff shortages

Facilitators
- Skillfulness of staff
- Flexibility in scheduling
Who are Being Reached?

Percent of Rural Caregivers Compared to Census Data

Race/Ethnicity

Caregiver Race/Ethnicity Compared to U.S. Census Estimates in New York City Region
Emotional Stress of Caregiving

Outcomes

- Health care utilization
- Nursing home placement
- Caregiver benefits

Enhanced Confidence and Competence

"It is so nice to have a professional tell me that I'm on track. I want to do the absolute best job I can do as my mother's care partner. With the help of your organization and the information you've shared, I feel like I am prepared to face the progression of her disease and I don't have to go it alone."

"It's been reassuring to hear that much of the behavior we've been witnessing is common among those suffering from dementia. We're getting better at handling her misdirected anger, confusion and fear. Talking with you about our trials, successes and failures has been extremely helpful."
Stress Reduction

“I woke up for the first time in a long time with a calm and a plan. You already have made a great difference in our lives and our parent's lives by giving us the lay of the land and the ‘permission’ to look at her as a unique person and case in figuring out what is the best way to move forward.”

Avoiding Nursing Home Placement

“I was so glad she was home when she died. My husband and my goal was to not have her in a nursing home and to take care of her at home - we accomplished this. I want to thank you for being a part of a program that is so important to caregivers and for all your help and understanding.”

Impact on New York State

- Strengthened infrastructure to address Alzheimer’s Disease
- Enhanced workforce
- More coordinated provider network
The Initiative in Context

- Caregiver Advise, Record, Enable (CARE) Act
- Paid Family Leave Act
- NYS Assisted Living Voucher Program
- Respite Education and Support Tools (REST)

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