

Alzheimer’s Disease Caregiver Support Initiative

Executive Summary: Year 1

The Alzheimer’s Disease Caregiver Support Initiative (ADCSI) is a 5-year grant initiative funded through the New York State Department of Health and designed to support caregivers and people with dementia in the community using evidence-based strategies. The ADCSI takes a two-pronged, systems approach to the investment—both focusing on community support while also equipping the medical system to provide early diagnoses, quality care management, and linkages to community services.



This is an executive summary of the first annual evaluation report.

The full report documents the scale of services provided under the initiative and uses preliminary data to analyze detailed characteristics of the population reached. The report also documents challenges and successes in grant start-up and implementation.

In future years, reports will include analyses of healthcare utilization and costs, and examine the impact on caregiver burden.

Summary of Selected Findings

The first year of the ADCSI was marked by capacity building efforts – including scaling-up infrastructure, training, and hiring staff.

- Providers reported a growing awareness and demand for services as they expanded outreach activities.
- Almost all providers reported forming new partnerships as a result of the grant, suggesting enhanced coordination between organizations and a strengthened network of providers.
- The most commonly reported staffing challenge was a lack of applicants with experience in dementia (39%).
- The most commonly reported service delivery challenge was participant recruitment (46%).

Though efforts in the first year were largely focused on building organizational capacity, New York State also saw a massive expansion of funding for community support services for caregivers and people with dementia, demonstrating extensive scale in both service availability and utilization.

- Work plan goals for community support services came close to being met, or were exceeded, in all program categories except respite care.

Core Community Support Services			
Service	Service Number	Individuals Reached	Average Number of Services Per Individual
Consultation Services	20,389	6,234	3.27
Support Groups	3,217	5,174	4.33
Educational Sessions	1,770	12,803	1.50
Respite Hours	49,897	1,188	42 hours
Helpline Calls	23,505	12,596	1.86

Documented workforce issues highlight a statewide need to invest in development and training of the dementia care workforce at multiple levels.

- Reported barriers to providing respite care included home health aide workforce shortages and a lack of respite providers, particularly in rural areas. Though some grant requirements were adjusted to allow for alternate models of respite, this remains as a barrier to service delivery.
- Over one third of providers experienced challenges hiring and retaining community support staff with experience in dementia.

Centers of Excellence for Alzheimer’s Disease (CEADs) offered substantial numbers of diagnostic services, care management, and professional training despite not being fully operational until mid-year.

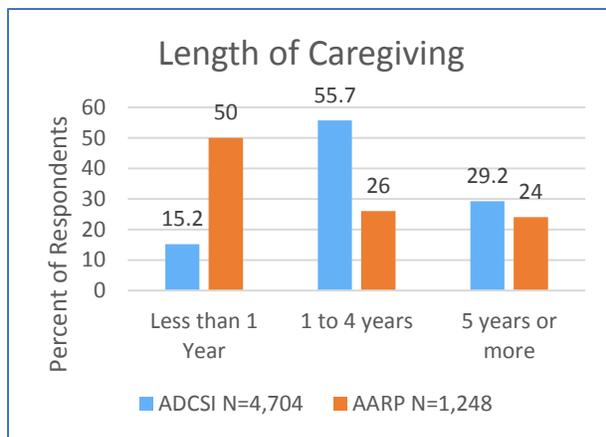
Select CEAD Services	
Service	Service Number
New Diagnostic Assessments	5,076
Care Plans Developed	5,880
Total Referrals Made to Community Services	18,359
Clinical Trial Information	1,949

- In addition to providing services to patients, CEADs trained 12,168 students, physicians, and healthcare professionals.
- On average, CEADs exceeded goals for the number of specialty care providers, non-physician providers, and students reached, while falling short in primary care physician training.

Compared to informal caregivers from a national sample, those who received services were older, more likely to be female, and more likely to be caring for a parent.

- The majority (76.6%) of caregivers providing demographic data self-identified as female. The average age of caregivers was 63.3 years old.
- Almost half (48.5%) of caregivers seeking services were 65 or older.
- The vast majority of informal caregivers reporting demographic data were family members, typically a daughter (37.8%) or the spouse/partner (30.7%) of a person with dementia.

Caregivers served by the ADCSI initiative appear to have been providing care for longer and at greater intensity when compared to a national sample of caregivers.



- Caregivers served by the ADCSI initiative reported higher levels of emotional stress and physical strain than those in the national sample of caregivers.
- Caregivers served by the ADCSI were also more likely to have been caring for longer and providing more hours of care per week than the national sample of caregivers.
- Over half of respondents reported spending 40 or more hours per week providing care.
- Approximately 30% of caregivers reported providing care for 5 years or more.

The caregivers served under the initiative were largely representative of the New York State population, with room for improvement within specific populations and regions.

- The available data suggests that in the first year overall, racial and ethnic minority populations were underrepresented when compared to the general NYS population and to a national caregiver sample. However, several regions had success reaching similar or slightly higher percentages of specific minority populations.
- Preliminary analysis suggests that rural regions had a more favorable service distribution than more densely populated regions compared to estimates of the New York State population aged 45 and older.

Additional results, including a discussion of the methods, limitations, data sources, and analysis, are included in the full report.