

New York State Alzheimer’s Disease Caregiver Support Initiative
Final Evaluation Report 1: Growth of Dementia Workforce Capacity in NYS

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

During this period, the initiative funded 36 contracts in eight regions across the state through four separate grant programs. Three of these grant programs focused on community support and education for informal caregivers and people with dementia and one grant program focused on clinical services and training for professional health care providers. The initiative aimed to provide both equitable distribution of services throughout the entire state and to increase access to evidence-based culturally competent support services to underserved (racial, ethnic, LGBTQ and rural) populations.

One of ADCSI’s goals is to enhance the dementia capable workforce across the state. To that end, two grant programs included funding specifically for building the capacity of the dementia workforce. The Centers of Excellence for Alzheimer’s Disease (CEAD) program funded ten centers to train physicians, health care providers and students on the detection, diagnosis, and treatment of Alzheimer’s disease and related dementia (AD/D) and medical providers and coroners on the importance of accurately reporting AD/D on death certificates. The Alzheimer’s Community Assistance Program (ALZCAP) funded organizations throughout the state to train key dementia-related constituencies, targeting dementia care providers, community gatekeepers, and faith leaders.

A comprehensive evaluation of the ADCSI for the period of January 2016 to May 2021 was conducted by the University at Albany School of Public Health in collaboration with the NYS Department of Health. One evaluation goal was to describe the growth of the dementia workforce capacity in NYS as a result of the ADCSI. This evaluation report focuses on that goal, and presents findings related to the implementation, evaluation and sustainability of activities aimed at building workforce capacity as well as on-going workforce challenges and recommendations for the future.

Dementia Care Workforce Needs

Nationally, a critical gap exists in the dementia care workforce,¹ and strengthening this workforce is recognized as a priority by the American Geriatrics Society, the National Academy of Sciences, and the American Public Health Association, among other organizations.^{2,3,4}

Over the course of their disease, a person with dementia may receive care and support from several different healthcare professionals, ranging from primary care physicians, neurologists, geriatricians and geriatric psychiatrists to nurses, social workers, pharmacists, rehabilitation specialists, psychologists and direct care workers.⁵ National shortages in this workforce, particularly in relation to those specializing in the care of older adults, are well documented. The National Center for Health Workforce Analysis estimates a significant and severe shortage of geriatricians by 2025.⁶ The Alzheimer’s Association reports that less than one percent of registered nurses, physician assistants and pharmacists identify as

geriatric specialists, and a recent survey of Masters in Social Work graduates found that only four percent had a focus on aging.^{7,8} As the U.S. population continues to age, the current shortage of direct care workers in the field of dementia care will continue to grow.⁹

Likewise, New York State faces a persistent shortage of qualified professionals with experience in dementia care and caregiver support.¹⁰ The number of graduates of geriatric medical programs decreased from 2009 to 2018 while adult psychiatrists and neurologists remain in high demand.¹¹ The NYS Department of Labor estimates that the demand for direct care workers will far exceed supply in the coming years.¹² Although the number of health care graduates in certain disciplines, such as nursing and nurse practitioners, rose over the past few years, uneven distribution remains an issue, particularly for primary care and mental health professionals.^{13,14,15}

In addition to an inadequate supply of specialists, workforce gaps include a deficit in training on best practices in dementia care.¹⁶ Providing high quality, patient-centered dementia care requires specialized training for each member of the team throughout each stage (early, middle, and late) of the disease.¹⁷ Yet the Alzheimer's Association reports that healthcare professionals often feel unprepared to adequately diagnose, treat, and support individuals with dementia.¹⁸ Creating a well-educated, culturally competent, integrated team is also key to expanding access and improving outcomes in underserved populations.

Evaluation Data Sources

Several sources of data were used to evaluate the impact of the ADCSI on the growth of the capacity of the dementia care workforce, including:

- Quantitative and qualitative data from quarterly progress reports submitted by ADCSI-funded organizations, which include detailed information on infrastructure development, staffing, training for healthcare providers, referrals for diagnosis and assessment, and partner collaboration;
- Periodic surveys of ADCSI-funded organizations to assess program implementation, such as start-up experiences, staffing, partnerships, and service provision barriers, facilitators, and sustainability;
- Surveys of training program participants, to assess knowledge gained and intended practice behavior change related to early detection, screening, and diagnosis;
- Monthly contractor meeting discussions.

Growth and Enhancement of a Specialized Workforce of Dementia Care Providers

The ADCSI spurred growth in the dementia care workforce across the state, both by the creation of new jobs, and by the enhancement of organizational capacity related to dementia care. ADCSI funding led to the creation of over 250 new staff positions at provider organizations. Subcontracts to other community-based organizations, such as Cornell Cooperative Extension, Catholic Charities, Jewish Family Services, and local Offices of Aging provided support for another 40 staff positions.

New staff received extensive dementia care training, which enhanced both individual competency and organizational capacity to respond to the growing needs of individuals with dementia and their caregivers. In addition to training provided from their own agencies, contractors relied on partnerships within the initiative to enhance the skills of their staff and volunteers. The statewide network of providers enabled organizations with less experience in dementia, caregiving, or culturally competent services to build their own dementia care capable workforce, and the majority of partners who received training and supervision through the network reported that they now have in-house capacity to

implement core services on their own. Monthly meetings among grant recipients and annual grantee meetings organized by NYS DOH provided additional opportunities for contractors to share best practices and lessons learned. Collaborative training highlights include:

- Cross-training between partners with expertise in dementia and those with expertise in providing culturally competent services to underserved caregivers;
- On-going supervision of education and support group leaders from experts within the initiative;
- Training and support to establish dementia-capable practices in satellite locations, including information on establishing diagnostic algorithms, referral procedures, and healthcare professional training;
- Embedding staff in partner organizations to improve care coordination.

Contractors also enhanced their workforce capacity by sending staff to receive training on specific evidence-based interventions such as “Savvy Caregiver,”¹⁹ “Powerful Tools for Caregiving,”²⁰ and the “NYU Caregiver Intervention.”²¹ Those receiving Master Trainer certification have contributed to enhanced capacity within their own organizations and across the state, by training staff at partner organizations.

Training Initiatives for Professional Providers and Students

One overarching aim of the ADCSI was to enhance the state’s dementia care workforce by training professional providers. The Centers of Excellence for Alzheimer’s Disease (CEAD) provided dementia-specific training to medical and allied health professionals and students within their own institutions and beyond, filling a gap in curricula and education requirements. Training topics included early detection and screening, diagnosis, disease treatment and management, dementia-related behavior, and death certificate reporting.

Over the course of the initiative, the CEADS provided almost 6,300 trainings to over 98,000 healthcare professionals and students, representing every county in NYS and a wide variety of disciplines (see Table 1). Almost a third (32%) of specialty care providers were neurologists. Non-physician health care providers and health professions students included nurse practitioners, physician assistants, nursing, social work, rehabilitation professionals, and other health care workers.

Table 1: Health Professionals Trained	Number of Individuals Trained	Percent of Total
Non-physician health care providers	35,155	36
Medical students	18,214	19
Primary care physicians	17,154	17
Specialty care physicians	12,834	13
Other health professions students	9,935	10
Death certificate training participants	5,360	5
Total Trained	98,652	100

CEADs employed various strategies to engage medical and healthcare professionals in training, including Grand Rounds, conference presentations, didactic sessions, webinars, case consultations, in-person office visits, and Project ECHO - Extension for Community Healthcare Outcomes tele mentoring and training. In addition to training staff and students within their own healthcare systems, CEADs collaborated with over 750 other healthcare systems, physician practices and practice groups, long-term care facilities, federally qualified health centers, colleges and universities, medical and healthcare professional associations and community-based organizations to train medical and healthcare professionals and students, patients and caregivers in-person on Alzheimer’s Disease and dementia.

The CEADs are affiliated with over half of New York State’s medical schools, which offered a unique opportunity to enhance the competency of the next generation of medical and healthcare professionals. Dementia care training to students included didactic sessions, journal clubs, case conferences and Grand Rounds along with experiential learning opportunities, such as shadowing, internships, clinical rotations, and fellowships. To expand training beyond their own institutions, CEAD providers partnered with local community and state colleges to incorporate dementia care training and experiential learning opportunities into the curricula of programs in nursing, social work, rehabilitation, and community health.

Training initiatives for Other Healthcare Workers and First Responders

The ADCSI also enhanced the capacity of other healthcare workers and first responders to meet the needs of individuals with dementia and their caregivers. ALZCAP contractors spearheaded training to other healthcare workers, such as patient care associates, and home health aides, who often have more direct patient contact than any other member of the healthcare team, and first responders, who frequently respond to calls involving persons with dementia (See Table 2). Contractors provided training on topics such as resources for skilled nursing homes, effective communication strategies, and understanding and responding to challenging behaviors.

Table 2: Paraprofessionals Trained	Number of Individuals Trained	Percent of Total
Professional providers	14,198	34
Long-term care staff	13,276	31
First responders	14,737	35
Total	42,211	100

Training for Key Community Members

The ADCSI has also built community capacity to support people with dementia and their caregivers by educating important community “gatekeepers,” and faith-based leaders (See Table 3). ALZCAP contractors led this training initiative, which provided community partners with the tools and resources to better identify and serve community members with dementia and their caregivers. Common training topics included knowing the signs and symptoms of dementia and overviews of programs and services.

Table 3: Community Trainings	Total Trained	Percent of Total
Faith-based community/leaders	15,800	50
Gatekeepers	13,098	42
Other	2,475	8
Total Trained	31,373	100

Outcomes of Training

In Year 3, CEAD providers implemented an evaluation among training program participants when possible. Five CEADs submitted training evaluations from 1,640 individuals, representing a variety of health professions (see Table 4). Topics covered in the trainings included early detection (73%), diagnosis (66%), care management (65%), behavioral issues (52%), palliative care (23%) or another

Table 4: Profession Represented by Trainee Evaluations	Number	Percent of Total
Student	464	28
Social Worker/Counselor	286	17
Physician (including residents and fellows)	202	12
Nurse	158	10
Nurse Practitioner/Physician Assistant	65	4
Rehab (PT, OT, etc.)	19	1
Other	446	27
Total	1,640	100

specialized dementia care topics (17%), with most trainings (78%) covering more than one topic.

Training evaluations focused on change in knowledge and intention to change practice behavior, such as adopting early screening or other recommended protocols.

- 88% of respondents reported that the training enhanced their knowledge of the subject matter. Improvements in knowledge were also noted by partner organizations (see boxes).
- 96% of respondents for whom the question was applicable, reported they were somewhat or very likely to implement practice changes as a result of the training.
- Intended practice changes reported by participants included implementing cognitive screening earlier, using recommended tools for assessing patients, referring patients to appropriate services, training staff on best practices, monitoring patients for polypharmacy issues, and reinforcing recommended protocols.
- Outreach and training efforts by the CEADs resulted in a 79% increase in referrals for diagnostic assessments, from 5,058 in Year 1 to 9,050 in Year 4, suggesting that training participants did in fact adopt screening recommendations. These referrals came from every county in the state, and the majority (64%) were from primary care physicians (64%).

“The residents from Family Medicine entering rotation this year were noticeably more familiar and knowledgeable about dementia than in the past. Residents volunteered information that they had received training on dementia last academic year from the CEAD” – VA Geriatric

“The registered nurse (RN) case manager reached out to make sure the referral process between our two offices (CEAD and Primary Care) was running smoothly. She wanted to share that the providers were using the screening tools we had recommended during our training and that these tools were helping families to recognize changes in their loved ones with dementia. She also shared that providers felt more confident about their medication management from our training.”

– Regional Center of Excellence

Thus, evaluation results demonstrate enhanced knowledge of the health care workforce throughout New York State and indicate a potential impact on professional practice behaviors.

However, 26% of respondents identified at least one barrier to implementing practice changes, such as:

- Lack of experience (44%)
- Lack of time to assess and counsel patients (29%)
- Lack of opportunity (22%)
- Lack of resources (20%)

CEADs used several strategies to help providers overcome these barriers. Examples include implementing role-playing techniques in training sessions, providing toolkits for primary care offices, coordinating workflow processes that support consultation and referrals among primary care providers and community support services, and providing technical assistance through Extension for Community Healthcare Outcomes (ECHO) teleconferencing (see box).

Overcoming screening barriers - Example:

Smaller primary practices without social workers may be reluctant to adopt early screening recommendations because they lack the time, knowledge and/or resources to implement care planning. To overcome this challenge, CEADS collaborated with Community Support Providers to educate primary care offices about the continuum of care available locally to support patients with dementia and their families on their journey.

Over the last year, the COVID pandemic fostered a quick transition to remote learning and telehealth/telemedicine, creating more opportunities to collaborate across the state on training activities. It also led the CEADS to request that NYS DOH compile a list of experts from within the initiative as a potential speakers' bureau that contractors could consult to enhance capacity within their specific regions.

Sustainability of Training

CEADs integrated several strategies to foster the sustainability of their training activities, including:

- Instituting the ECHO program to increase access to training (Centers using the ECHO program reached a greater number of participants);
- Acquiring additional outside funding to support training efforts;
- Partnering with Geriatric Workforce Enhancement Centers (GWECs) to expand training opportunities;
- Developing enduring resources, such as new assessment protocols, online modules, and a virtual library;
- Updating curricula;
- Institutionalizing new experiential opportunities, including use of telehealth/telemedicine;
- Establishing agreements or Memoranda of Understanding (MOUs) to provide training to other schools and colleges;
- Collaborating within the network to enhance capacity within their institutions and regions.

Summary of Findings

The evaluation of the Alzheimer's Disease Caregiver Support Initiative indicates that:

- The ADCSI created a substantial number of new staff positions and fostered enhanced individual competency and skills in dementia care among existing and new organizational staff.
- The ADCSI increased the capacity of funded organizations and their partners to provide dementia-related services. As a result, access to caregiver support services was increased throughout the state. In addition, CEADs assessed and diagnosed patients for cognitive decline from every single county in the state and every priority-underserved population.
- Almost 100,000 current and future health care professionals received dementia-related training. These training programs reached healthcare professionals in every region of the state. In addition, over 42,000 other healthcare workers and first responders, and 31,000 key community members received dementia-related training.
- Participant evaluations indicate that healthcare professional trainings were effective in enhancing provider knowledge about dementia care, and increasing intent to adopt recommended practices.
- Referrals to CEADs for diagnostic assessments increased by 79% from Year 1 to Year 4 of the initiative, indicating an increase in screening practices throughout the state, and reflecting strengthened linkages between primary and specialty care.
- The ability to share resources and expertise within the ADCSI network helped organizations increase their capacity to provide quality care to individuals with dementia and their caregivers. This was particularly evident during the COVID-19 pandemic when providers collaborated across the network to offer educational opportunities to dementia care staff, patients and caregivers.

The network demonstrated sustainability during this challenging time, as providers with more resources extended training and support services to less well-resourced providers, ensuring continuity of services across the state.

By enhancing both individual provider competency and organizational capacity, the ADCSI has strengthened the dementia care workforce in New York State, thereby enhancing the state's ability to continue to respond to the needs of individuals with dementia and their caregivers.

On-going Dementia Care Workforce Challenges

Despite the successes of the initiative in strengthening the dementia care workforce, challenges remain:

- While the number of geriatricians in NYS rose during 2015 to 2019,²²the NYS population continues to age, which will lead to *continued shortages in geriatric specialists* such as geriatricians and geriatric psychiatrists, and there are few training fellowships available in these disciplines.
- *Reimbursement for dementia care services* is not commensurate with other high tech hospital services. This potentially results in lower prioritization of these types of services within health care systems, and disincentivizes trainees from pursuing these specialties, further contributing to the workforce shortage.
- Contractors noted that a major gap in the dementia care workforce is the *shortage of direct care workers* (such as patient care associates, home health aides and respite providers). Low pay, lack of opportunities for advancement, and COVID-related hesitancy to enter or remain in the healthcare workforce were cited as factors contributing to these shortages.
- There is a *small pool of bilingual, culturally competent dementia care professionals*.
- *Recruitment and retention of qualified and experienced dementia care professionals (RNs, SWs, etc.)* remains challenging for some contractors. Low salaries and large caseloads often lead to staff turnover and significant time and effort is required to onboard and train new staff.
- *Lack of consistent, competency-based curriculum and training on dementia care* and best practices across disciplines remains a gap in the education of health care professionals.
- *Access to, and reimbursement of, telehealth services* increased temporarily through a waiver process during the pandemic. Providers reported that telehealth services were uniquely valuable in dementia care, enhancing access for homebound patients in familiar surroundings. Telehealth was also found to be an effective, sustainable way to train students and residents during the pandemic.
- The percentage of primary care physicians *billing for cognitive screening and care planning* remains low.²³

Recommendations for Future Enhancements to the Dementia Care Workforce

These evaluation findings lead to the following recommendations:

- Given its demonstrated effectiveness in reaching participants in all areas of the state, continue to support the ADCSI model for disseminating dementia care training for current and future health care professionals.
- Emphasize collaboration among networks of providers to improve the quality and accessibility of community support services and training throughout the state.

- Support expansion of the use of Project ECHO for training and consultation services, expanding provider access to specialty providers such as geriatric psychiatrists, given its success in reaching participants and in sustaining training during the pandemic.
- Promote training to the full team of healthcare professions involved in dementia care to ensure comprehensive and complementary enhancements to the dementia care workforce.
- Seek ways to incentivize geriatric/dementia care and advocate for parity with salaries and reimbursement for other services.
- Implement loan forgiveness, paid internships and mentoring programs to improve the pipeline from college to the dementia care workforce.
- Develop consistent training requirements for direct care and other healthcare workers, and increase training that focuses on dementia care for direct care workers.
- Provide flexible funding so that agencies can create service, salary and training tiers with more opportunities for advancement.
- Advocate for continued use of telehealth/telemedicine for dementia care and ensure commensurate reimbursement for use. Priority areas include ensuring access to telemedicine for homebound individuals with dementia and expanding telehealth to partners in underserved communities.
- Foster inter-professional teams among healthcare and community support providers to improve coordination/care management of services to individuals with dementia and their caregivers.
- Improve the assessment of training effectiveness and the adoption of recommended screening practices by instituting post-training practice change evaluation and/or a statewide survey of dementia care knowledge and practice of primary care practices in New York State.

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