

New York State Alzheimer’s Disease Caregiver Support Initiative

Final Evaluation Report 3 for the Period 2015-2020: Estimates of Economic Impact on NYS

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The Alzheimer’s Disease Caregiver Support Initiative (ADCSI) is a landmark investment by the New York State Department of Health (NYSDOH) in community support and health services for people with all forms of dementia and their caregivers. From 2015 – 2020, the New York State Department of Health (NYSDOH) invested over \$26.2 million annually in this initiative. The ADCSI takes a two-pronged systems approach: focusing on supporting caregivers and people with dementia in their communities, while also enhancing the capacity of medical and health care professionals statewide to provide early diagnoses, quality care management, and linkages to community support.

During this period, the initiative funded 36 contracts in eight regions across the state through four separate grant programs. Three of these grant programs focused on community support and education for informal caregivers and people with dementia and one grant program focused on clinical services and training for professional health care providers. The Alzheimer’s Disease Caregiver Support Initiative was designed based on research demonstrating that an array of support services leads to improved caregiver outcomes and delayed nursing home placement, with associated cost savings to Long-term Services and Supports (LTSS), including to payors such as Medicaid.

A comprehensive evaluation of the ADCSI for the period of January 2016 to May 2021* was conducted by the University at Albany School of Public Health in collaboration with NYSDOH. Consistent with the evaluation goal to examine the economic impact of the initiative, this report documents estimated cost savings to New York State (NYS) from delayed nursing home placements as a result of services provided through the initiative. Although this report emphasizes the benefits of delayed nursing home placement, the report also explores other sources of potential economic impact related to service utilization, including avoidable hospitalizations for people with dementia.

Prevalence and Cost of Care of Dementia in NYS

An estimated 410,000 individuals in New York State are living with Alzheimer’s Disease or another related dementia (AD/D).^{1,2} Dementia places considerable financial burden on the person with dementia, family caregivers, employers, the healthcare system, and the state. It is estimated that over half a million family caregivers provided 774 million hours of unpaid assistance in New York in 2020, valued at \$14.6 billion.³ Higher healthcare costs for caregivers as compared to non-caregivers amounted to an extra \$881 million of healthcare spending in 2017 in New York State alone.⁴

In 2018, approximately 407,000 (12.2%) of all Medicare enrollees in NYS had a diagnosis of dementia.⁵ Nationally, the Alzheimer’s Association estimated total payments for dementia care at \$355 billion dollars in 2021, with the average per-person healthcare and long-term care payments from all sources for Medicare beneficiaries with dementia equaling \$52,481.⁶ Using this average, the estimated total healthcare and long-term care costs for dementia in NYS in 2021 is approximately \$21 billion dollars.

* The evaluation period differs slightly from the time period for the initiative referenced previously because each 5-year grant program started at a slightly different time. This report is based on data from January 2016 to May 2021.

New York State's share of these costs are substantial, exceeding \$5.45 billion dollars in Medicaid expenses in 2020.⁷ Approximately thirty percent (30%) of all individuals in NYS with dementia are state-based Medicaid recipients, incurring some of the largest per-person expenses.⁸ Nationally, the average annual Medicaid expense for a person with dementia (including both community-based and facility-dwelling beneficiaries) is \$8,700 higher than for individuals without dementia, with the bulk of higher costs attributed to residential or nursing home placements.⁹

While the majority (70%) of individuals with Alzheimer's Disease and related dementias live in the community, a significant portion live in long-term care facilities. The Alzheimer's Association estimates that nationally, individuals with dementia are almost four times as likely as other Medicare beneficiaries to have a nursing home placement,¹⁰ and people with Alzheimer's disease and other dementias account for almost 50% of all nursing home residents.¹¹ A retrospective study found that approximately 29% of community-dwelling residents with dementia receiving home care services in New York transitioned permanently to nursing homes from 2007 to 2012.¹² Median time to placement after diagnosis has been reported to range from four to seven years.¹³

The average per diem cost of nursing home care in New York ranges from \$357 in Central New York to \$455 in Long Island, with annual per person costs[†] estimated at over \$140,000.^{14,15} Medicare only provides funding for short-term placements in skilled nursing facilities, with Medicaid serving as the primary payor for sixty-three percent (63%) of all nursing home placements in New York State.¹⁶ While Medicaid payments for nursing homes in New York State are generally lower than average, ranging from \$170 to \$323 a day,¹⁷ the cost is significant, with estimated fee-for-service expenditures on nursing home facilities amounting to over \$5.49 billion in 2018.¹⁸

The total cost of dementia care in NYS is significant. Individuals with dementia are more likely to have higher hospitalization expenses, more frequent hospitalizations, and experience more preventable hospitalizations and/or emergency department (ED) visits than individuals without dementia.^{19,20} The U.S. Department of Health and Human Services reported that nationally, almost one-quarter (23.5%) of all hospitalizations for people with dementia aged 65 and over from 2013 to 2015 were considered preventable.²¹ A study of ED use among individuals with dementia in Indiana from 1999 to 2009 found that, in any given year, approximately half of dementia patients had at least one ED visit, with 58% of those individuals having a return visit within 30 days.²² A recent analysis of ED visits in a nationally representative sample of Medicare beneficiaries supports these findings.²³ In 2018 in New York State, the rate of hospital readmission within 30 days for a Medicare beneficiary with dementia was 23.7% and the average number of ED visits per beneficiary was 1.46 per year.²⁴ These healthcare expenses are costly, with the average Medicare payment for an ED visit for a person with dementia at \$6,028.^{25,26}

In an effort to reduce potentially avoidable hospitalizations, ED visits, and nursing home placements, researchers have investigated a number of factors associated with healthcare use in people with dementia, including the role of informal caregivers. A recent international systematic review reported that caregiver burden was associated with increased institutionalization.²⁷ Other studies have reported an increase in the risk of hospitalization associated with caregiving factors, such as length of time as a caregiver, hours per week caregiving, physical strain, healthcare tasks, disease severity and caregiver burden.^{28,29} Additionally, relationship strain and inflammation biomarkers associated with chronic stress in caregivers have been identified as factors related to urgent care use for people with dementia.^{30,31}

[†] This includes Medicaid, Medicare, private insurance, and self-pay.

Increased access to early detection, counseling, and support services, similar to those offered through the NYS Alzheimer’s Disease Caregiver Support Initiative, have resulted in better outcomes for both caregivers and people with dementia.^{32,33} Caregiver support services that improve caregiver well-being have previously been reported to delay nursing home placement for people with dementia, with estimates for the average delay ranging from 329 days to almost five years.^{34,35} In other research, caregiver support and education programs were found to be critical in preventing healthcare crises.³⁶ In addition to caregiver support programs, care coordination, which is integral to the ADCSI initiative, has been shown to delay nursing home admissions.³⁷ Based on this research, the ADCSI emphasized expanding the reach of both diagnostic and care coordination services for people with dementia and caregiver support services for their caregivers.

Evaluation Data Sources

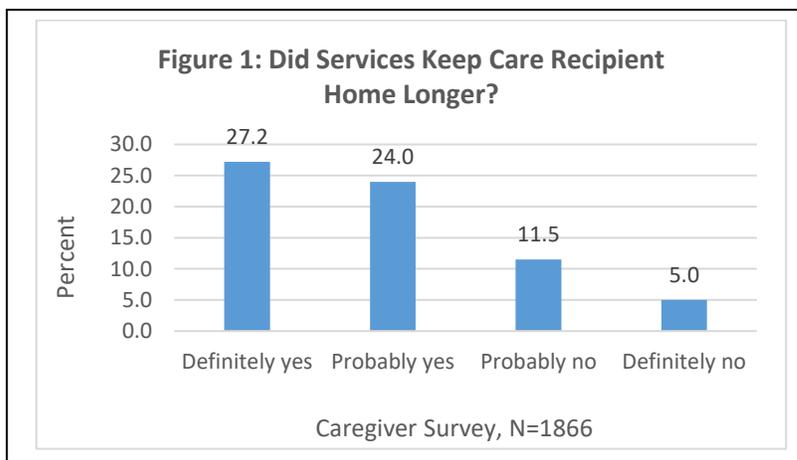
Data sources used to evaluate the impact of the ADCSI on the cost of health and long-term care services and supports for people with dementia, include the following:

- A survey of caregiver participants, conducted in the third year of the initiative, assessed outcomes such as caregiver burden, benefits of services, positive aspects of caregiving, self-reported healthcare utilization, and reported nursing home delay. Caregivers who participated in programs and services funded through the NYS ADCSI between January 2018 and July 2019 with known email addresses (approximately 22,500 caregivers) were invited to complete an online questionnaire. A total of 1,866 current and previous caregivers completed the survey.
- Contractor quarterly progress reports and annual budgets were used to estimate the cost of services.
- Voluntary self-reported information on demographics, caregiving, and diagnosis-related information was collected from service participants, at or near the time of first service use. Approximately 100,000 caregivers served through the ADCSI provided this information.
- Cost savings due to nursing home placement delay were estimated using data on average nursing home costs in NYS and by NYS region.³⁸ Data sources for other healthcare and long-term care costs include the NYS DOH,³⁹ The Center for Medicare and Medicaid Services (CMS),⁴⁰ the American Association of Retired Persons (AARP),⁴¹ and the Alzheimer’s Association.⁴²

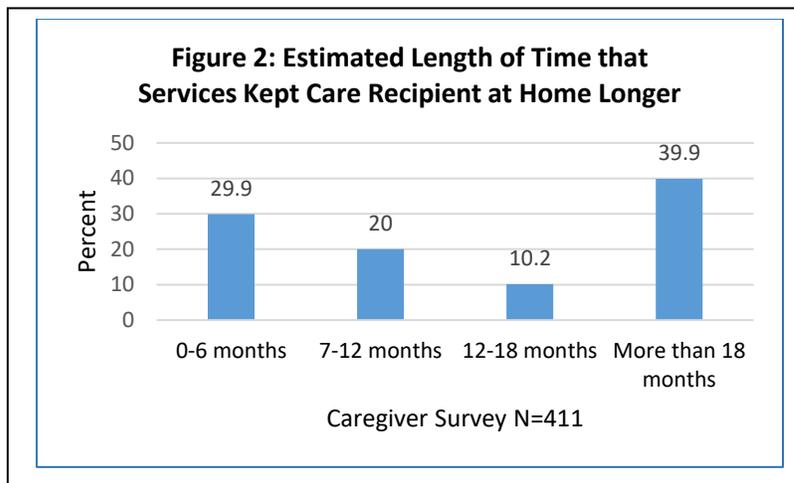
Nursing Home Placement Delay

Nursing home placement delay can only be estimated with self-report.⁴³ Among the caregivers who received ADCSI services and responded to the participant survey, approximately half reported that the services they received “definitely” or “probably” kept the person with dementia they care for home longer than if they hadn’t received services (27% definitely; 24% probably; 1866 caregiver respondents total). See Figure 1.

Those who responded definitely or probably yes were then asked to estimate how much longer they were able to keep the care recipient at home. Figure 2 illustrates this self-



reported estimate of nursing home placement delay among the subsample of 411 caregivers that provided an estimate. The average is approximately 12 months. An additional 34% of respondents agreed that services helped delay nursing home placement but couldn't estimate the amount of time. Among a different subset of respondents whose care recipient had already been placed in a nursing home at the time of the survey, the average estimated delay to nursing home placement was reported to be about 9 months.



Estimated Nursing Home Cost Savings

These data were extrapolated to the total number of unique individuals receiving services during the five-year evaluation period of the initiative (N = 102,408), and were used, along with average nursing home costs in NYS and by NYS region, to estimate cost savings due to nursing home placement delay.⁴⁴

One limitation is the assumption that the sample of survey respondents is representative of all caregivers who used ADCSI services. Survey respondents were largely representative of the overall sample of ADCSI caregivers with some minor differences. Survey respondents were slightly more likely to be younger, female, a spouse, less racially diverse, less likely to live with their care recipient, and reported higher annual household incomes than the overall sample of ADCSI participants.

However, on average, caregivers who responded to the survey participated in a greater variety and total number of services than the average caregiver who participated in ADCSI services. In addition, caregivers who responded that services helped their loved ones remain home longer reported even *higher service usage* than the overall survey sample and ADCSI caregivers participating in the initiative. These caregivers participated, on average, in 3.18 different kinds of service and 8.7 total units of support services. Approximately 54% of caregivers who responded to the survey participated in 3 or more different services compared to 11% of the overall ADCSI sample (N=102,408); 43% of survey respondents reported participation in 8 or more sessions compared to 10% of the overall ADCSI sample (over a five-year period).

Due to this limitation, the cost savings estimates were calculated using a conservative approach, which assumed that only ADCSI participants who participated in 3 or more different services *or* 8 or more total service sessions experienced nursing home placement delay. This equates to 14.3% of ADCSI participants or 14,648 caregivers over the duration of the five-year evaluation period. At an average annual nursing home cost of \$140,000, an average one-year placement delay for this subset of participants equals \$2.05 billion in nursing home cost savings across the first five years of the initiative.[‡]

[‡] This estimate is lower than cost savings estimates calculated for earlier, preliminary evaluation reports which applied survey results of self-reported nursing home placement delay to all ADCSI participants. Final, more detailed analyses were able to account for service use patterns in the estimation of cost savings, resulting in the estimates presented here.

This is a conservative underestimate for two reasons. First, progress report data indicate 125,000 – 150,000 caregivers actually used ADCSI services, but detailed utilization data is only available for 102,408 caregivers, so this estimate does not include as many as 47,500 participants for whom utilization data is missing. Second, as described above, it is based on the conservative assumption that nursing home placement delay *only* occurred beyond a certain threshold of service use, but lower levels of service utilization *may* also have led to nursing home placement delay for some participants.

Net Cost Savings Estimates due to Nursing Home Placement Delay

The total cost of the community support provided through the initiative was approximately \$107.5 million over the five years. It can be assumed the net estimated cost savings due to nursing home placement delay, using the most conservative estimate of cost savings, was in excess of \$1.9 billion, over the course of the initiative. This translates into an estimated \$17.7 of nursing home cost savings for each dollar invested (i.e. \$1.9 billion/\$107.5 million). Approximately 20% of ADCSI participants were caring for someone on Medicaid; alternatively, should nursing home placement occur at the same rate for this subpopulation (and this may be a conservative assumption), the Medicaid nursing home savings could be estimated to be \$400 million.

Over the course of the initiative, contractors provided over 1.19 million units of service to caregivers, which averages to an approximate cost of \$90 per unit of service.[§] Based on this per-unit cost, the average cost of service per caregiver who said that services kept their loved one home longer was approximately \$786.

The average annual cost of healthcare (not including skilled nursing facilities) for a community dwelling Medicare beneficiary aged 65+ with dementia has been estimated to be approximately \$36,000.^{45,46} Thus the incremental per person net cost savings of delaying nursing home placement for ADCSI participants is estimated to be approximately \$103,000 per year. ($\$140,000$ average annual nursing home cost – $\$786$ for ADCSI services – $\$36,000$ annual healthcare expenses = $\$103,214$). This does not account for other costs, such as housing costs, informal care costs, etc. for a person with dementia living in the community.

Other Healthcare Service Utilization

Survey respondents who were current caregivers were also asked about their care recipient's hospitalizations and emergency department visits during the six months prior to the survey. One quarter (23.8% or 229) of respondents reported that their care recipient had an overnight stay (3.56 days average) in the hospital during the previous 6 months. This is significantly lower than the average of 23 inpatient days per Medicare beneficiary with dementia in 2012 reported by Bynum and colleagues in 2016.⁴⁷ Approximately 37.5% (387) of current caregivers indicated that their care recipient had one or more visits to the emergency room over the previous 6 months, which is comparable to what is reported in the literature.^{48,49} The national Alzheimer's Association estimates the average annual emergency department visits per person with dementia in New York State was 1.46 visits in 2018.⁵⁰ In comparison, caregiver survey respondents reported an average of .93 visits during the previous 6 months.

While caregiver survey respondents reported fewer hospitalizations and slightly higher ED visits when compared to national and state indicators, this data cannot be accurately compared due to the

[§] This is a rough estimate of the cost per unit of service. This was calculated as the total cost of caregiver support services divided by the total units of service delivered (\$107.5 million divided by 1,192,596 units of service = \$90.14 per unit). This is likely an underestimate of units of service as not all contractors reported respite service in units which likely results in an overestimate of cost per unit of service.

differences in survey questions and time frames attached to survey responses.⁵¹ Lack of information about individual healthcare costs or healthcare utilization of care recipients prior to participation in the initiative limits final determinations about the impact of services on cost and healthcare outcomes.

Caregiver Characteristics and Service Use Related to Healthcare Utilization Outcomes

Analysis of the caregiver survey data indicate significant differences between caregivers whose care recipients experienced better healthcare utilization outcomes and those who did not. In bivariate analyses, caregivers more likely to report that services kept their loved one with dementia home longer were on average younger (average age 64.0 vs 67.3), more racially diverse (BIPOC 85.3% vs. 73.4% white), and providing care to a parent as opposed to a spouse. In addition, caregivers who reported higher before-services caregiver burden, more positive aspects of caregiving, and who participated in a greater variety and total number of services for a longer period of time were significantly more likely to report that services kept their loved one with dementia at home longer than caregivers who did not.

Bivariate analyses also indicate significant differences in healthcare outcomes among those who used different services. Respondents who participated in care consultations and respite services were significantly more likely to report that services delayed institutionalization of their care recipient as compared to those who didn't use those services. Participants in educational programs were significantly less likely to report ED visits for their care recipient during the previous six (6) months compared to caregivers who did not participate in education programs.

In multivariate regression analyses that examined service participation as a predictor of nursing home placement delay while controlling for a variety of caregiver and caregiving characteristics,⁵ greater service use, in terms of duration of service use, extent of participation, and participating in a greater number of different services, all predicted nursing home placement delay. In addition, participation in care consultations, respite, education, and joint enrichment were each predictive of nursing home placement delay. In addition, the person with dementia having Medicaid, greater caregiver burden, greater perceptions of positive aspects of caregiving, and living with the person with dementia also significantly predicted nursing home placement delay.

Summary

Evaluation results indicate the ADCSI has contributed to reducing costs by delaying nursing home placement for initiative participants. Notably, half of caregiver survey respondents reported that they felt that ADCSI services helped keep their loved one at home longer. Based on estimates derived from survey findings and ADCSI service utilization, the estimated nursing home cost savings due to delay in nursing home placement is in excess of \$2 billion across the first five years of the initiative. This translates to an estimated savings of \$17.7 for each dollar invested in the initiative over the five years.

Not surprisingly, the evaluation results indicate that ADCSI services are more likely to lead to better healthcare utilization outcomes among highly burdened caregivers, such as those reporting greater perceived caregiver burden and those living with their care recipient.

Evaluation results provide evidence of the effectiveness of utilization of ADCSI services in reducing healthcare utilization. Caregivers who participated in more variety and longer duration of services reported better healthcare utilization outcomes for their care recipient, including delayed nursing home

⁵ Variables controlled for included caregiver age, gender, race, self-rated health, relationship to person with dementia, length of time and hours per week spent caregiving, living arrangement, Medicaid status, caregiver burden, and perceptions of positive aspects of caregiving.

placement, fewer ED visits, and fewer hospitalizations, than caregivers who used fewer services for shorter time periods. In analyses that controlled for the effects of caregiver burden and other caregiver and caregiving characteristics, greater use of ADCSI services (greater number and variety of services and longer duration) was significantly predictive of reported nursing home placement delay. These findings highlight the impact of ADCSI services in helping caregivers keep their loved one at home longer.

While the ADCSI has reached a tremendous number of caregivers, a relatively small proportion (approximately 14.3%) of caregivers participate in services at levels that more conclusively predict nursing home placement delay. While lower levels of participation may also have important benefits, encouraging greater participation in ADCSI services will likely lead to greater realization of better healthcare utilization outcomes and greater cost savings for New York State.

The flexibility of the services provided by the ADCSI, allowed service providers to tailor services to the needs of caregivers and people with dementia and resulted in caregivers accessing a variable array of different services. Findings from the caregiver survey suggest that care consultations, respite, education services, and joint enrichment provided the most benefit in terms of delaying nursing home placement. This in turn brought cost savings to the state. In the future, linking Medicare, Medicaid or SPARCS data to caregivers and persons with dementia participating in services may provide a better opportunity to analyze the impact of services on healthcare cost.

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Appendix – Methodological Details

Caregiver Survey:

To better understand the utilization patterns and the impact of services on participants, caregivers who participated in programs and services funded through the NYS ADCSI between January 2018 and July 2019 were invited to participate in a questionnaire via Survey Monkey, an online survey and data management tool. The survey was sent to all caregivers with known e-mail addresses, approximately 22,500 caregivers. A total of 1,866 current and previous caregivers completed the survey and were included in the analyses reported here. Statistical analyses of survey data was conducted using SPSS.

Survey participants were mostly female (80%) and Caucasian (78%) with an average age of 65. Approximately 25% of respondents reported an annual household income of less than \$50,000. Over one in five (22.7%) current caregivers provided assistance to someone on Medicaid. The majority of respondents resided in either New York City (30.3%) or Northeastern New York (23.8%); however, caregivers from 57 out of the 62 counties are represented in the survey data.

Respondents were equally likely to be providing care to a parent (44%) or to a spouse or partner (43.6%) with dementia. Approximately 44.3% of current caregivers provided 40 or more hours of care per week and 62.3% indicated that they are caring for a friend or family member with middle stage or moderate dementia.