

# New York State Alzheimers Disease Program

David Hoffman  
Bureau Director, Division of Long Term Care  
Office of Health Insurance Programs

## Enormous Public Health Implications

- 2/3<sup>rd</sup>s of people with dementia live in the community.
- In 2011 there were an estimated 960,000 caregivers in New York.
- The health and wellbeing of people with dementia and their caregivers is at risk.

Alzheimer's Association, (2013). 2013 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 9, 208-245.

## Caregivers

- Caregiving for individuals with Alzheimer's disease is an emotionally and physically demanding job
- Stress associated with caregiving can lead to health problems for the caregiver
- Caregivers' often experience financial stress and employment problems
- The number of caregivers will continue to increase as the number of individuals with Alzheimer's increases
- Projected numbers will overwhelm current system of services

Alzheimer's Association, (2013). 2013 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 9, 208-245.

## In New York State...

- There are an estimated 320,000 individuals with Alzheimer's disease.
- By 2030 this number is expected to increase to 350,000.
- This number is likely to be underrepresented due to the lack of early detection and underreporting on death certificates.

Alzheimer's Association, (2013). 2013 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 9, 208-245.

## Cognitive Impairment in NYS Nursing Homes

- In 2009 there were 232,754 total nursing home residents
  - 40% had moderate to severe cognitive impairment
  - 25% had very mild to mild cognitive impairment
  - 35% had no identified cognitive impairment
- In 2011 the average cost of nursing homes were:
  - \$248 per day/\$90,520 per year for private rooms
  - \$222 per day/81,030 per year for semi-private rooms
  - Costs were sometimes higher for residents with Alzheimer's disease

Alzheimer's Association, (2013). 2013 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 9, 208-245.

## NYSDOH Response

- Long and proactive history of addressing challenges of Alzheimer's disease
- State DOH funds community-based programs that fill gaps in the healthcare and support systems
- Fund interventions crucial to effective disease management

## Program History

- Governor Mario Cuomo convenes Blue Ribbon Panel
- 1987 – Legislation created Alzhiemers Disease Assistance Centers (Article 27 of the PHL)
- 1988 – First contacts funded (ADACs)
- 1990s – Community Service Programs
- 2000 – NYS Office for Aging (SOFA) Collaboration
- 2007 – NYS Coordinating Council for Services Related to Alzheimer's Disease and Other Related Dementias
- 2008 – Alzheimer's Community Assistance Program – statewide effort
- 2009 – First report released by the NYS Coordinating Council for Services Related to Alzheimer's Disease and Other Related Dementias
- 2011 - 2<sup>nd</sup> Report released
- 2013 – 3<sup>rd</sup> Report released

## Goals of the Alzheimer's Disease Program

- Use evidence-based strategies to ameliorate the impact of Alzheimer's disease on individuals and families
- Delay the institutionalization of individuals with Alzheimer's disease
- Maintain the quality of life of both the Alzheimer's disease patient and the patient's family members

## Evidence Base of Program

- A study by Mittleman (2006) showed that nonpharmacological interventions for caregivers can delay nursing home placement.
  - The intervention in this study is called the “NYU Intervention”
- Showed that with a similar array of services institutional placement can be postponed by 557 days.

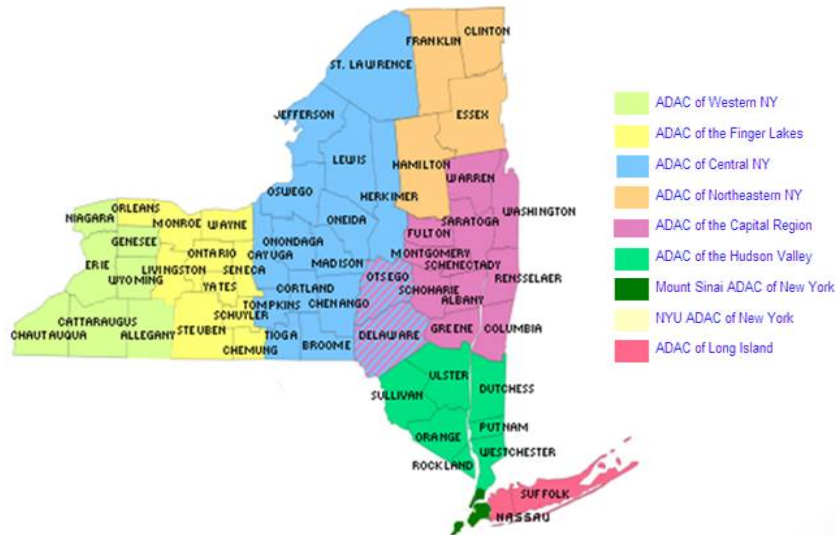
Mittleman, M. S., Haley, W. E. Clay, O. J. & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. *Neurology*, 67, 1592-1599.

## NYSDOH Alzheimer's Disease Program Components

- **Alzheimer's Disease Assistance Centers (ADACs)**
  - 9 funded in NYS
  - Centers for Excellence that provide diagnosis and assessment, patient management and care, provide training, education and consultation
  - Clearinghouse of information on Alzheimer's disease
  - Most affiliated with universities and hospitals



# ADAC Locations & Regions Served



## NYSDOH Alzheimer's Disease Program Components Cont.

- **Alzheimer's Community Assistance Programs (AlzCAP)**
  - Statewide services provided through the 7 NYS Alzheimer's Association Chapters
  - Provide community-based support services for patients and family members:
    - Support groups (primarily for family members and caregivers)
    - 24-hour helpline
    - Training and education of family and non-family caregivers, volunteers, and home health care personnel
    - Volunteer respite services including provider training
    - Care consultation and outreach

## NYS Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias

- Reports released in 2009, 2011 and 2013
- Periodic council meetings
- Hours of research and drafting
- Input from consumers, providers, advocates
- Input from several state agencies
- Visit the following link to find NYS reports on Alzheimer's disease:  
[http://www.health.ny.gov/diseases/conditions/dementia/reports\\_data.htm](http://www.health.ny.gov/diseases/conditions/dementia/reports_data.htm)

## Coordination is Key

- Department of Health (Medicaid, LTC, Public Health, Health Facilities)
- State Office for Aging (Community Supports)
- State Education Department (Office of Professions)
- Office of Mental Health (Community Services)
- Office for Persons with Developmental Disabilities (Community and Other Supports)
- Office for Temporary and Disability Assistance (Support Services, Adult Protective Services)
- Providers and Advocates

## Recent Actions

- Coordination with State Office for Aging Dementia Capability Project
- Dear Colleague Letter to all physicians on early detection
- Briefing for Governor's Staff on Alzheimer's Disease Issues
- Convened meetings of State Health Commissioner and Director of State Office for Aging
- Updated State Web Pages for Alzheimer's Disease and Other Dementias
- Exploring collaboration with LTC rebalancing initiatives (MFP, FIDA, BIP)

## Coming Next

- Develop more health promotion messages for seniors
- ADACs to develop curricula for pre-service and in-service training for health professionals
- Revisit training opportunities for direct care workforce
- Expand awareness on advance care planning
- Focus on early detection
- Promote Reaching Older Americans with Research (ROAR)
- Focused demonstration project to impact disparities



# Conclusion

- We have a long way to go
- Public/Private Partnerships must be part of the solution
- Data; workforce; caregiver training and support are essential
- Public awareness can lead to quality
- The clinical/community linkage is key
- Advance planning is required for quality