

New York State Alzheimer’s Disease Caregiver Support Initiative

Final Evaluation Report 2 for the Period 2015-2020: Effects on Caregiver Health and Well-Being

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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 initiative aimed to provide both equitable distribution of services throughout the entire state and to increase access to evidence-based culturally competent support services to underserved (racial, ethnic, LGBTQ and rural) populations.

The Alzheimer’s Disease Caregiver Support Initiative was designed based on research demonstrating that an array of support services leads to improved caregiver outcomes. Therefore, one of ADCSI’s goals was to improve caregiver health and well-being. The three grant programs focused on community support and education funded 24 organizations through 26 contracts to make evidence-based services for caregivers available across the state. These services included an array of core services, including consultation services, support groups, education and training, respite and a 24-hour helpline, and additional services provided by some organizations.

The University at Albany School of Public Health conducted a comprehensive evaluation of the ADCSI for the period of January 2016 to May 2021^a in collaboration with NYSDOH. Two goals of the evaluation were to assess the impact of ADCSI services on *access* to support services and on *caregiver outcomes*. This evaluation report focuses on those goals, and presents findings related to access to caregiver services across NYS, including reach to members of underserved communities, benefits of services to caregivers, and caregiver well-being.

Impacts of Caregiving on the Caregiver and Person with Dementia

An estimated 410,000 individuals in New York State are living with Alzheimer’s Disease or another related dementia (AD/D).^{1,2} Alzheimer’s disease and other dementias pose a great financial and social toll not only on the person with dementia, but also on family caregivers, employers, and the healthcare system. Over half a million family caregivers provide 774 million hours of unpaid assistance in New York annually, valued at \$14.6 billion.³ Higher healthcare costs for caregivers as compared to non-caregivers amount to an extra \$881 million of healthcare spending in New York State alone.⁴

Caring for someone with dementia has psychological, social, health and financial impacts. A recent study of dementia caregiving in the U.S. showed that caregivers of people with dementia (PWD) experience higher levels of depression, anxiety and stress when compared to other caregivers.⁵ Approximately 30 percent of caregivers in this study reported high levels of physical strain, which can lead to injuries and other health problems. High burden, stress and physical strain significantly impact health outcomes, and declining health status, sleep

^a 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.

disturbances, compromised immune function and increased mortality among dementia caregivers have been documented in caregiving research. Caregivers have also reported positive outcomes from caring for someone with dementia, including self-efficacy, fulfillment, and positive family relationships.⁶ In addition to emotional and physical health impacts, caring for someone with dementia has financial consequences: almost 20 percent of caregivers of PWD report high financial strain, often due to the cost of care and loss of income and/or employment for both the caregiver and the PWD.⁷

Benefits of Caregiver Interventions

Compelling evidence indicates that multicomponent psychoeducational caregiver support services that are flexible and tailored to the needs of the caregiver and the person with dementia result in the best outcomes.^{8,9} A meta-analysis conducted by the U.S. Preventive Services Task Force found that non-pharmacologic interventions for caregivers and/or caregiver and person with dementia dyads improved caregiver burden and depression.¹⁰ A number of systematic reviews support those findings, indicating that psychoeducational interventions for caregivers of people with dementia can help enhance caregiver quality of life, improve self-efficacy, and reduce anxiety, stress and burden.^{11,12} These types of support services that improve caregiver well-being have also been found to delay nursing home placement for the person with dementia.¹³

ADCSI Structure and Services Provided

The ADCSI was based on a large body of empirical evidence, accumulated over 20 years, demonstrating the effectiveness of interventions for caregivers in reducing caregiver stress and burden and other negative outcomes. The ADCSI translated this evidence into a scalable public health approach to make evidence-based caregiver support services available across New York State. Three distinct ADCSI grant programs focused on community support and education for caregivers and people with dementia. The Regional Caregiver Support Initiative funded ten contracts to organizations to provide the core services of care consultation, support groups, education and training programs, respite, and outreach and community awareness activities, plus an additional service of their choice (e.g. caregiver wellness programs, joint enrichment opportunities, care support teams, technology-based services, and others). The Alzheimer's Community Assistance Programs funded one contract to a statewide coalition to provide the core services of care consultation, support groups, caregiver education, training for professionals and other community leaders, outreach and community awareness activities, and a 24-hour helpline. The Caregiver Support Initiative for Underserved Communities funded 15 smaller contracts that provided for intake assessment and outreach and community awareness activities, plus one or more of the following: support groups, education and training programs, caregiver wellness programs, joint enrichment programs. About sixty percent of contractors provided these services in Spanish as well as English, and several contractors also provided services in a variety of other languages, including Chinese, Russian, Italian, Haitian Creole, French, Yiddish, and Korean.

Consultation services include care consultations, family consultations, and intake assessments, all of which have a focus on care planning and linkages to clinical and community services. Ninety percent of ADCSI contractors provided a flexible number of assessments or care consultations based on caregivers' needs. In addition, nearly all contractors also provided a variety of other, regular supportive contacts with caregivers, such as telephone or email check-ins, or reminders of upcoming programs.

Caregiver support groups provide emotional support, information, resources, and a platform for caregivers to share strategies and lessons learned with other caregivers of persons with dementia. Support groups were conducted in person, virtually and/or via telephone, and all support groups transitioned to a remote format in Spring 2020 because of the COVID-19 pandemic. Eighty percent of ADCSI contractors offered drop-in, ongoing support groups, while about 60% of contractors offered support groups with a defined number of sessions. Support groups were often designed for specific audiences. Half of ADCSI contractors offered support groups for

spouses/partners; other support groups were designed for adult children, young adults, male caregivers, LGBTQ caregivers, early-stage dementia (for both caregivers and PWDs), middle/late-stage dementia, and young onset dementia. All contractors offered open forum support groups, and about half also offered topical or curriculum-based support groups.

The most common optional services were caregiver wellness programs and joint enrichment opportunities which bring together people with dementia and their caregivers in a safe, supportive environment. Joint enrichment activities included participation in choral, art appreciation and literary groups, trips to sites of historical or cultural interest or Memory/Alzheimer’s Cafes.

ADCSI Evaluation Data Sources

To evaluate the impact of these ADCSI services on caregiver outcomes, the following data sources were used:

- Quarterly progress reports were submitted by each funded agency that included service goals and objectives, detailed data on number of service units provided and number of caregivers participating in each service, and lessons learned. Five years of quarterly reports were used for this evaluation.
- Information on demographic characteristics, caregiving background, and diagnosis-related information was collected from service participants by provider agencies at or near the time of first service use. This voluntary, self-reported information provided data on approximately 25,000 caregivers annually, for an approximate total of 100,000 by the end of this initiative.
- 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 placement 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.

Provision of Caregiver Services across NYS

During the evaluation time period, the ADCSI provided over 1.19 million units of service to caregivers, reaching caregivers in every county of the state. Table 1 details the number of services provided and number of caregivers reached. Although the COVID-19 pandemic impacted the delivery of in-person services, the ADCSI was successfully able to transition to remote delivery of services to continue to provide community support and education services. These remote services in some cases were able to reach caregivers who were not able to access in-person services.

Table 1. ADCSI Community Support Providers – Year 1 to Year 5 Number of Services Provided and Individuals Served				
Service	Number of Service Units Provided	Unique Individuals Served	Duplicated individuals Served	Average Services per caregiver
Care consultation	167,648	74,247	NA	2.3
Support group session	19,126	27,378	93,701	3.4
Education sessions	11,575	56,856	98,095	1.7
Respite	617,120 hours	13,248	NA	46.6 hours/per caregiver
Helpline calls	117,311	62,701	NA	1.9
Joint enrichment events	3,387	13,760	35,181	2.6

Approximately two-thirds of caregivers self-reported some demographic information to service providers, although response rates for each item varied from 82% to 24%. The majority of caregivers who participated in this data collection were female (76.6%) and white (74.7%), with an average age of 63. Most were family members, typically either a spouse/partner (32%) or a daughter/son (52.2%). Almost half (48.8%) reported a household income of less than \$50,000 annually, with 45.7% being retired and 34.3% working full time. About half (50.4%) provided care for 40 hours or more per week, and just over half (53.5%) lived with the person they assist. Most (81.7%) caregivers experienced moderate to high levels of stress and more than half (56.6%) reported moderate to high levels of physical strain.

As compared to a national sample of dementia caregivers (See Table 2), ADCSI caregivers tended to be older, more likely to be female, more likely to be a spouse, slightly more likely to be of lower income, and slightly more likely to be more educated. Because evidence indicates that older caregivers, spouse caregivers, and caregivers of lower income are more likely to experience negative effects of caregiving, this indicates that the ADCSI was effective in reaching vulnerable caregivers.

Table 2: Select Characteristics of Dementia Caregivers Compared to a National Sample	ADCSI	AARP¹⁴ N= 372
Average age of caregivers (N=63,274)	62.7	53.9
Female Gender (N=83,479)	76.6%	58%
Relationship to care receiver (N=38,949)		
Spouse	32.0%	12%
Daughter or son	52.2%	42%
Annual Household Income (N=31,512)		
Less than \$50,000	48.8%	42%
\$50,000 - \$99,999	35.7%	35%
Educational attainment (N=56,478)		
Less than high school degree	2.8%	7%
High school graduate	20.3%	26%
Some college or associate's degree	28.7%	29%
Bachelor's degree or more	48.2%	39%

Reach to Priority Underserved Populations

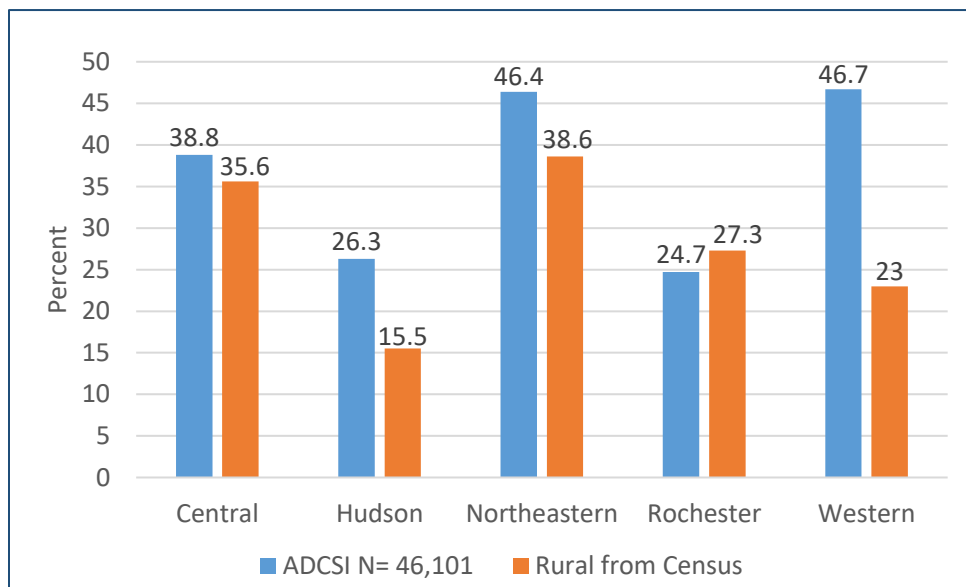
Rural Caregivers

Of caregivers reporting residency status, 10,555 (22%) lived in rural areas. Rural populations were reached at high rates when compared to NYS census data in four out the five ADCSI regions with substantial rural populations. (See Figure 1) Rural caregivers were mostly white (94.6%) with lower levels of formal education, more likely to have a friend or family member helping, and less likely to report very high levels of stress or physical strain than their urban or suburban counterparts. Almost one-quarter (24.1%) of rural caregivers were referred to caregiver support services by another community service organization.

With respect to service utilization:

- A higher percentage of rural caregivers participated in support groups, educational sessions, joint enrichment, and respite services than urban or suburban caregivers.
- Rural caregivers were also more likely to try different services but return less frequently for repeat services than urban caregivers.

Figure 1. Percent of Rural Caregivers by Region Compared to 2010 Census Data¹⁵



Racial and Ethnic Minority Caregivers

Populations reached by the initiative include caregivers who reported over 40 different primary languages and over 20 different religious affiliations. One-quarter of all caregivers reporting race self-identified as Black, Indigenous or a Person of Color (BIPOC). Overall, minority populations were under-represented in the ADCSI caregiver population when compared to the general NYS population (25.3% vs. 30.4%) and to caregivers nationally.¹⁶ However, some regions successfully reached priority underserved racial and ethnic minority populations at rates higher than or comparable to US Census data. For example, in New York City, the majority of caregivers self-identified as non-White (see Figure 2) and providers in the Hudson Valley and Finger Lakes areas reached Black/African American caregivers at rates comparable to those reported in the U.S. Census. The most frequent referral source for support services cited by Black/African American caregivers was healthcare providers (18.1%).

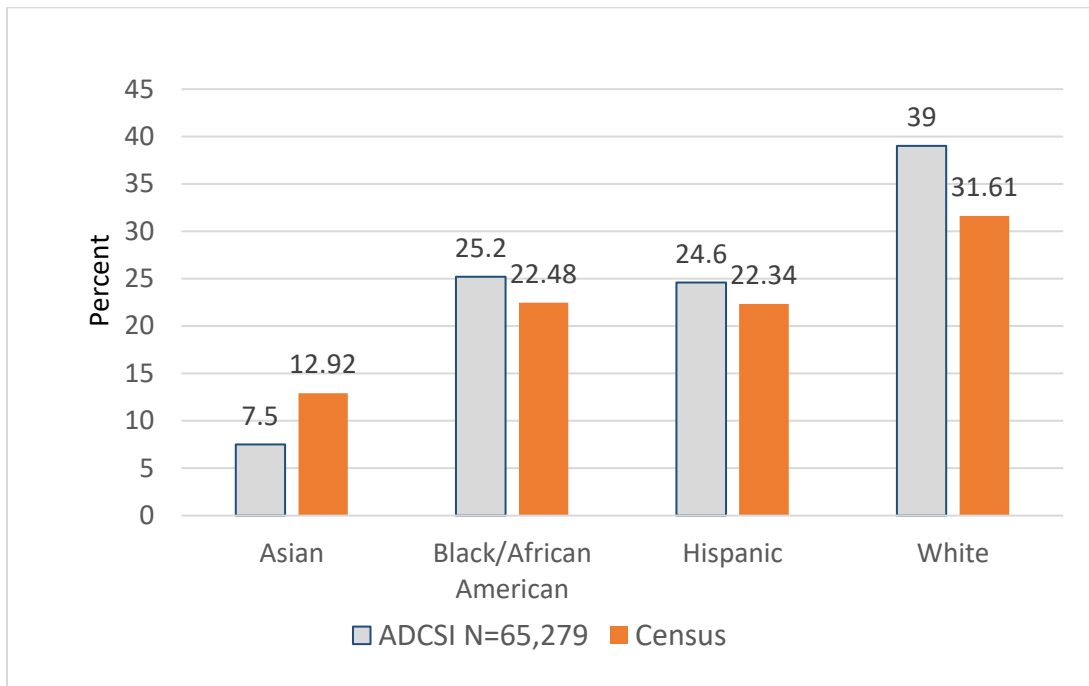
BIPOC (Black, Indigenous and People of Color) caregivers receiving ADCSI services were more likely to be younger (57.4 vs. 63.7 yrs. of age), the primary caregiver (80.2% vs. 74.3%), employed full-time (41.1% vs. 32.3%), and more likely to report annual household incomes of less than \$50,000 (62.8% vs. 44.9%) than white caregivers. BIPOC caregivers reported very high levels of stress (40.7% vs. 28.4%) and physical strain (23.8% vs. 15.5%) compared to their white counterparts.

With respect to service utilization:

- BIPOC caregivers were more likely to participate in care consultations and wellness programs and less likely to participate in support groups and educational sessions than white caregivers.

- On average, BIPOC caregivers participated in more care consultations, wellness programs and respite services than white caregivers.
- Hispanic caregivers were less likely to participate in educational sessions than caregivers of other racial and ethnic backgrounds.

Figure 2. Caregiver Race/Ethnicity Compared to U.S. Census Estimates: NYC¹⁷



LGBTQ caregivers

Almost 3 percent (1,094) of ADCSI caregivers self-identified as LGBTQ. When compared to a national sample (8.3%), LGBTQ caregivers are likely under-represented in the ADCSI.¹⁸ Although LGBTQ caregivers participated in services in all regions, over one quarter (27.7%) of caregivers identifying as LGBTQ were from the NYC region.

Demographic characteristics of LGBTQ caregivers participating in ADCSI services are similar to those from a national sample. As compared to heterosexual caregivers participating in ADCSI services, LGBTQ caregivers were more likely to be male, a son, younger, more racially diverse and report higher stress levels and less likely to be retired, the primary caregiver or live with their care receiver.¹⁹

With respect to service utilization:

- On average LGBTQ caregivers had fewer total contacts and participated in fewer total different services than their heterosexual counterparts.
- LGBTQ caregivers participated in all services less frequently than non-LGBTQ caregivers except for education (64.4% vs. 55.6%).

Outcome: Caregiver Benefits

The sample of caregivers surveyed in 2019 were asked to what extent they perceived experiencing 13 benefits of participating in ADCSI services. Results, presented in Table 3, indicate high levels of perceived benefits. The

most commonly reported benefits related to improved knowledge and skills and increased quality of life for the care recipient. Moreover, more than half of caregivers surveyed reported experiencing at least 8 different benefits.

Table 3: Perceived benefit from participation in caregiver support services	% Respondents who Agreed or Strongly Agreed N = 1507-1539
Increased my knowledge and understanding of Alzheimer’s disease and/or other dementias	84%
Improved my knowledge of caregiver and dementia-related resources and supports	82%
Increased my knowledge and understanding of the caregiving role	82%
Improved my ability to provide care (or made me feel better able to manage this disease)	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%

To examine the relationship between service use and caregiver benefits, multiple regression analyses were used to predict caregiver benefits from level of service use, among current and previous caregivers, while controlling for several covariate variables. Covariates included age, gender, race, self-rated health, relationship to care recipient, length of caregiving, hours per week caregiving, dementia severity, living arrangement, and Medicaid status. Several regression models were run, each using different variables representing service use. These variables were:

- The total number of the six different services used at least once
- The duration of service use
- A summary variable that combined number of different services used with level of participation in each service, referred to below as “level of service participation.”
- Six variables indicating use/nonuse of each service
- Six variables indicated level of participation in each service

Results indicated that greater perceived benefits were significantly associated with (1) the number of different services used, (2) the duration of service use, and (3) greater levels of service participation. In addition, when individual service use was examined, perceived benefits were associated with any use of respite and joint enrichment, and level of participation in respite, wellness, and joint enrichment.

Outcome: Caregiver Burden

Caregiver burden is “a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience.”²⁰ High caregiver burden is associated with a variety of negative outcomes for caregivers and their care recipients, including depression, physical illness, decreased quality of life, and early nursing home placement.²¹ Previous research on the effectiveness of psychosocial interventions for family caregivers of people with dementia has demonstrated small but positive effects on reducing caregiver burden.²²

A widely used, validated measure of caregiver burden is the Zarit Burden Interview (ZBI).²³ The survey of caregivers who participated in ADCSI services included the four-item, short form of the ZBI.²⁴ When compared to caregivers in other intervention studies,²⁵ caregivers who participated in ADCSI services reported relatively higher levels of burden, with 69% scoring higher than the cutoff reported to be associated with probable depression, indicating that the ADCSI was reaching highly burdened caregivers.²⁶

Respondents were also asked to complete the burden scale in relation to the time before they began using services. Such retrospective pre-test measures are a valid evaluation alternative to baseline, pre-intervention measures when true pre-test measures are not available.²⁷ Current after-services burden was significantly lower than the retrospective pre-services burden ($p < .001$), and the size of the difference is consistent with effect sizes seen in other caregiver interventions.^{28,29}

Multiple regression analyses were used to predict both caregiver burden and reported change in caregiver burden from service use, among current caregivers, while controlling for several covariate variables. Covariates included age, gender, race, self-rated health, relationship to care recipient, length of caregiving, hours per week caregiving, dementia severity, living arrangement, and Medicaid status. Several regressions were run, each with the different variables representing service use as described previously.

Results indicated that lower caregiver burden was significantly associated with (1) the number of different services used and (2) greater levels of service participation. In addition, when individual service use was examined, lower burden was associated with any use of respite and joint enrichment, and level of participation in education.

Results indicated that greater reported change in burden was significantly associated with (1) the number of different services used and (2) greater levels of service utilization. In addition, when individual service use was examined, greater change in burden was associated with any use of respite and joint enrichment, and level of participation in education.

Outcome: Positive Aspects of Caregiving

Caregivers can also find their role rewarding and fulfilling, and caregivers who experience these positive aspects experience fewer negative psychological sequelae.³⁰ To examine the relationship between ADCSI service use and positive aspects of caregiving, the caregiver survey included the validated, 7-item Positive Aspects of Caregiving (S-PAC) scale.³¹ Compared to the sample of family caregivers (not only dementia caregivers) with which this scale was validated, ADCSI caregivers, on average, reported fewer positive aspects of caregiving.³²

Multiple regression analyses were used to predict the positive aspects of caregiving measure from service use, among current caregivers, while controlling for several covariate variables. Covariates included age, gender, race, self-rated health, relationship to care recipient, length of caregiving, hours per week caregiving, dementia severity, living arrangement, and Medicaid status. Several regressions were run, each with the different variables representing service use as described previously.

Results indicated that the positive aspects of caregiving were significantly associated with (1) the number of different services used and (2) greater levels of service participation. In addition, when individual service use was examined, greater positive aspects of caregiving was associated with any use of education and joint enrichment, and level of participation in education.

Outcome: Delayed Nursing Home Placement

Nursing home placement delay can only be estimated with self-report.^{33,34} Respondents to the caregiver survey were asked, "In your opinion, did the services you received help keep the person with dementia who you care for living at home longer than if these services were not available?" 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).

Multiple regression analyses were used to predict self-reported nursing home placement delay from service use, among current and previous caregivers, while controlling for several covariate variables. Covariates included age, gender, race, self-rated health, relationship to care recipient, length of caregiving, hours per week caregiving, dementia severity, living arrangement, and Medicaid status. Several regressions were run, each with the different variables representing service use as described previously.

Results indicated that self-reported nursing home placement delay was significantly associated with (1) the number of different services used, (2) duration of service use, and (3) greater levels of service participation. In addition, when individual service use was examined, self-reported nursing home placement delay was associated with any use of care consultations, respite, education and joint enrichment, and level of participation in care consultations, respite, and joint enrichment.

Limitations

A limitation is that the evaluation of these outcomes is based on a survey sample, and not the entire population of caregivers who used ADCSI services. However, survey respondents were largely representative of the overall population of ADCSI caregivers with some minor differences. 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. In addition, 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. Although we can’t extrapolate the exact findings to the entire population of caregivers to draw conclusions, for example, about how much total caregiver burden was reduced due to ADCSI services, the survey sample provides a valid way to examine the relationship between service use and caregiver outcomes.

Summary

During the first five years of the ADCSI initiative covered by this report, the ADCSI provided a substantial and impressive number of community-based caregiver support services and reached a considerable number of caregivers across the state of New York. Moreover, this reach was comprehensive, extending into every county of the state.

The ADCSI was very successful at reaching rural populations throughout the state, and very successful at reaching Black, Indigenous or Person of Color (BIPOC) caregivers especially in New York City. The ADCSI was less successful at reaching BIPOC caregivers in other regions of the state and LGBTQ caregivers, although these populations were represented in the caregivers served by the initiative.

The evaluation of the Alzheimer’s Disease Caregiver Support Initiative indicates that participation in ADCSI services was related to positive caregiver outcomes. Based on a survey of caregiver participants, more perceived benefits of services, reduced caregiver burden, greater positive aspects of caregiving, and self-reported delayed nursing home placement were all significantly associated with use of a greater number of different services and with greater levels of service participation. In addition, perceived benefits and delayed nursing home placement were also significantly associated with duration of service use.

With regard to specific services, this evaluation indicates that respite services and joint enrichment activities may be especially associated with positive caregiver outcomes, although because most ADCSI participants

utilized a variety of services, it is impossible to clearly understand the specific relationship between each type of service and caregiver outcomes.

The consistency of findings across different outcomes and different measures of service utilization leads to the conclusion that ADCSI service use is contributing to positive outcomes among caregivers. Given the reach of this initiative, and the firmly established research evidence linking these caregiver outcomes to physical, psychological, and financial consequences for caregivers and people with dementia, these evaluation results indicate that the ADCSI is positively impacting the lives of caregivers and people with dementia across New York State.

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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.