



# Alzheimer’s Disease Caregiver Support Initiative

## Evaluation Report Year 1

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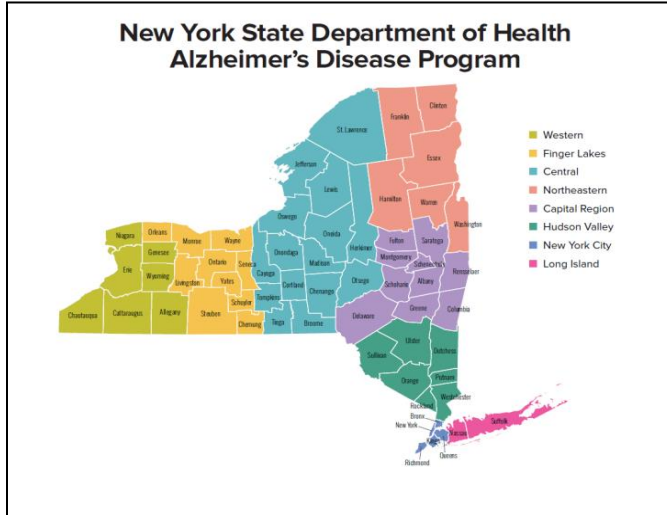
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## Executive Summary

The Alzheimer's Disease Caregiver Support Initiative (ADCSI) is a 5-year grant initiative funded through 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.

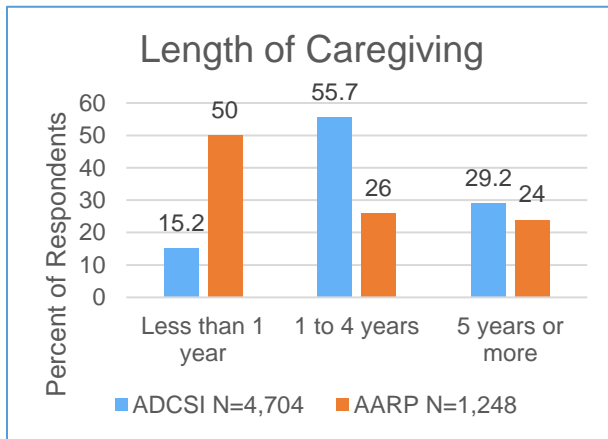
- In addition to providing services to patients, CEADs trained 12,168 students, physicians, and healthcare professionals.
- On average, CEADs exceeded goals for the number of specialty care providers, non-physician providers, and students reached, while falling short in primary care physician training.

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

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.**

## Introduction

The New York State Alzheimer's Disease Caregiver Support Initiative (ADCSI) is a landmark \$25 million investment in community support and health services for people with all forms of dementia and their caregivers.

This edition of the annual evaluation report offers a preliminary review of the first year of the 5-year initiative, including an overview of the initiative, evaluation strategies, and a discussion of implementation experiences and preliminary findings. This report primarily focuses on assessing the reach of the initiative and capacity-building activities accomplished in the first year.

## Alzheimer's Disease and Other Dementias In New York State

Alzheimer's disease, the most common form of dementia, is fatal, and is currently recognized as the sixth leading cause of death in the United States. An estimated 390,000 New Yorkers currently have Alzheimer's disease, a number that is projected to grow to 460,000 by 2025.

Alzheimer's disease and other dementias pose an immense financial and social toll on the person with dementia, family caregivers, employers, and the healthcare system. Over 1 million caregivers provide 1.1 billion hours of unpaid assistance in New York, valued at \$14 billion. Higher healthcare costs for caregivers as compared to non-caregivers amount to an extra \$800 million of healthcare spending.<sup>1</sup>

## Overview: Alzheimer's Disease Caregiver Support Initiative (ADCSI)

The ADCSI is based on an array of evidence dating back to the 1990s on effective interventions to provide community support for people with Alzheimer's disease and other dementias (AD/D), and their caregivers.<sup>2</sup> The ADCSI translates this research into a scalable, public health approach that makes evidence-based services available across New York State. The scope of this initiative is groundbreaking, and will provide services to caregivers at a level unprecedented nationally, making NYS a national leader in dementia support services.

The ADCSI aims to address current issues in dementia care, including the following and more:

- Early and accurate diagnosis
- Caregiver health
- Improved care for people with dementia
- Healthcare utilization costs
- Dementia capable workforce
- Underreporting of Alzheimer's disease
- Disparities in access to dementia care

The ADCSI takes a two-pronged, systems approach to its investment — both focusing on supporting caregivers and people with dementia in their communities, while also enhancing the capacity of medical and healthcare professionals statewide to provide early diagnoses, quality care management, and linkages to community support.

### Community Support and Education

#### Grant Programs

- Regional Caregiver Support
- Alzheimer's Community Assistance
- Caregiver Support for Underserved Communities

#### Core Services

- Care consultations and assessments
- Support groups
- Education
- Respite
- 24 hour helpline

### Diagnostics and Professional Training

#### Grant Program

- Centers of Excellence for Alzheimer's Disease

#### Core Services

- Diagnosis and assessment
- Care management
- Medical provider training
- Promotion of clinical trials

## ADCSI Grant Projects

The ADCSI funds four grant projects, three of which provide an infrastructure of community support and education for caregivers and people with dementia. These projects provide a set of overlapping core services, including consultation services, support groups, education and training, respite and a 24-hour helpline. Additional services are provided by each grant project, as detailed below. The fourth grant project, the Centers of Excellence for Alzheimer’s Disease, enhances the medical and healthcare community’s ability to provide early and accurate diagnoses, facilitates care management and linkages to community services, and trains professionals.

### Regional Caregiver Support Initiative

Total Funding: \$15 million

Number of Contracts: 10 regional contracts annually funded at \$1.5 million each

#### Project Description and Goals:

This grant project aims to improve the overall well-being and quality of life for people with AD/D and their caregivers, and is focused on regional distribution of evidence-based caregiver services throughout all eight regions of the state (see Figure 1).

Long term objectives include: development and sustainability of an innovative array of support services; improved coordination of and access to new and existing support services; expansion and enhanced access to respite services; improved health and well-being of caregivers and individuals with AD/D; and delayed institutionalization of diagnosed individuals.

#### Services

- Care Consultation and Family Consultation
- Support Groups
- Education and Training Programs
- Respite
- Additional Evidence-Based Support Service (selected from the following):
  - Access services
  - Caregiver companion
  - Care support teams
  - Caregiver wellness programs
  - Environmental skill-building
  - Joint enrichment opportunities
  - Technology-based services
- Outreach/Community Awareness

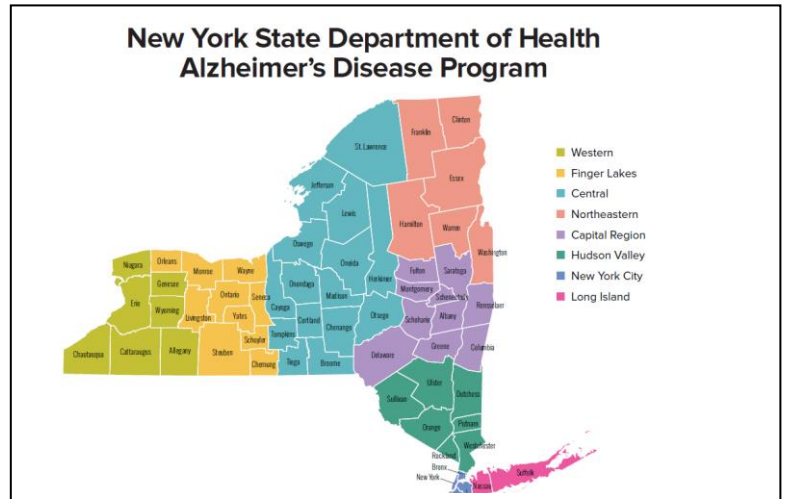


Figure 1: New York State Alzheimer’s Disease Program

The following organizations were awarded contracts for a 5-year period:

Agency	Region
Alzheimer’s Association, Central New York Chapter	Central New York
Alzheimer’s Association, Hudson Valley Chapter	Hudson Valley
Catholic Charities of Buffalo	Western New York

Lifespan of Greater Rochester, Inc.	Finger Lakes
New York University School of Medicine	New York City
Northeast Health Foundation, Inc.	Capital District
Parker Jewish Institute for Health and Rehabilitation	Long Island
Presbyterian Senior Services, Inc.	New York City
Research Foundation for SUNY Plattsburgh	Northeastern New York
Sunnyside Community Services, Inc.	New York City

***Alzheimer’s Community Assistance Program***

Total Funding: \$5 million annually

Number of Contracts: 1 contract to an agency capable of delivering statewide services

Project Description and Goals:

This project aims to provide quality support services to people with dementia and their caregivers throughout New York State on a 24-hour basis. This grant also focuses on furthering the goal to become a dementia-capable New York State by training key constituencies across the state, targeting dementia care professionals, community gatekeepers, and faith leaders.

Services

- Care Consultation
- Support Groups
- Caregiver Education
- Training for Professionals, Gatekeepers, and Faith Leaders
- 24-hour Helpline
- Outreach/Community Awareness

The Alzheimer’s Association, NYS Coalition was awarded a contract for a 5-year period and subcontracted the following chapters and agencies to provide service coverage throughout all regions of the state:

Alzheimer’s Association, Capital Region Chapter
Alzheimer’s Association, Central New York Chapter
Alzheimer’s Association, Hudson Valley Chapter
Alzheimer’s Association, Long Island Chapter
Alzheimer’s Association, New York City Chapter
Alzheimer’s Association, Rochester and Finger Lakes Chapter
Alzheimer’s Association, Western New York Chapter
CaringKind, New York City

***Caregiver Support Initiative for Underserved Communities***

Total Funding: \$1.5 million

Number of Contracts: 15 contracts annually funded at \$100,000 each

Project Description and Goals:

The goal of this grant project is to fund innovative models to reach caregivers of individuals with Alzheimer’s disease and other dementias, either or both of whom are members of underserved communities, by recognizing and addressing the need for culturally competent support initiatives and stress reduction strategies.



Services

- Intake Assessment
- One or more of the following:
  - Caregiver support groups
  - Education and training programs
  - Caregiver wellness programs
  - Joint enrichment programs
- Outreach/Community Awareness

The following organizations were awarded contracts for a 5-year period.

<b>Agency</b>	<b>Communities</b>	<b>Region</b>
Alzheimer’s Association, Hudson Valley Chapter	Hispanic/Latino, African American	Hudson Valley
Alzheimer’s Association, Rochester and Finger Lakes Chapter	African American	Finger Lakes
CaringKind	Various (Queens)	New York City
Chautauqua Opportunities, Inc.	Rural Poor, Hispanic/Latino	Western New York
Family and Children’s Association	African American, Hispanic/Latino	Long Island
Jamaica Service Program for Older Adults, Inc.	Hispanic/Latino, African American, Various (Queens)	New York City
Jewish Community Center of Staten Island	Hispanic/Latino, African American, Various (Staten Island)	New York City
Lutheran Home of Central New York	Rural isolated	Central New York
New York Memory Center, Inc.	Various (Brooklyn)	New York City
Pride Center of Western New York, Inc.	LGBTQ	Western New York
Regional Aid for Interim Need, Inc.	Hispanic/Latino	New York City
Resource Center for Independent Living, Inc.	Rural isolated	Capital Region
Riverstone Senior Life Services	Various (N. Manhattan)	New York City
Sunnyside Community Services, Inc.	Hispanic/Latino	New York City
Syracuse University	African American	Central New York

***Centers of Excellence for Alzheimer’s Disease (CEAD)***

Total Funding: \$4.7 million

Number of Contracts: 10 contracts annually funded at \$470,000 each

Project Description and Goals:

The CEADs are responsible for medical services for the diagnosis, management, and treatment of individuals with AD/D; support and referral of patients and their caregivers to community services; and

expanding the healthcare system’s capability by training providers and students on the detection, diagnosis, and treatment of AD/D. Centers of Excellence are also collaboratively developing and implementing a training module to educate health care providers and coroners on the accurate depiction of AD/D cause of death on death certificates.

Services

- Diagnosis and assessment
- Patient care management
- Medical provider training
- Community referrals

The following institutions were awarded contracts for a 5-year period:

Agency	Region
Albany Medical College	Central New York
Columbia University School of Medicine	New York City
Glens Falls Hospital	Northeastern New York
Montefiore Health System	Hudson Valley
New York University School of Medicine	New York City
SUNY at Buffalo	Western New York
SUNY at Downstate Medical Center	New York City
SUNY at Stony Brook	Long Island
SUNY at Upstate Medical University	Central New York
University of Rochester	Finger Lakes

### **ADCSI Statewide Evaluation Design**

A comprehensive, statewide, multi-level evaluation of this initiative is being carried out by researchers at the School of Public Health, University at Albany, State University of New York in collaboration with the New York State Department of Health. This evaluation will examine the process and outcomes of the initiative, with an emphasis on how New York State has changed as a result. In addition to documenting the effect of these expanded caregiver support services on a variety of patient, caregiver, and health system outcomes, the evaluation will significantly contribute to the national evidence base related to AD/D support services, and generate important evidence for future programmatic and policy decisions at both the state and national levels.

The broad, overall evaluation goals include:

1. To document the statewide implementation of the ADCSI in terms of the type and extent of services provided and utilized, the population served, and the costs associated with implementation;
2. To examine the fidelity and impact of implementation of evidence-based caregiver support services; and
3. To document the outcomes and impact of the ADCSI on individuals with dementia and their caregivers, on organizations providing Alzheimer’s support services, and on New York State. Outcomes to be considered are avoidable emergency department visits, unnecessary hospitalizations, and nursing home placement, as well as caregiver stress and burden, and caregiver physical and mental health outcomes.

## RE-AIM Evaluation Framework

The evaluation is guided by the RE-AIM evaluation framework, which is designed to shape comprehensive evaluations of public health projects, and to understand the public health impact of projects that translate research into practice.<sup>3</sup> According to this framework, understanding the full impact of a project requires examining the following five different domains:

Reach	The extent to which the intended population is reached
Effectiveness	The impact on key outcomes
Adoption	The extent to which programs are adopted
Implementation	The extent to which programs are implemented as intended or designed, and the characteristics of implementation, such as costs
Maintenance	The sustainability of changes over time

The evaluation questions to be addressed within each domain are as follows:

**Reach:** Who is ADCSI reaching? Are they representative of the NYS population? Are they representative of caregivers? Is the target audience being reached?

**Effectiveness:** What is the impact on important outcomes: health care utilization, caregiver outcomes, time to diagnosis, organizational outcomes?

**Adoption:** Are physicians adopting recommended screening practices? What influences contractors' decisions to adopt certain programs or services?

**Implementation:** What programs and services are delivered? Are they implemented as intended? What are lessons learned for contractors and NYS?

**Maintenance:** What is sustained and institutionalized? Is there enhanced capacity at organizations and in the state? Is there policy change?

## Methods and Data Sources

This evaluation utilizes a mixed methods approach and incorporates both quantitative and qualitative data from a variety of sources, as follows:

- Information collected by providers from clients and patients
- Information collected by providers from health care provider training participants
- Information collected directly from providers in work plans, progress reports, and periodic survey assessments
- Available data, such as data from the Behavioral Risk Factor Surveillance System, the NYS Medicaid Data Warehouse and the U.S. Census. Data from the American Community Survey 2011-2015 Estimates for individuals aged 45+ are used for regional comparisons.

- Site visit reports prepared by NYSDOH ADCSI grant managers

In order to evaluate the reach of the ADCSI, in Year 1 providers collected voluntary, self-reported demographic, caregiving background and diagnosis-related information from caregivers receiving core services. Providers' ability to initiate data collection, management and reporting varied, and often depended on factors outside of individual grantee control. Due to delays in funding, some programs were not immediately operational. The selection and development of appropriate data management systems to collect the demographic data was also a key factor in achieving capability. By mid-year, most community support providers had initiated demographic data collection from caregivers. Data collected between April 1, 2016 to March 31, 2017 is included in this report, although for many providers, this only includes a partial year of data.

Twenty-five (25) community support providers and three (3) CEAD providers provided demographic data on 30,409 informal caregivers who participated in data collection.

### **Ancillary Projects**

The evaluation of the ADCSI also includes ancillary projects on specific topics of interest. The first such project focused on the special issues that employed caregivers face when trying to balance the demands of work and caregiving, and identified programs and policies that facilitate caregivers' efforts to balance work and caregiving. The results of this project are included in this report.

### **Limitations**

Some limitations to the information contained in this report must be acknowledged. First, it's possible there is some duplication among the numbers reported here because of caregivers served by multiple programs. Second, because data collection from caregivers began partway through year one, and because participation in data collection was not required in order for caregivers to receive services, response rates are somewhat low, and naturally varied across providers and across individual questions among those who participated. Among caregivers who participated in data collection, response rates for individual sociodemographic questions ranged from 72.5% (gender) to 17.4% (religious affiliation). Approximately 15% (range 13.1 to 16.6%) of caregivers responded to caregiver background questions (hours per week spent caregiving, length of caregiving, primary caregiving status, etc.). Finally, while this evaluation documents the experience of this initiative, there is no comparison group of organizations and caregivers not receiving services. This limits the ability to draw causal conclusions.

### **Time Frame Covered in this Report**

The New York State Department of Health (NYSDOH) began funding each of the four grant projects at slightly different times. Because of these different start dates, each grant project follows a different reporting period schedule. This report reflects the following time frames:

- Alzheimer's Community Assistance Program – April 1, 2016 to March 31, 2017
- Regional Caregiver Support Initiative – January 1, 2016 to December 31, 2016
- Caregiver Support for Underserved Communities – March 1, 2016 to February 28, 2017
- Centers for Excellence in Alzheimer's Disease - March 1, 2016 to February 28, 2017

## The Implementation Experience

For Year 1, evaluation of the implementation of ADCSI focused on providers' perspectives and experiences with program start up. Information related to these topics was collected directly from providers in work plans, progress reports, and periodic surveys.

### Staffing

All providers created new staff positions either fully or partially funded through this initiative: 186 new staff positions were fully funded and 78 were partially funded. The number of new fully-funded positions ranged from 1 to 18 for individual organizations, while the number of new partially-funded staff positions ranged from 1 to 9 per organization. At the end of Year 1, about a third (39%) reported not having adequate staff to support the required activities. Similarly, one-third of providers (34%) reported not having adequate staff to support the demand for their programs and services from their client population. A shortage of staff to serve diverse and underserved populations and densely populated areas was highlighted, as was a need for outreach managers and medical providers (such as neurologists, geriatric psychiatrists, and social workers). Several providers reported that the need for staffing increased as awareness among the community grew.

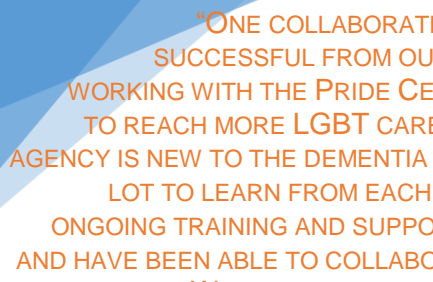
Nearly all providers (79%) experienced challenges in staffing the project or in hiring new staff. The most common challenge was a lack of applicants with experience related to dementia. Other common challenges included:

Staffing/Hiring Challenges	% of Providers Experiencing
Lack of applicants with experience in dementia	39
Staff turnover	37
Lack of applicants with desired qualifications	34
Salary insufficient to attract qualified staff	26
Staffing issues at partner agencies	18

To overcome staffing challenges, more than half of providers revised their staffing plans, about a third revised staff workloads and a few providers increased salaries. Other strategies to overcome staffing challenges included in-house professional development and training, sending staff to attend training programs to improve knowledge and skills, and utilizing volunteers.

### Partnerships

Almost all providers developed new partnerships with other organizations as part of this initiative, with 92% of providers reporting informal partnerships, and 59% reporting formal relationships, characterized by a contract or other written agreement. All partnerships involved delivery of services and referrals, and two-thirds of partnerships involved staff training and partnerships involved shared facility use, which enabled providers to offer programming at a number of new sites, ranging from two to more than 100.



“ONE COLLABORATION THAT HAS BEEN SUCCESSFUL FROM OUR POINT OF VIEW IS WORKING WITH THE PRIDE CENTER. WE WANTED TO REACH MORE LGBT CAREGIVERS AND THEIR AGENCY IS NEW TO THE DEMENTIA FIELD SO WE HAD A LOT TO LEARN FROM EACH OTHER. WE OFFER ONGOING TRAINING AND SUPPORT TO THEIR STAFF AND HAVE BEEN ABLE TO COLLABORATE ON MULTIPLE PROGRAMS. WE HAVE A REALLY POSITIVE WORKING RELATIONSHIP AND ARE WORKING TOGETHER TO RECRUIT PARTICIPANTS, ADDRESS CHALLENGES WITH ATTENDANCE, AND SHARE KNOWLEDGE.”

The most important factors in choosing partner organizations were:

- the target audience of the partner organization
- common organizational goals or similar missions
- the location of the partner organization
- history of previous collaboration

Almost all providers reported benefitting from these partnerships. Common benefits included:

- Mutual support and decreased duplication leading to enhanced services available
- More opportunities for outreach and engagement
- Sharing best practices
- Meeting organization's mission and goals
- Increased referrals
- Increased awareness for all agencies involved
- Enhancement of services available
- Formation of long-term and trustworthy relationships

Only a quarter of providers reported negative outcomes from partnerships:

- Duplication of services and competition among providers
- Partners not meeting deliverables

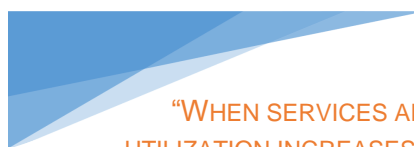
## **Service Delivery**

Not surprisingly, providers experienced challenges in implementing and delivering services during the first year. Participant recruitment and reaching the target audience were the most common barriers reported. Other service delivery challenges and the percent of providers experiencing them are indicated below:

<b>Program Implementation and Delivery Challenges</b>	<b>% Experiencing</b>
Participant recruitment	46
Reaching target audience	43
Staff hiring	30
Staff retention	25
Lack of capacity to accept new referrals	20
Lack of demand for specific services	20
Finding appropriate locations for programs	14
Capacity to open/operate necessary satellite locations	14
Offering sufficient programs to meet demand	8
Staff training	5

As the year progressed, providers reported that outreach efforts (e.g., door-to-door postcards; community presentations; advertising; language accessible care consultations; and on-site care assessments at partner facilities) were beginning to result in increased numbers of individuals seeking these services. As community awareness of services grows, demand for services is expected to increase.

Specific implementation barriers, and strategies used to address them also varied by type of service, as demonstrated in Table 1.



“WHEN SERVICES ARE PUBLICIZED, UTILIZATION INCREASES. WE HAVE TO BALANCE PUBLIC AWARENESS EFFORTS WITH WHAT CAN BE DELIVERED ...WE COULD PROVIDE MORE PROGRAMMING WITH INCREASED FUNDING.”

**Table 1: Service-Specific Implementation Barriers and Strategies**

Service	Implementation Barriers	Implementation Strategies
<b>Consultation Services</b>	<ul style="list-style-type: none"> <li>• Lack of family members to participate in family care consultations</li> <li>• Individuals not self-identifying as caregivers</li> <li>• Limited interest in services</li> </ul>	<ul style="list-style-type: none"> <li>• Hiring and training culturally competent, qualified staff</li> <li>• Sub-contracting out services</li> <li>• Developing partnerships with other community-based organizations for referrals</li> <li>• Adding care consultation sites at traditionally underserved locations</li> </ul>
<b>Support Groups</b>	<ul style="list-style-type: none"> <li>• Recruitment of volunteer facilitators and locations, especially in rural and underserved communities</li> <li>• Consistency of attendance by participants</li> <li>• Engagement of underserved populations</li> <li>• Participant time constraints</li> </ul>	<ul style="list-style-type: none"> <li>• Collaborations between providers to train support group facilitators</li> <li>• Engagement of a Spanish speaking community leader to co-facilitate a support group</li> <li>• Spanish speaking support groups</li> <li>• Support groups that provide healthcare tips</li> <li>• Telephone support groups</li> <li>• Support groups in traditionally underserved communities</li> </ul>
<b>Educational Programs</b>	<ul style="list-style-type: none"> <li>• Difficulty in securing host locations for educational events</li> <li>• Lack of participants at specific locations</li> <li>• Caregiver time constraints</li> </ul>	<ul style="list-style-type: none"> <li>• Collaboration with partners to host educational events</li> <li>• Virtual educational options</li> <li>• Trainings for millennials</li> <li>• Implementation of webinars and other web-based educational opportunities</li> </ul>
<b>Respite</b>	<ul style="list-style-type: none"> <li>• Lack of respite partners, especially in rural areas</li> <li>• Lack of trained home health aides</li> <li>• Time constraints (to recruit/train respite volunteers and to match care recipients with appropriate volunteers)</li> <li>• Agency volunteer requirements</li> <li>• Lack of understanding about respite</li> <li>• Some caregivers appeared intimidated by the scholarship process</li> <li>• Medicaid/MLTC restrictions limited caregivers' ability to access respite for stress reducing rather than employment or health-care related activities</li> </ul>	<ul style="list-style-type: none"> <li>• Meet with respite providers to brainstorm solutions to barriers</li> <li>• Expand recruitment of volunteers and respite providers</li> <li>• Modify hours/schedules for respite care and training</li> <li>• Reorganize staff workloads to prioritize respite coordination</li> <li>• Increase outreach and education to families about respite, respite scholarships and Medicaid reimbursement options</li> <li>• NYSDOH grant management policy changes to allow consumer directed model of respite care in response to respite provider shortages</li> </ul>
<b>Promotion of Clinical Trials</b>	<ul style="list-style-type: none"> <li>• Lack of clinical trial availability in service area</li> </ul>	<ul style="list-style-type: none"> <li>• Standardization of promotional materials</li> <li>• Playing an educational video about clinical trials in the waiting room</li> <li>• Provide a listing of available trials</li> </ul>

## Funding

A little over half of all providers (59%) reported that the funding received through ADCSI is sufficient to meet their goals, while 41% report that funding is insufficient. Providers funded through the Regional Caregiver Support and the Caregiver Support for Underserved Communities programs appeared to be more likely to report that their funding was sufficient. One-third have been able to leverage funds to acquire other sources of funding. For example, several providers have been successful at securing funding from private foundations to enhance and expand their ADCSI-funded work. Similarly, two providers feel that the ADCSI funding has brought greater attention to certain services and as a result, has enhanced their ability to secure additional individual donations to support these services.

## How Did ADCSI Serve New York State in Year One?

### Community Support and Education

While the first year of the ADCSI was marked by capacity building efforts – including building program infrastructure, training and hiring staff – New York State still saw extensive community support services for caregivers and people with dementia. This section of the report focuses on the set of core community support services, while a later section details the clinical services provided by the Centers of Excellence.

Capacity to initiate service delivery varied across grant projects and individual agencies. Delays in processing some contracts impeded staff hiring and training until the agreements were finalized. Most providers started offering caregiver services by summer 2016.

The total number of core services provided statewide and the total numbers of individuals served is presented in Table 2. These numbers are compared with the initial Year 1 goals set by providers in their work plans.

Service	Number	Goal for Services Provided *	% of Service Goal	Individuals Reached	Goal for Individuals Reached*	% of Reach Goal	Average number of service per individual
Consultation Services	20,389	29,219	69.8%	6,234	6,959	82.2%	3.27
Support Group Sessions	3,217	4,327	74.4%	5,174	2,939	176%	4.33
Educational sessions	1,770	3,181	55.6%	12,803	9,082	141%	1.50
Respite (hours)	49,897	233,547	21.4%	1,188	2,580	44.4%	42 hours
Helpline calls	23,505	22,650	103.8%	12,596	11,129**	88.2%	1.86

\* Goals set by providers represent rough projections based on much smaller grant projects; these may require adjustment in future years. \*\* Not all contractors provided a goal for reach for this service.

### Consultation Services

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. To an extent, consultation service details and structure varied across grant projects and across agencies. The most common service, care consultations, are provided by trained professionals to the caregiver and other



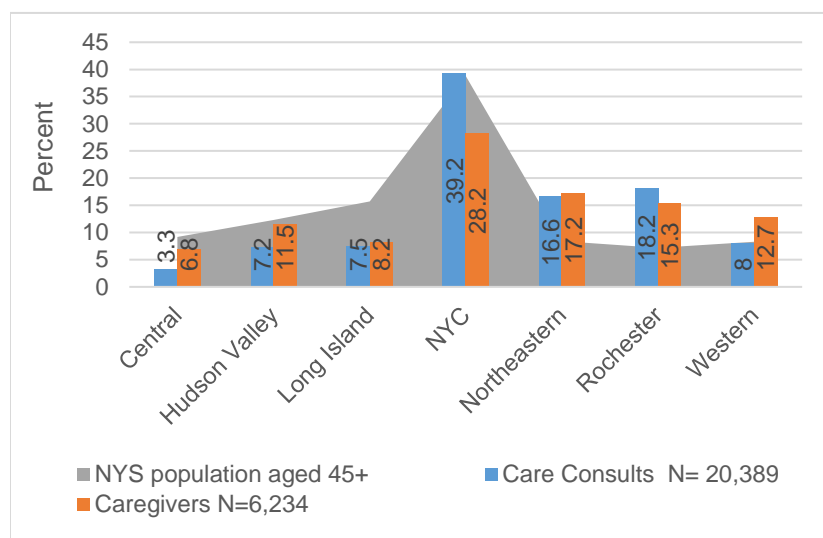
family members, incorporating personalized assessment, service plan development, trouble-shooting and periodic updates.

During the first year, **20,389 consultation services** were provided to **6,234 individuals and families for an average of 3.27 consultations** per caregiver unit. An additional 1,180 individuals accessed an online tool, Alzheimer’s Navigator®, to help them identify their needs and develop an action plan, similar to the care consultation process.

Some differences in ability of each grant project to provide care consultations were observed. The Alzheimer’s Community Assistance Program, a pre-existing program that scaled to greater size under the grant, surpassed its annual goal for number of consultation services, while new providers funded by the other two projects reported lower than anticipated numbers of care consultations. Much of the variation between providers may be attributed to delays in program start up and lag times in funding distribution. New providers also reported requiring additional time to build infrastructure and organizational capacity to start delivery of program services, spending the first quarter recruiting, hiring, and training qualified staff to conduct care consultations and other dementia-specific program services. New providers also reported devoting time and energy during the first quarters to establishing agreements, policies and protocols with

partners, sub-providers and host site locations before initiating service delivery.

**Figure 2: Distribution of consultations by region compared to estimates of NYS population aged 45 and over**



Source for population data: U.S. Census Bureau, 2011-2015 American Community Survey 5-year Estimates.

To better understand the regional reach of consultation services, the percent of care consultations and caregivers served in each region were compared to each region’s proportion of the NYS population aged 45 and over. Population estimates for each region were derived from the 2011-2015 American Community Survey 5-year estimates (U.S. Census).<sup>4</sup> The population aged 45 and older was selected for comparison because the majority (90%) of caregivers served under this initiative fall into that age category.

As illustrated in Figure 2, this preliminary analysis indicates that providers in the Northeastern New York, Rochester-Finger Lakes region, and Western New York areas were able to reach higher percentages of caregivers when compared to the overall percent of the NYS population for that region. For example, the Northeastern NY region contains just under 10% of the NYS population aged 45+, yet that region provided 16.6% of the total care consults and served 17.2% of the total caregivers receiving care consults.

### Support Groups

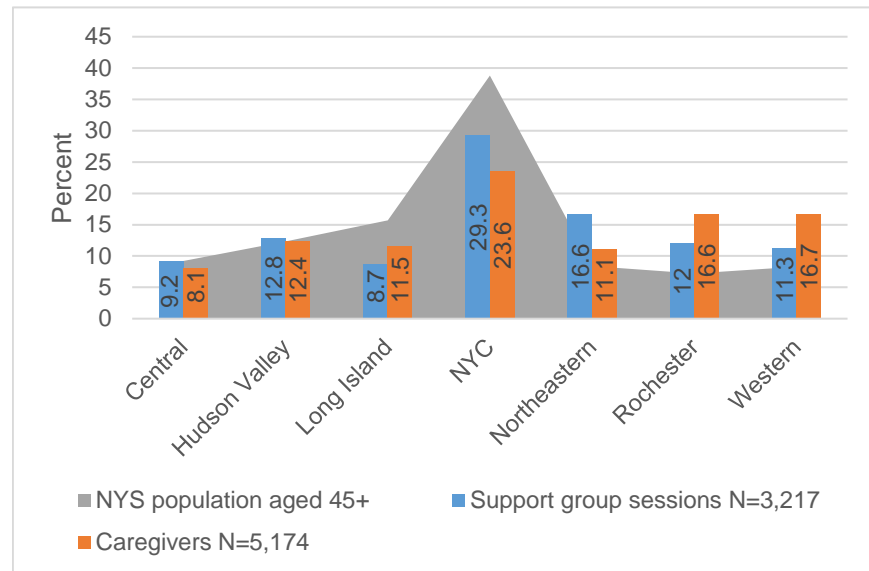
Caregiver support groups provide emotional support, information, resources, and a platform for caregivers to share strategies and lessons learned with other caregivers of persons with dementia. Support groups are conducted in person, virtually and/or via telephone and are designed to meet the

specific needs of the communities to be served, including considerations of culture and language, and time of day the groups are offered.

Providers served **5,174 individuals with 3,217 new and expanded support group sessions**. On average, **participants attended 4.33 support group sessions each**, and the average number of participants per session was 7. The initiative also provided support to an additional 3,070 caregivers and people with dementia through the online community at ALZConnected®.

Comparison of regional support group implementation and caregiver participation with American Community Survey population estimates suggests a more favorable distribution of services and reach in upstate and less populated regions of the state, compared to New York City and Long Island, as illustrated in Figure 3. For example, the Western region, which accounts for just under 10% of the NYS 45+ population, accounted for 11.3% of the support group session provided and 16.7% of the caregivers served by support groups.

**Figure 3: Distribution of support group sessions by region compared to estimates of NYS population aged 45 and over**



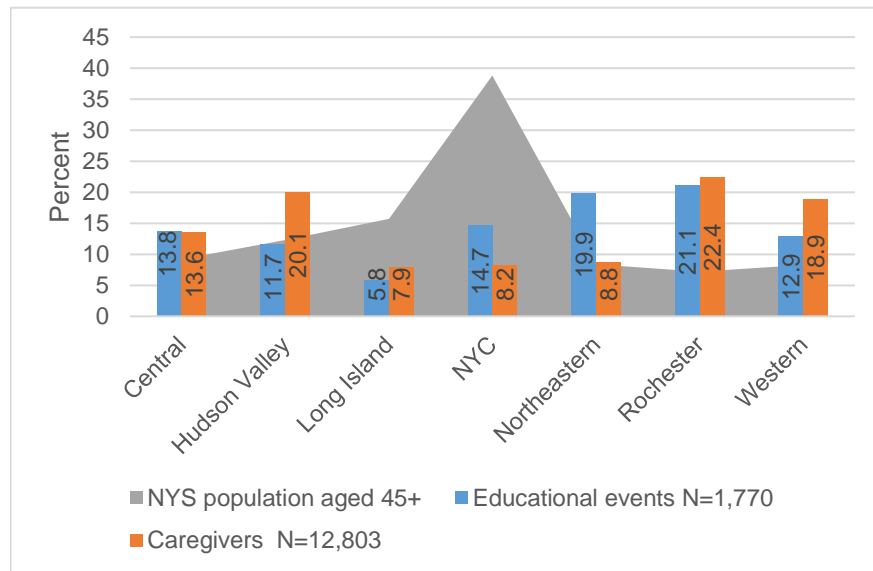
Source for population data: U.S. Census Bureau, 2011-2015 American Community Survey 5-year Estimates.

### Education and Training Programs

Education and training programs provide necessary knowledge and information to enable caregivers to navigate through the progression of AD/D and to better prepare for their role. These programs are on a range of topics, which include, but are not limited to, AD/D and its progression, behavior management strategies and interventions, coping skills, resource availability, and caregiver wellness.

Across the state, providers delivered **1,770 educational sessions**, the majority of which were conducted in small in-person settings, **averaging approximately 11 participants each**. Providers also organized 19 large conferences reaching 2,267 caregivers. **A total of 12,803 caregivers and people with dementia were reached through educational programs**, averaging 1.5 sessions attended per individual served. Another 667 individuals enrolled in the online EssentiALZ® Care program that trains caregivers to provide high-quality care to their care recipients. Community support providers successfully met most annual

**Figure 4: Distribution of educational sessions by region compared to estimates of NYS population aged 45 and over**



Source for population data: U.S. Census Bureau, 2011-2015 American Community Survey 5-year Estimates.

education objectives. In general, providers attained greater than expected reach for educational programs in fewer sessions than originally planned.

Comparison of regional education session offerings and caregiver participation with NYS population estimates indicates regional variation as illustrated in Figure 4. Namely, education and training programs reached proportionately more caregivers in all of New York except Long Island and New York City. Two educational programs help explain these differences in reach. First, all regions

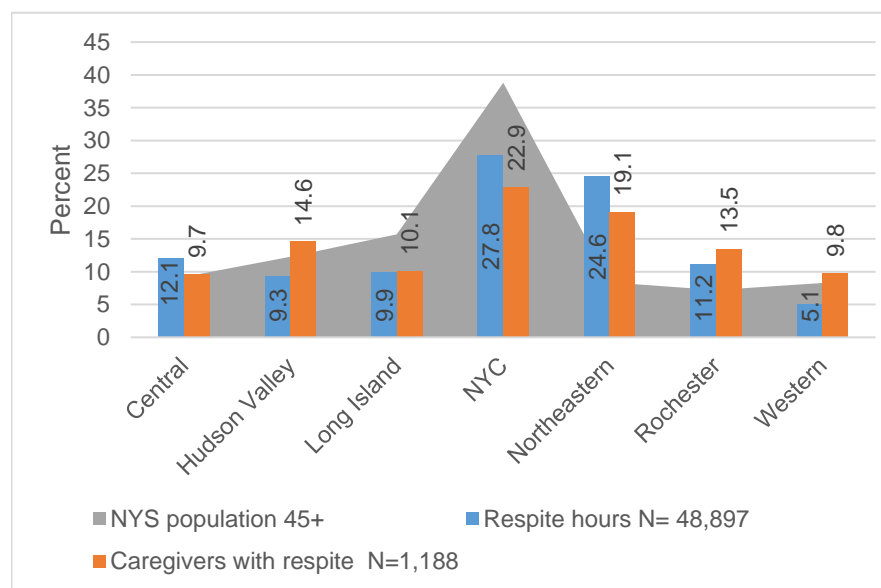
except New York City held a large caregiver conference during the reporting period which significantly impacted overall reach. Second, Western New York provided training through the online program EssentiAlz® which expanded reach considerably.

## Respite

Respite provides short-term relief to caregivers by offering a temporary reprieve from caregiving duties. Respite is intended to strengthen the family system while protecting the health and well-being of both the caregiver and care recipient. In this initiative, respite can be provided through home care, adult day programs, short-term residential care, or community-based volunteer respite programs.

Providers offered **49,897 hours of respite care to 1,188 caregivers for an average of 42 hours of respite per caregiver**. An additional 156 caregivers received referrals to respite services. The majority of

**Figure 5: Distribution of respite services by region compared to estimates of NYS population aged 45 and over**



Source for population data: U.S. Census Bureau, 2011-2015 American Community Survey 5-year Estimates.

caregivers (56.2%) received in-home respite care. Approximately 22% of care recipients attended social adult day respite services and another 13% received medical adult day services. A small portion of caregivers received volunteer, consumer directed, and overnight respite hours at assisted living or nursing home facilities. Regional comparisons, illustrated in Figure 5, again show that reach of respite services was comparatively greater in certain regions, namely Northeastern NY and Rochester-Finger Lakes.

### 24-hour Helpline

As a part of the Alzheimer’s Community Assistance Program, the Alzheimer’s Association and Caring Kind provide 24 hour, 7 day a week helpline services to individuals affected by dementia and their caregivers. During Year 1, providers responded to **23,505 helpline calls serving 12,596 individuals, for an average of 1.86 calls per caller.** The reach of helpline call services was comparatively greater in the Central New York, Long island, Rochester and Western New York regions as compared to other regions of the state.

### Additional Services

Joint enrichment opportunities help reduce isolation by bringing together people with AD/D and their caregivers in a safe, supportive environment. Activities might include participation in choral, art appreciation and literary groups, trips to sites of historical or cultural interest or Memory/Alzheimer’s Cafes.

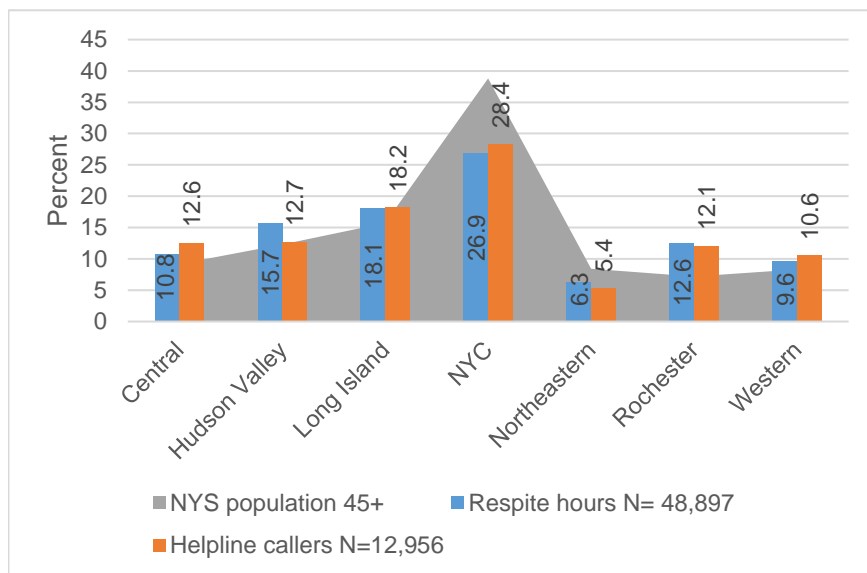
Providers hosted approximately **250 social engagement and joint enrichment activities for 2,751 caregivers and individuals with dementia.** Average participation was just over 11 individuals per event. Individuals attended an average of 1.64 events, with a range of 1 to 37 events during the reporting period.

Regional Caregiver providers also offered a number of unique services to meet the needs of individuals and families affected by dementia. Programs were developed and offered based on identified gap areas and contractor resources. New and expanded services offered by some providers included caregiver wellness programs, companion services, care support teams, peer mentoring, transportation, and technology assistance. A total of 983 individuals accessed these services. Another 132 individuals accessed safety programs, such as Medic Alert ® and Safe Return. In addition, beyond delivering direct services to caregivers and individuals with dementia, the **Initiative for Underserved Communities provided 1,014 referrals to partner organizations** for more in-depth services.

Another objective of ADCSI is to expand education and dementia care training to other important constituencies, such as professional caregivers, first responders, organizational gatekeepers, faith-based organizations, and other community-based partners. The Alzheimer’s Community Assistance Program provided the majority of this training. In sum, these professional trainings included:

- 296 in-person and online educational sessions included 4,450 professional providers

**Figure 6: Distribution of helpline calls by region compared to estimates of NYS population aged 45 and over**



Source for population data: U.S. Census Bureau, 2011-2015 American Community Survey 5-year Estimates.

- 373 first responders participated in on-line dementia care training
- 103 educational programs reached 1,950 gatekeepers to services at community-based organizations across the state
- 34 educational events were held with 243 faith-based leaders
- 3,504 individuals were reached through 83 dementia education sessions provided to faith-based congregations
- 63 dementia education programs were held with 851 members of traditionally underserved communities
- 179 program managers were trained on Connect2Culture®, a program to help cultural organizations develop activities for people with dementia and their caregivers.

## Community Awareness

Providers expended significant effort toward increasing awareness of Alzheimer’s disease and dementia during Year 1. Providers developed and implemented both active and passive outreach activities to reach target populations. Altogether, providers implemented **3,219 active events reaching 89,939 individuals**.

- 56% of these individuals were reached through 757 health fairs and other community gatherings
- 20,871 individuals were reached with over 1,000 community/mixed educational programs and events
- 1,000 outreach events reached 8,459 physicians and other healthcare professionals

A few providers specifically reported outreach to diverse communities, and over 9,000 individuals from diverse communities were reached through 329 outreach activities. Another 74 outreach activities were conducted in Spanish, with total attendance of 631.

Providers also engaged in a wide variety of passive outreach activities. Providers reported a significant media footprint using both traditional and social media, as illustrated in Table 3.

Other passive outreach activities included:

- Almost 1,200 advertisements posted on billboards and public transportation
- More than 235,000 posters and brochures distributed
- 169,596 newsletters disseminated
- 195,795 e-mail subscribers received updates and information about dementia programs and services

In total these media activities are estimated to have led to a total of approximately 100 million media impressions, defined as any interaction between a piece of content and an audience member.

<b>Table 3: Community awareness activities</b>	
<b>Traditional Media</b>	<b>Spots (PSAs/Ads)</b>
Television	2,702
Radio spots	2,351
Television interviews	18
Radio interviews	26
Press releases	161
Newspaper articles	354
<b>Social Media</b>	<b>Posts</b>
Facebook	13,000
Twitter	3,009
Other social media	195
<b>Total</b>	<b>21,816</b>

## Clinical Services and Professional Training

This next section of the report focuses on clinical services and professional training provided by the Centers of Excellence for Alzheimer's Disease (CEADs).

<b>Table 4: Centers of Excellence diagnostic and patient care services</b>			
<b>Services</b>	<b>Total Individuals Reached</b>	<b>Work plan Goal</b>	<b>% of Goal</b>
Diagnostic Process			
New Diagnostic Assessments	5,076	4,885	103.9%
Referrals Received from providers	5,058	3,785	133.6%
Patients and caregiver consultations to review diagnostic assessment	6,737	4,885	137.9%
Primary care provider consultations	5,621	4,465	125.9%
Patient Management and Care			
Care Plans Developed	5,880	4,400	133.6%
Care Consultations	4,044	4,365	92.6%
Total referrals made to community services	18,359	14,850	123.6%
Clinical Trial information	1,949	724	269.2%

Ten CEADs were solicited to start in the first year. However, the procurement process resulted in 6 CEADs receiving funding as of March 2016 and 3 additional not commencing until July 2016. A CEAD serving the Northeastern New York Region was not identified until Year 2 so this report only includes data from the 9 CEADs that were operational between March 1, 2016 and February 28, 2017.

### ***Diagnostic Process***

CEADs performed **new diagnostic assessments** on patients residing in **98% of designated counties** throughout the state. A number of CEADs reported providing services to patients outside of their designated coverage area, including individuals residing in other CEAD designated cover areas; individuals from areas without a CEAD, such as the North Country; and out-of-state patients.

The **average number of patient assessments per CEAD was 564, with a range of 152 to 983**. Most CEADs conduct the new patient assessments directly, but a few partner with primary care and specialty care practices to conduct assessments at locations throughout the region.

**The majority (60.2%) of referrals to CEADs for diagnostic assessments came from primary care providers.** Referrals were received from every county in the state except one – Schuyler county.

Once a patient assessment is complete, CEAD staff meet with patients and their family members and/or caregivers to review the results. A main focus of these consultations is to promote an integrative approach that provides support to persons with dementia and their caregivers. During the reporting period, CEAD staff conducted **6,737 consultations with patients and their family members** and/or caregivers to review the results of the diagnostic assessments. CEADs also provided **5,621 consultations to primary care providers** regarding the care and management of their patients with AD/D.

## ***Patient Management and Care***

CEADs developed **5,880 care plans for individuals diagnosed with AD/D** to promote access to a comprehensive and coordinated array of health care and support services that meet the patient's specific needs. The average number of care plans completed by CEADs was 653 (range 152-1,476).

A key role of the CEAD is to review the care plan with individuals diagnosed with dementia and their caregivers. In year 1, CEAD staff provided **4,044 initial care consultations** to review the CEAD assessment and discuss specific recommendations for services and supports. As a part of this process, CEADs provided **18,359 referrals to various service providers** across the state. All regions and over 90 counties received referrals from the CEADs. The majority of CEADs reported on referrals for common services such as home care, adult day programs, skilled nursing care, support groups or to specific organizations providing support to caregivers.

CEADs also followed-up with patients or caregivers and community providers to ensure that care plan recommendations and referrals were completed. However, over 50% of CEAD providers reported challenges to follow-up with community providers. Reported barriers include:

- HIPAA regulations and strict confidentiality policies that prohibited providers from sharing client information with CEAD providers
- Variations among providers as to best practices for patient care and follow-up
- Difficulty reaching primary care physicians in a timely manner

Dementia care management requires periodic evaluation and revision of the care plan as the disease progresses and patient circumstances change. CEADs noted that as patients and caregivers become more aware of needs and available services, many have become more proactive in requesting revisions to their care plans.

CEADs also provide technical assistance to community-based medical providers regarding the diagnosis, treatment, disease progression and palliative care of patients with dementia. Reported challenges for providing technical assistance include:

- the comprehensive nature of the care plans and evaluations provided to community-based partners limited the need for additional technical assistance;
- lack of appropriate mechanisms to track requests for technical assistance, especially informal ones;
- lack of a clear definition of what technical assistance consists of and to whom it is provided; and
- an overestimation of primary care physician (PCP) receptiveness to this service.

Finally, as part of patient care management, CEADs play an essential role in promoting the benefits of and encouraging participation in clinical trials. During the year, CEADs **promoted clinical trials to almost 2,000 individuals**. One CEAD reported that the lack of available clinical trials in its service area was a barrier to promotional activities.

## ***Training and Education***

A priority for the CEADs during year 1 was to conduct outreach with healthcare providers, focusing on the importance of:

- early diagnosis and the role of the CEAD in this process
- assessing the physical, emotional and behavioral well-being of caregivers

In total, **CEADs disseminated information on these two topics to 4,768 healthcare and affiliated providers**. CEADs adopted a variety of outreach strategies to promote these messages, including direct mail marketing, group events, one-on-one communications, and academic detailing. Over one-third of the healthcare professionals reached were primary care providers and another 20% were medical specialists.

Outreach activities also targeted other healthcare and affiliated professionals, including emergency department staff, discharge nurses, social workers and case managers.

The majority of outreach was targeted to professionals affiliated with healthcare organizations, including hospitals, private practices and community health centers. Some CEADs expanded outreach activities to include senior centers, libraries, faith-based institutions and other community-based organizations. A few CEADs reported adapting their outreach strategies to increase efficiencies by targeting larger practices rather than individual providers. One promising practice noted by CEADs was to partner with community service providers on outreach activities.

Another key objective was to provide training to primary and specialty care physicians, non-physician providers, and students in medical or health professions.

<b>Table 5: Centers of Excellence professional trainings</b>			
<b>Trainings</b>	<b>Total Individuals Reached</b>	<b>Work plan goal</b>	<b>% of goal</b>
<b>Education programs to physicians</b>	309	173	178.6
Primary Care Physicians (PCPs) trained	1,487	2,560	58.1
Specialty Care Physicians trained	2,036	1,594	127.7
<b>Education programs to non-physician health care providers</b>	221	116	190.5
Non-physician HC providers trained	3,178	2,550	124.6
<b>Education programs to students</b>	193	109	177.1
Medical students trained	3,770	2,119	177.9
Health Professions students trained	1,697	1,725	98.4

Note: CEADs did not consistently submit data on type of physicians, and non-physicians trained.

### **Physicians**

During the year, CEAD providers provided **333 educational programs to 1,274 primary care physicians and over 2,000 specialty care physicians**. Grand Rounds and professional lectures constituted the majority of educational sessions. In addition, another 373 physicians were reached through web-based programming.

On average, CEADs exceeded goals for the number of events and the number of specialty care providers reached while falling short (53.67%) of the goal of reaching over 2,500 primary care physicians. Delays in staff on-boarding due to contract delays, clinician time constraints, competing priorities, and weather challenges in rural regions were identified as the primary challenges to meeting this goal.

CEAD providers have identified a number of promising practices to increase efficiencies and expand reach. One-third of CEADs have increased accessibility of educational offerings through distance-based activities, including webinars, teleconferencing, and on-demand educational programs. CEADs reported implementing the following strategies to expand access:

- telehealth sessions from “Project ECHO” incorporated into weekly educational offerings
- medical education webinars recorded and posted on YouTube and iTunes University
- collaboration and cross-training with other CEADs and community support providers



In addition to these educational offerings, CEADs began to collaborate on the development of a curriculum for death certificate training.

### ***Non-physician Health Care Providers***

CEADs provided **221 trainings and educational programs to 3,178 non-physician healthcare providers** who care for patients with dementia and their caregivers within their designated regions.

Approximately 24% of training participants were social workers, 18% were nurses, and another 10% were nurse practitioners or physician assistants. The remaining 48% of participants were allied health professionals such as home health aides, nutritionists, pharmacists, mental health counselors, and physical therapists.

Efforts of note to reach non-physician healthcare professionals include the following collaborations:

- NYS Office of Mental Health
- NYS Department of Corrections
- non-physician professional associations

Efforts of note include the following strategies:

- formalize relationships with non-physician professional organizations
- develop agreements to provide training at health-profession programs at colleges and universities
- provide continuing education credits to nurses and social workers

### ***Medical and Health Professional Students***

During the year, CEADs provided **193 educational programs to 3,770 medical students and 1,697 students in other health professions**. Most student education was provided in Grand Round formats and professional lecture series. CEADs reported educating a wide variety of students involved in dementia care including psychiatry interns, pharmacy residents, and dental residents. One highlight was a collaboration between several CEADs and community support providers to develop, record and post presentations on areas of subject matter expertise. CEADs reported other longer-term efforts to institutionalize educational efforts. Discussions with internal and external partners are ongoing to develop formal curriculum, educational programs and internships for health professions students.

### ***Underserved Communities***

A priority for the ADCSI is to reach underserved communities to raise awareness of AD/D, the importance of screening and early diagnosis, the benefits of participation in clinical trials, and the role of the CEAD. In Year 1, the CEADs implemented **200 activities that reached 2,700 individuals in underserved communities**. CEADs partnered with community support providers to conduct outreach to rural, limited English proficiency, and other traditionally underserved populations. Providers noted that collaborating with caregiver providers enabled them to exceed Year 1 goals for this objective. In addition to in-person community awareness events, providers reported making 77 contacts with health reporters, issuing 18 press releases, and designing new websites to publicize CEAD services. Three CEADs reported a total of 7,097 website hits in Year 1.

## Who was Reached by ADCSI in Year One?

A main objective of the ADCSI is to provide equal access to services to all individuals and families affected by dementia across the state. To better understand whether ADCSI is meeting this objective, the demographic information voluntarily provided by caregivers was compared to 2011-2015 American Community Survey (ACS) 5-year estimates published by the U.S. Census Bureau. This data provided an opportunity to evaluate the reach of the initiative both regionally and statewide by comparing characteristics of caregivers served with characteristics of the NYS population.

Similarly, caregivers served by this initiative were compared with a national sample of caregivers. The AARP 2015 Caregiving in the U.S. Report provides a profile of unpaid family caregivers in the United States, based on a national study of caregivers conducted by The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute in 2014.<sup>5</sup> This national caregiver sample represents all informal caregivers, not just those caring for someone with dementia.

**It should be noted that because of the limitations due to missing data, comparisons of the ADCSI Year 1 caregiver population with NYS and national caregiver populations are only preliminary and conclusions should not be drawn.**

### Caregiver Demographic Characteristics

The caregivers described in this section are all informal caregivers – that is, families, friends and neighbors that help provide unpaid care to an individual with dementia. In Year 1, 30,409 caregivers participated in some voluntary data collection. However, as detailed on page 9, response rates varied widely by individual item.

**The majority (76.6%) of caregivers providing demographic data self-identified as female. The average age of caregivers was 63.3 years old (range 10 to over 100 years of age). Almost half (48.5%) of caregivers seeking services were 65 or older.**

**Age and Gender:** As expected, caregivers served by the ADCSI tended to be older as compared to the general NYS population. ADCSI caregivers and care recipients also tended to be older than the national sample of informal caregivers. Females are also overrepresented, even when compared to caregivers nationally.

**Table 6: Caregiver age and gender characteristics compared to a national sample of caregivers**

Caregiver Characteristic	Statewide Caregiver Initiative	AARP 2015 Caregiver Sample
<b>Age</b>	N=15,569	N=1,248
Average age of caregivers	63.3	49.2
Average age of care recipients	80.2	69.4
<b>Gender of Caregiver</b>	N= 22,060	
Female	76.6 %	60 %
Male	23.3 %	40 %
Transgender	< 1	Not available

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S. and ADCSI data.

**Relationship to Care Recipient:** 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. Nationally, 42% of respondents in the 2015 AARP study provided care to their parents compared to 50% of ADCSI caregivers, and nationally, spouses and partners also represented a smaller proportion of caregivers. However, further analysis of the national data indicates that as caregiver age rises, the care recipient is more likely to be a spouse, at frequencies similar to the NYS data.

**Employment Status:** A majority of ADCSI caregivers were either retired (45%) or unemployed (10%). One-third reported working full-time. Nationally, caregivers were more likely to be employed (60%) compared to caregivers seeking services in NYS (44.6%).

A majority (60%) of respondents in the 2015 AARP study indicated caregiving had impacted their employment in some form or fashion compared to 34% of caregivers (n=3,629) receiving services in NYS. In the ADCSI, 45.7% of employed caregivers (N=1,513) reported impacts to their employment. Of those whose employment was impacted, cutting back on hours at work was the most frequent impact cited by caregivers (27.9%) compared to 14% in the national study. Among the national sample of caregivers, among those whose work was impacted, almost 50% indicated that taking time off or flexing job hours were the most common job impacts due to caregiving.

**Education:** Caregivers receiving services reported high levels of educational attainment, with over 40% having a bachelor's degree or higher. On average, caregivers reported higher educational attainment when compared to the general NYS population and to the national sample of caregivers.

**Table 7: Caregiver relationship to care recipient compared to a national sample of caregivers**

Relationship	ADCSI	AARP
	N=9,207	N=1,248
Daughter or son	50.2 %	42.0%
Spouse or partner	30.7 %	12.0 %
Sibling	3.5 %	3.0 %
In-law	5.6 %	9.0 %
Grandchild	1.8 %	7.0 %
Other relatives	4.5 %	12.0 %
Non-relative (friend, neighbor, etc.)	3.7 %	15.0 %

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S. and ADCSI data.

**Table 8: Caregiver employment status compared to a national sample of caregivers**

Employment Status	ADCSI	AARP
(N=6,101)	N=6,101	N=1,248
Full Time	33.4%	60%
Part Time/Temporary	11.2%	
Retired	44.6%	
Student	0.7%	
Unemployed	9.7%	

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S and ADCSI Data.

For all regions, except Long Island, caregivers receiving services had higher levels of education as compared to the NYS population. Long Island providers reached a higher percentage of individuals with high school diplomas (41.5%) as compared to the NYS population (26.9%).

**Income:** While services were provided to individuals from all income levels, approximately half of caregivers (50.5%) reported an annual household income of less than \$50,000. This represents a higher percentage than the NYS populations overall, but is similar to the national sample of caregivers.

Providers in all regions of the state consistently served a higher percentage of lower-income caregivers as compared to ACS data. See Appendix 2 for detailed regional data.

**Table 9: Caregiver level of education compared to New York Census data and a national sample of caregivers**

Education Level of Caregiver	ADCSI	ACS NYS	AARP
	N= 13,036		N=1,248
Less than high school	2.9%	14.4%	8.0 %
High school graduate	24.6%	26.7%	28.0 %
Some college, associate's degree or technical school	28.6%	24.7%	30.0 %
Bachelor's degree	22.0%	19.4%	20.0 %
Post/professional degree	21.9%	14.8%	15.0 %

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S; U.S. Census Bureau, American Community Survey 2011-2015 Estimates; and ADCSI data.

**Table 10: Caregiver income compared to New York Census data and a national sample of caregivers**

Annual Household Income	ADCSI	ACS NYS	AARP 2015
	N= 6,098*		N=1,248
Less than \$50,000	50.5%	43.3%	47%
\$50,000 - \$99,999	33.4%	28.3%	30%
\$100,000 +	14.7%	28.4%	23%

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S; U.S. Census Bureau, American Community Survey 2011-2015 Estimates; and ADCSI Data.

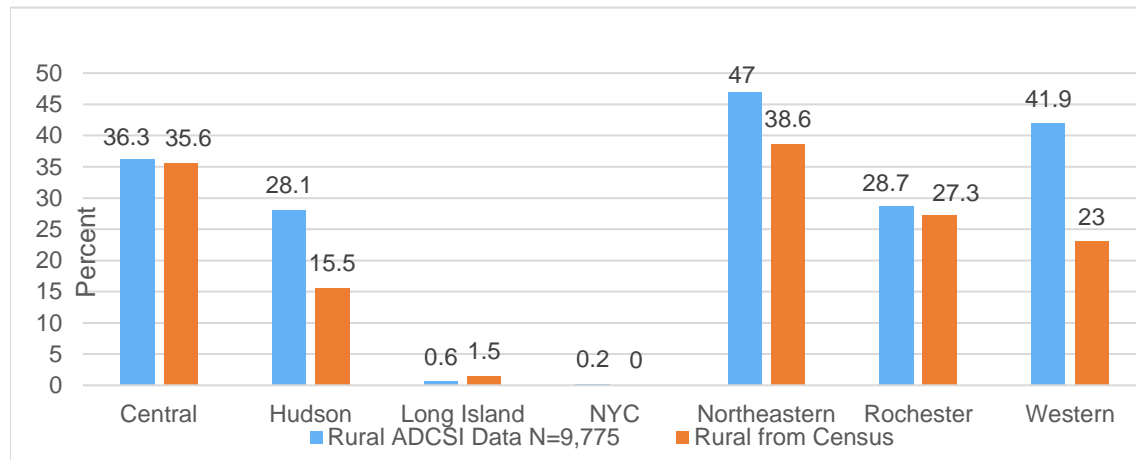
\*Note: 86 caregivers reported other categories not included here

## Underserved Populations

A key aspect of ADCSI is to conduct outreach to traditionally underserved caregiver groups. Priority underserved populations during Year 1 included geographic, ethnic, religious and/or linguistically isolated caregiver populations, as well as African-American, Hispanic and LGBTQ caregivers.

**Rural Residence:** New York is a geographically diverse state, which can create significant challenges for the delivery of services to individuals and their families affected by dementia. Sixty-five percent of caregivers who participated in data collection identified the geographic characteristics of their place of residence. Over 50% of these caregivers reported living in urban settings, 30.8% in suburban areas, and 17.2% in rural locations. Sixteen percent of caregivers in the national study were from rural areas compared 17% reported in the New York State caregiver data.

**Figure 7: Percent of Rural Caregivers Compared to 2010 Census Data**



Data sources: ADCSI Data and U.S. Census Bureau, 2010 Census data.<sup>6</sup>

As indicated by the graph, the ADCSI was effective in reaching rural caregivers. When compared to the 2010 Census, community service providers in the Hudson Valley, Northeastern New York and Western New York were particularly successful in reaching this target population.

**Race:** Over 50% of caregivers who participated in data collection provided demographic information about their race or ethnicity. Most of these caregivers described themselves as White or Caucasian (76.5%). The available data suggests that minority populations were underrepresented when compared to the general NYS population and to caregivers nationally.

Regionally, providers demonstrated success in reaching diverse populations. Data from the Central New York, Hudson Valley, and New York City regions indicate that a

**Table 11: Race/Ethnicity of Caregivers Compared to national samples of caregivers**

Race/Ethnicity	ADCSI	ACS NYS	AARP 2015
	N=16,141		N=1,248
American Indian/Alaskan Native	0.4%	0.4%	^
Asian	2.3%	8.0%	6%
Black/African American	10.9%	15.6%	13%
Native Hawaiian/Other Pacific Islander	0.0%	0.0%	^
Other*	1.8%	11.4%	2%
White/Caucasian	76.5%	64.6%	62%
Hispanic	8.1%	18.4%	17%

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.; U.S. Census Bureau, American Community Survey 2011-2015 Estimates; and ADCSI Data. Notes:

\* Other includes multi-racial, bi-racial and Hispanic is a separate category in the ACS data.

similar or slightly higher percentage of non-white populations are being reached through this initiative when compared to NYS data. In particular, Blacks/African Americans accessed services at slightly higher rates in these areas. Demographic data suggests that lower than expected percentages of caregivers from Asian or Hispanic backgrounds accessed services in all regions of the state when compared to the Census data. Again, this data is viewed with caution as race/ethnicity categories do not exactly align across the two data sources. See Appendix 2 for detailed regional data.

**Language:** Almost 95% of caregivers indicated that English was their primary or preferred language, while Spanish (3.4%) and Chinese (1%) were identified as the other most frequently primary or preferred languages. However, caregivers reported 26 different primary or preferred languages, including Greek, Haitian-Creole, Korean and Russian.

**Religious Preference:** Religion and/or spiritual beliefs are important for some individuals and may influence care needs. Although only 17.4% of caregivers who participated in data collection reported their religious affiliation, this data indicates that providers are reaching caregivers with a wide variety of religious affiliations. Of those who reported, 42.6% self-identified as Catholic, 25.2% Protestant, 11.2% as Christian, 5.2% as Jewish, and less than 1% other religions. Over 8% of caregivers indicated that they practiced no religion.

**Sexual Orientation:** Almost one-quarter (23.8%) of caregivers participating in data collection responded to a question on sexual orientation. Of those, 97% self-identified as heterosexual, 2.8% as gay or lesbian and less than 1% as bi-sexual or other sexual orientation. Lower percentages of individuals served under this initiative reported LGBTQ orientation than those in the national study (3% vs. 9%).

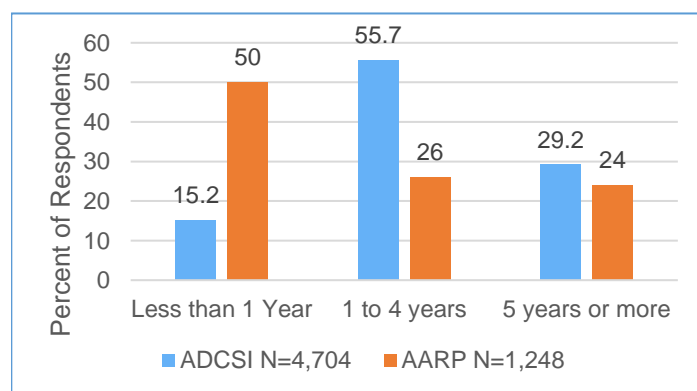
## Caregiving Background

Approximately 5,000 individuals provided information about their caregiving experiences. Approximately three-quarters (77%) of these reported being the primary caregiver. The majority of respondents (53.4%) indicated that the person they were helping lived with them. One quarter of caregivers lived close by (less than 20 minutes away) while another 14% lived between 20 minutes and 1 hour away from their care recipient.

Caregivers receiving services from NYS providers were slightly more likely to live with their care recipient than those in the national caregiver sample (53.4% vs. 34%). Approximately 74% of caregivers from the 2015 AARP study either live with or within 20 minutes of their care recipient compared to 79.1% of caregivers from the NYS data.

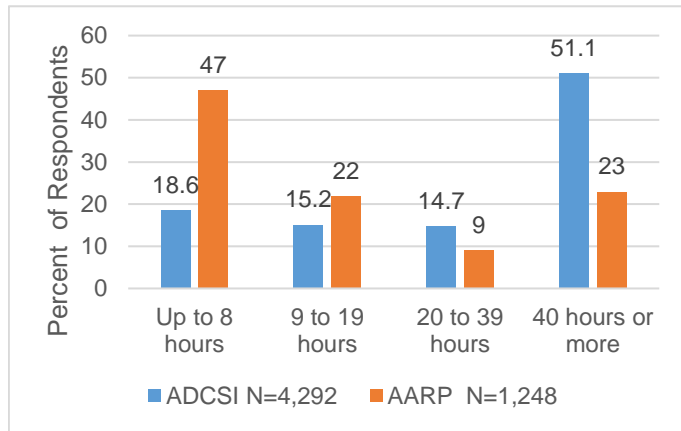
Almost 75% of ADCSI caregivers reported having assistance with their caregiving duties. One-quarter indicated that a paid professional also provided care to their friend or family member with dementia. Over forty percent (43.9%) received assistance from another relative or friend. A small percentage (3.2%) received assistance from both professionals and family members.

**Figure 8: Length of time caregiving compared to a national sample**



Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.; U.S. Census Bureau, American Community Survey 2011-2015 Estimates; and ADCSI Data

**Figure 9: Hours of care provided compared to a national sample**



Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S; U.S. Census Bureau, American Community Survey 2011-2015 Estimates; and ADCSI Data. Note: Hours of care provided vary slightly—AARP hours of care categories are 9-20 hours, 21-40 hours and 41+

As Figure 8 indicates, respondents dedicate a significant portion of their time to caregiving. Almost two-thirds had been providing care for at least two years. 50% of caregivers in the national sample had been providing care for less than a year compared to 15.2% in the NYS sample.

Over half of respondents reported spending 40 or more hours per week providing care. As indicated in Figure 9, caregivers served under this initiative dedicate more hours to caregiving than the national caregiver sample.

### Caregiver Stress and Strain

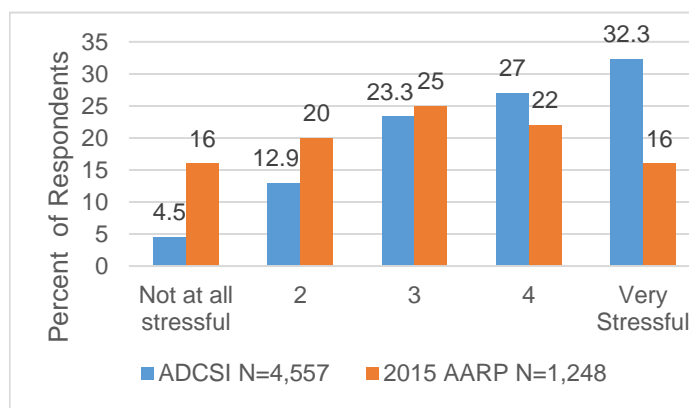
The level of a caregiver’s stress may also be an indication of support seeking behavior. Almost a third of caregivers participating in data collection indicated they experienced very high levels of stress. More than 80%

reported at least moderate stress levels. Caregivers served by the ADCSI initiative reported higher levels of emotional stress and physical strain than those in the national sample of caregivers.

There were some key differences between caregivers reporting higher versus lower levels of stress.

- In terms of service utilization, caregivers self-reporting higher levels of stress, on average accessed services at a higher rate (4.46 contacts) than caregivers reporting no stress (3.31 contacts).
- Consistent with the research literature on caregiving, gender, income, living status and length of time spent caregiving were also related to the level of stress experienced by caregivers receiving services by ADCSI.

**Figure 10: Emotional stress of caregiving compared to a national sample**



Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S; and ADCSI data.

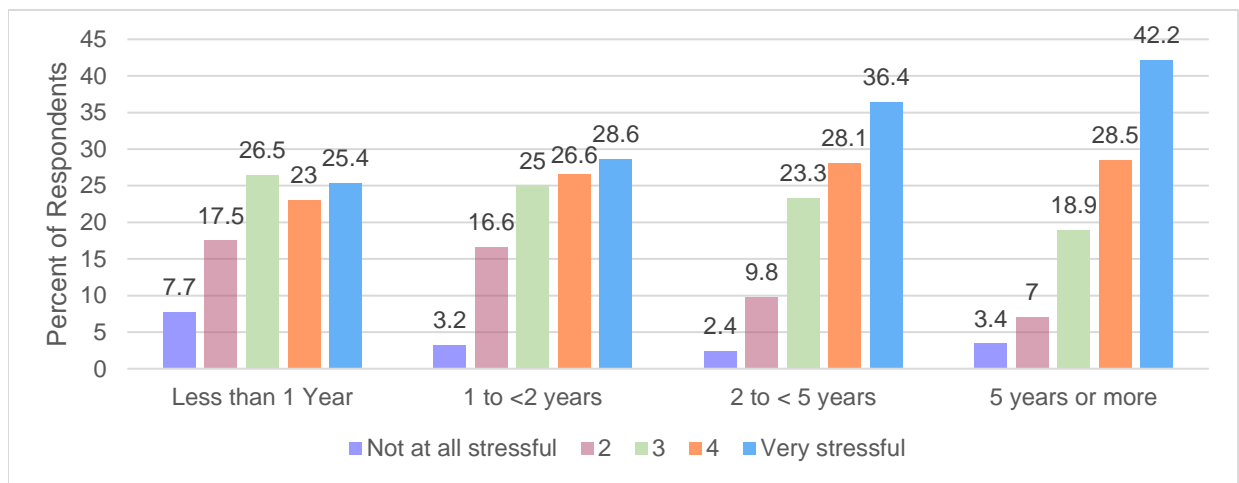
- 37.5% of women reported “very high levels” of stress compared to 26.3% of men.

- Caregivers living with their care receivers also reported higher levels (4 or 5) of stress (65.5%) than non-residential caregivers (57%) (N=3,622).

- Of the 2,952 caregivers who provided information on both annual household income and caregiver stress levels, 19% reported annual household incomes below \$50,000 and very high stress levels. However, less than 10% of Individuals with annual incomes above \$50,000 reported high levels of stress.

- As indicated in Figure 11, increasing levels of stress were associated with the length of time spent caregiving.
- No significant differences in stress levels appeared by employment category. Approximately one-third of full-time employed and retired caregivers reported very high levels of stress.

**Figure 11: Caregiver stress level by length of caregiving, N=3,766**



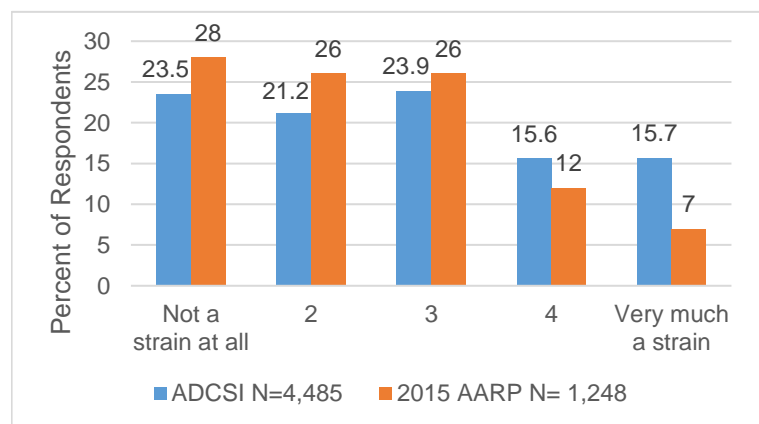
Data source: ADCSI data.

The level of physical strain experienced by caregivers is more evenly distributed among caregivers served by ADCSI, as illustrated in Figure 12.

Differences also emerged between caregivers reporting high versus low levels of physical strain:

- Unemployed and retired caregivers reported the highest levels of physical strain.
- Caregivers with annual household incomes of less than \$50,000 reported very high levels of physical strain at almost double the rate of caregivers with higher income levels (19.1% vs. 10.5% N=3,398).
- Higher levels of physical strain were also reported by caregivers who lived with their care receiver than for non-residential caregivers (36.1% vs. 25.1% N=4,107).
- Twenty-two percent of individuals in a caregiving

**Figure 12: Physical strain of caregiving compared to a national sample**



Data source: ADCSI data.



role for 5 or more years reported very high levels of physical strain compared to less than ten percent of those serving as caregivers for less than 1 year (N=4,222).

- Caregivers experiencing more physical strain may seek out more services from providers. An upward trend is noted, with caregivers receiving ten or more service contacts reporting greater percentages of very high strain.

## Referral Source

Caregivers were referred to community support services through a variety of sources as indicated in table 12. Over 40% of caregivers reported a referral source. The most common referral source was the Alzheimer’s Association (23.9%), followed by community service providers (including other providers (17.8 %), and healthcare providers (13.4%)), family members or friends (12.3%) and advertisements (12.1%).

Minor variations in referral sources were noted by geographic region. Over 6,000 caregivers provided information about both their geographic location and the referral source. Of those, caregivers from rural regions reported a higher percentage of referrals from the Alzheimer’s Association (19.2%), community service providers (26.8%) and healthcare providers (22.7%) than caregivers in urban areas. Caregivers in urban areas relied on referrals from family members and friends (17.1%) and internet/website searches (12.9%) more frequently than caregivers from other geographic regions. Community service providers and other contractors also provided over twenty percent of referral for urban caregivers. In suburban areas, healthcare providers were the most frequent source of referrals to services (26.1%), followed by the Alzheimer’s Association (22.2%).

Variations in referral sources were also noted by caregiver race (N=8,013). Black and African American caregivers reported receiving higher percentages of referrals from their healthcare providers (24.8%) compared to White/Caucasian caregivers (14.8%). Hispanic and Latino caregivers tended to rely more heavily on recommendations from family members and friends than other racial and ethnic groups (17.3%). The most frequently cited referral source for White or Caucasian caregivers was the Alzheimer’s Association (26.5%).

Referral Source			Rural	Urban	Suburban
	N	%	N=837	N=4,125	N=1,176
Advertisement	1,528	12.1	12.4	11.6	10.9
Alzheimer’s Association	3,006	23.8	19.2	6.1	22.2
Community service	2,240	17.8	26.8	22.8	16.4
Employer or colleague	79	.6	1	0.4	1.5
Family member or friend	1,551	12.3	10.5	17.1	12.2
Healthcare provider	1,686	13.4	22.7	14.2	26.1
Internet/Website	1,220	9.7	1.4	12.9	2.6
Other	901	7.2	4.8	7.2	6.9
Own agency	385	3.1	1.2	7.8	1.3

Data source: ADCSI data

## Persons with Dementia

Caregivers were also asked for basic information about the person they care for. The average age of the care recipient was 80.2, with a range of 22-100+ (N=6,722). The majority (62.4%) of care recipients were female (N=7,900). Care recipient race was reported as 67.5% White or Caucasian, 15.2% as Black or African American, 11.9% as Hispanic or Latino, and 3.4% as Asian (N=5,943).

Diagnosis status was reported by caregivers for 7,260 care recipients. The most common dementia diagnoses reported were Alzheimer's disease (39%) and unspecified dementia (34%), while 11% had not yet received a diagnosis. Specific diagnoses are detailed in Table 13.

<b>Dementia Diagnosis</b>	<b>N</b>	<b>%</b>
Alzheimer's Disease	2,847	39.2
Dementia Unspecified	2,455	33.8
Dementia Suspected/No diagnosis received	821	11.3
Vascular Dementia	282	3.9
Mild Cognitive Impairment	187	2.6
Mixed Dementia	156	2.1
Other Dementia	174	2.4
Frontotemporal Dementia	141	1.9
Lewy Body Dementia	119	1.6
Parkinson's Disease	78	1.1
<b>Total</b>	<b>7,260</b>	<b>100.0</b>

Data source: ADCSI data

A primary goal of ADCSI is to identify and diagnose individuals with dementia at an earlier stage. Caregivers were asked to report when they first noticed symptoms of dementia and when they first received a diagnosis.

Approximately 3,000 caregivers provided information about when they first started to notice symptoms of dementia in their family member or friend. The mean date for noticing symptoms reported by caregivers was 2012 (range 1970-2017).

Over 4,000 caregivers provided information about the date of dementia diagnosis. The mean diagnosis date was reported as 2013 (range 1986-2017). Over 1,800 caregivers provided information on both symptom appearance and diagnosis dates.

The data suggests a trend, with the number of individuals receiving a diagnosis within one year of symptom identification increasing each year. This trend will be explored further in upcoming years.

## Themes from Year One

- In its first year of implementation, the NYS Alzheimer's Disease Caregiver Support Initiative has **enhanced the capacity of the state and of individual organizations** to serve people with dementia and their families. This enhanced capacity is represented not only by the number of new staff positions throughout the state and more personnel trained in dementia-related services, but also by new organizational linkages and partnerships, suggesting enhanced coordination between organizations and a strengthened network of providers.
- ADCSI providers perceive that **greater capacity leads to greater demand**. The number of people served under this initiative still represents the tip of the iceberg in terms of the number of people with AD/D and their caregivers, as it is estimated that there are 390,000 people with Alzheimer's disease or a related dementia in NYS, and 1 million caregivers.
- New York State saw **extensive community support services** for caregivers and people with dementia, with most core services reaching between 5,000 and 13,000 individuals. This demonstrates extensive scale in both service availability and utilization in just the first year of the initiative. The majority of providers' service delivery and participation goals were largely achieved or exceeded, which is notable considering that most providers were not operational until mid-year.
- Similarly, the 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.
- The experience of this initiative demonstrates that **scale up is more efficient and rapid when organizations are starting from pre-existing programs** as opposed to starting programs that have to build a new infrastructure around community support for caregivers.
- **Service coverage across the state was extensive**, with community support services, diagnostic services and professional training provided in every region. In most areas, services were distributed in proportion to the population of the region, with room for improvement in specific areas of the state. For most services, service coverage was proportionally equal or greater than the population in Upstate regions, while the coverage in Long Island and New York City tended to be proportionately lower than the size of the population. This may be due to differences in program start up or structure, or to variations in tracking services. Alternatively, this may mean that the investment of funds in the state should be distributed differently in more densely populated areas. More investigation of this observation will be undertaken in future years.
- Preliminary data indicate that the caregivers served under the ADCSI were largely representative of the New York State population, with areas of strength and room for improvement within specific populations and regions. The available data suggest that the initiative has been successful at **reaching lower income and rural caregivers** in Year 1.
- The data also suggest that **racial and ethnic minority populations were underrepresented** when compared to the general NYS population and to national caregiver samples. However, several regions had success reaching similar or slightly higher percentages of specific minority populations.

- The ADCSI in Year 1 appears to be **reaching more highly educated caregivers** as compared to the NYS population, and indicates a need for greater outreach to individuals with lower levels of education in future years.
- This data suggests that **ADSCI is reaching people for whom caregiving is a significant aspect of their lives**. The caregivers served by this initiative appear to have been providing care for longer and at greater intensity, and report higher levels of emotional stress and physical strain, when compared to a national sample of caregivers. This suggests that the ADCSI is reaching caregivers in high need. While this is an important target population for this initiative, this may also suggest that caregivers are less likely to seek out services before their burden has intensified to a certain level, and that greater efforts should be made to reach caregivers earlier in their caregiving role, when services may be effective at preventing or minimizing future burden. This question will be examined further as the initiative progresses.
- Documented workforce issues highlight a statewide **need to invest in development and training of the dementia care workforce** at multiple levels. Providers commonly reported experiencing challenges in hiring and retaining community support staff with experience in dementia. In addition, home health aide workforce shortages and a lack of respite providers have impacted the ability to offer respite care, particularly in rural areas.

## Appendix 1: Balancing Caregiving and Employment – An Ancillary Project

A significant proportion of people who become caregivers for an individual with dementia are employed. Taking on the caregiving role sometimes necessitates dramatic life changes that can have significant implications for caregivers' employment status, future earnings, and retirement. In fact, a recent Alzheimer's Association study found that 35% of dementia caregivers experience household income loss because of employment changes due to caregiving.<sup>4</sup>

The research team conducted an ancillary project to better understand how employment and caregiving interact, and to identify workplace policies and programs that facilitate caregivers' ability to balance their dual employee and caregiver roles. Three pilot focus groups with 21 caregiver participants were conducted in the Fall of 2016 to understand caregiver perceptions of workplace characteristics that facilitate or hinder the caregiver role.

Focus group results were used to design an anonymous web-based survey of caregivers. The survey was pilot tested in February 2017. Two providers advertised the survey to their clients and 45 individuals responded to the survey.

The survey questionnaire was slightly modified based on the results of this pilot test, and in Summer 2017, 11 providers disseminated the survey among caregivers they serve. As of September 2017, 108 caregivers responded to the survey during this second wave.

Although 153 individuals in total responded to the survey during either the pilot or regular implementation phase, only 86 met the eligibility criteria of currently providing unpaid, or voluntary, care for a friend or family member with dementia and being employed while being a caregiver (either currently or previously).

Thirty percent of respondents were previously employed and 70% were currently employed. About 70% worked full-time.

The sample was largely female (82%), White (89%), and highly educated (68% with at least a college degree). The majority (64%) considered themselves to be the primary caregiver. The hours per week spent caregiving and the length of time they had been a caregiver varied, illustrated in Table A1.1.

Key findings from this survey include:

- Among the 30 respondents whose employment status changed while they were a caregiver, 83% reported that the change was due to their caregiver role. For the large majority, the change meant working less or not at all.
- Respondents reported that caregiving frequently interfered with their work as follows:
  - Worrying about care recipient during work hours – 58%
  - Leaving early or arriving late – 39%
  - Leaving work in the middle of the day – 27%
  - Feeling withdrawn from work tasks – 41%
  - Needing to take personal calls – 61%

Caregiving Characteristic	Percent of Respondents
Hours per week providing care	
Less than 10	22
10 to 19	17
20 to 39	14
40 hours or more	41
Length of time caregiving	
Less than 2 years	31
2 to <5 years	35
5 years or more	34

- Respondents reported that work responsibilities frequently interfered with their caregiving as follows:
  - Having to unexpectedly stay late – 19%
  - Having to take work home – 27%
  - Thinking about work responsibilities after work hours – 47%
- The majority of respondents reported a supportive work environment as follows:
  - 72% at least somewhat agreed that “My supervisor understood my caregiving demands”
  - 65% at least somewhat agreed “My supervisor listened when I would talk about my caregiving responsibilities”
  - 63% at least somewhat agreed “My supervisor acknowledged that I had caregiving obligations”
  - 64% at least somewhat agreed “I felt comfortable bringing up the issue of my caregiving responsibilities with my supervisor”
- In addition, because of caregiving
  - 65% either agreed or strongly agreed that they have less energy for work
  - 25% either agreed or strongly agreed that they have missed too many days
  - 37% either agreed or strongly agreed that they have been dissatisfied with the quality of their work
  - 82% either agreed or strongly agreed that they worry about their care recipient while at work
  - 12% either agreed or strongly agreed that phone calls from their care recipient interrupts their work
- Respondents reported using the following types of leaves for caregiving purposes:

**Table A1.2: Type of leave used for caregiving**

	% who had available	Utilization, if available %
Family Medical Leave Act	49	48
Paid Sick Leave	62	86
Paid Vacation Time	58	93
Paid Family Leave	13	100

- Respondents reported whether the following workplace programs or policies were available to them, and whether they utilized them to assist with their caregiving:

**Table A1.3: Available workplace policies and utilization by caregivers**

	% who had available	% who utilized
Compressed work schedule	31	29
Flexible scheduling	61	87
Shift coverage	54	56
EAP services	50	18
Make/receive personal calls	82	116
Flex spending account	53	5
Work from home	32	3

- 48% of respondents reported not taking leave for caregiving purposes, even though they needed to. The most common reasons were because they could not afford to lose wages, they thought

they might lose their job if they took leave, and they felt responsible for their co-workers having to take on additional work.

- Whether or not they had certain policies available to them, respondents identified the following policies as most helpful in balancing work and caregiving:
  - Flexible arrival and departure times (70%)
  - Ability to obtain shift coverage (26%)
  - Ability to compress schedule (54%)
  - Ability to work from home (58%)

## Appendix 2: Regional Demographics of Caregiver Served

To better understand whether ADCSI is meeting this objective, the demographic information voluntarily provided by caregivers was compared to 2011-2015 American Community Survey (ACS) 5-year estimates published by the U.S. Census Bureau. The ACS data was tabulated for 7 regions in New York State. The following are comparisons of individuals served by CS&E contractors compared to the percent of the adult population in each of these regions. A preliminary analysis of the data by region help identify areas where contractors had success in reaching vulnerable populations, such as in Long Island among caregivers with lower levels of educational attainment (Table A2.1), with African American caregivers in Central New York and Hispanic Caregivers in New York City (Table A2.2), and with lower income caregivers across Upstate New York (Table A2.3).

**Table A2.1: Caregiver Demographic Data- Education Category by Region compared to U.S. Census Estimates**

Region	NENY N=1,739		CNY N=2,087		HV N=1,067		LI N=2,175		NYC N=1,889		Rochester N=1,668		WNY N=1,413	
	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %
Highest Level of Educational Attainment														
Less than high school degree	2.6	9.8	2.6	10.6	3.1	12.2	1.2	9.7	4.9	19.6	3.7	10.3	3.8	10.0
High school graduate	24.8	31.3	21.1	31.8	20.2	26.4	41.5	26.9	19.2	24.1	19.7	29.3	22.5	31.7
Some college or an associate's degree	30.6	29.5	32.8	30.4	25.8	24.0	22.8	25.2	22.3	20.6	31.8	29.9	33.8	30.9
Bachelor's degree	22.1	16.2	21.0	15.0	25.9	19.9	17.1	21.1	26.8	21.0	21.1	17.0	22.1	15.3
Post/ Professional degree	19.8	13.3	22.4	12.2	25.0	17.5	17.4	17.2	26.8	14.7	23.7	13.5	17.8	12.2

Data source: Census data tabulated for regions from the 2011-2015 American Community Survey 5-Year Estimates. ADCSI (non-CEAD) caregiver self-reported demographic data.

**Table A2.2: Caregivers Demographic Data - Race by Region compared to American Community Survey Estimates**

Region	NENY N=1,861		CNY N=2,216		HV N=1,406		LI N=2,099		NYC N=3,492		Rochester N=2,073		WNY N=1,836	
Caregiver Race	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %
American Indian/ Alaskan Native	0.7	0.4	..6	0.4	0.2	0.4	0.1	0.2	0.1	0.4	0.4	0.3	1.1	0.7
Asian	0.8	2.6	0.7	2.8	1.8	4.5	1.8	6.0	7.2	13.5	0.2	2.5	1.1	2.3
Black/African American	2.1	5.9	9.1	5.6	12.1	11.5	7.6	9.4	25.1	24.5	6.5	10.1	6.5	9.9
Other*	0.8	3.7	1.0	3.6	2.3	10.5	2.5	8.4	3.1	18.2	1.2	3.8	1.0	3.7
White	92.7	87.4	87.5	87.5	72.8	73.1	81.6	75.9	41.8	43.3	86.5	83.2	88.6	83.4
Hispanic**	2.8	4.2	1.1	3.8	10.7	18.4	6.2	16.8	22.7	28.9	5.1	5.8	1.7	4.4

Data source: Census data tabulated for regions from the 2011-2015 American Community Survey 5-Year Estimates. ADCSI (non-CEAD) caregiver self-reported demographic data.

Notes: \*Other includes multi-racial and bi-racial. \*\* Hispanic is a separate category in the 2011-2015 ACS Estimates and comparisons may not be accurate.

**Table A2.3: Caregivers Demographic Data – Annual Household Income by Region compared to American Community Survey Estimates**

Regions\	NENY N=939		CNY N=1,035		HV N=399		LI N=243		NYC N=1,143		Rochester N=967		WNY N=551	
Income Categories	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %	%	ACS %
Less than \$25,000	16.5	21.3	20.2	24.7	17.3	16.7	17.7	11.8	35.3	27.0	21.6	24.0	20.9	25.8
\$25,000 - \$49,999	30.2	22.8	31.3	24.9	29.6	17.4	21.0	14.4	25.6	20.3	29.7	24.8	41.0	24.6
\$50,000 - \$79,999	24.7	19.3	18.8	19.1	24.6	15.1	23.9	14.1	15.6	15.5	21.4	18.4	17.4	18.4
\$75,000 - \$99,999	14.8	13.3	14.4	12.3	11.5	12.2	18.9	13.0	10.1	10.9	13.1	12.8	10.9	12.4
\$100,000+	13.7	23.3	15.3	19.0	17.0	38.6	18.5	46.7	13.4	26.4	14.2	20.4	9.8	18.8

Data source: Census data tabulated for regions from the 2011-2015 American Community Survey 5-Year Estimates. ADCSI (non-CEAD) caregiver self-reported demographic data.



## References

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<sup>1</sup> Alzheimer's Association. 2017 Alzheimer's disease facts and figures. *Alzheimers Dement* 2017; 13:325-373.

<sup>2</sup> Maslow K. *Translating Innovation to Impact: Evidence-Based Interventions to Support People with Alzheimer's Disease and their Caregiver at Home and in the Community*. Washington, D.C.: Administration on Aging; 2012.

<sup>3</sup> Glasgow RE, Vogt TM, & Boles SM (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health*, 89, 1323-1327.

<sup>4</sup> U.S. Census Bureau. (2011-2015). *American Community Survey 5-year Estimates*. [Data file]. Available from <https://www.census.gov/programs-surveys/acs/data.html>

<sup>5</sup> 2015 Report. Caregiving in the U.S. Conducted by AARP Public Policy Institute and the National Alliance for Caregiving. June 2015.

<sup>6</sup> U.S. Census Bureau. (2010). *2010 Census Summary File 1, Table P2*. [Data file]. Available from [https://www2.census.gov/census\\_2010/04-Summary\\_File\\_1/](https://www2.census.gov/census_2010/04-Summary_File_1/)