



University of California  
San Francisco

*UCSF Health Workforce Research Center  
on Long-Term Care*

## Research Report

---

# Dementia Care Specialist Workforce in California: Role, Practice, Training, and Demand

Jason D. Flatt, PhD, MPH, Brooke A. Hollister, PhD &  
Susan A. Chapman, PhD, RN

January, 2018

---

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U81HP26494, Cooperative Agreement with the U.S. Bureau of Health Professions, National Center for Health Workforce Analysis. Opinions and recommendations do not necessarily represent those of the Bureau or other government agency.

Please cite as: Flatt, JD, Hollister, BA and Chapman, SA (2017). Dementia Care Specialist Workforce in California: Role, Practice, Training, and Demand. San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care. UCSF Health Workforce Research Center, 3333 California Street, Suite 265, San Francisco, CA, 94118

Copyright © 2017 The Regents of the University of California

Contact: Jason D. Flatt, PhD, MPH; [jason.flatt@ucsf.edu](mailto:jason.flatt@ucsf.edu), 415-476-9477

# Dementia Care Specialist Workforce: Role, Practice, Training, and Demand

---

## Table of Contents

Table of Contents.....	2
Table of Figures.....	3
Table of Tables.....	3
Dementia Care Specialist Workforce: Scope of Practice, Training, and Demand .....	4
Executive Summary .....	4
Introduction .....	4
Methods .....	4
Results .....	5
Conclusions and Recommendations.....	5
Dementia Care Specialist Workforce: Scope of Practice, Training, and Demand .....	6
Background .....	6
Methods.....	8
Key Informant Interviews .....	8
Data analysis.....	9
Results.....	9
Overview .....	9
California’s Dementia Care Specialist Training Program .....	9
Meeting Dementia Care Specialist CMS Requirements .....	10
Dementia Care Specialist – Qualifications.....	12
Dementia Care Specialist – Role and Practice.....	13

DCS Role and Scope of Work.....	13
Case Loads.....	14
Dementia Care Specialist - Knowledge.....	14
Utility of the Tier 1 and Tier 2 Training.....	14
Dementia Care Specialist – Caregiver Support .....	16
Dementia Care Specialist – Referral to Community Resources .....	17
Dementia Care Specialist – Future Demand .....	18
Facilitators and Challenges .....	19
Discussion, Policy Implications and Future Directions.....	21
Limitations.....	21
Conclusion.....	22
Acronyms Used in this Report .....	24
References.....	25

**Table of Figures**

Figure 1. Percent Increase in the Population of California and in Californians with Alzheimer’s .....	7
--	---

**Table of Tables**

Table 1. Content for the Tier 1 and Tier 2 Dementia Care Specialist Training Program .....	23
---	----

## **Dementia Care Specialist Workforce: Scope of Practice, Training, and Demand**

### **Executive Summary**

#### ***Introduction***

Over five million older adults in the U.S., some 630,000 of them in California alone, are currently living with Alzheimer's disease and related dementia (ADRD). This number is expected to rise to 16 million people nationally, with over a million in California by 2050.<sup>1</sup> Effective care coordination and referral to services and support for patients with ADRD and their caregivers can help to decrease unnecessary medical services utilization and care costs, delay institutionalization, and improve quality of life for patients and caregivers.<sup>2-4</sup> Dementia Care Specialists (DCSs) have been proposed as a workforce solution to assist caregivers with care coordination, provide disease education, to educate them about behavioral management strategies, and to provide caregivers with support and linkage to community services, all aimed at keeping older individuals safely in their homes. Currently, little is known about the roles, training, or qualifications of DCSs in California, and whether this workforce, in fact, holds promise for effective dementia care management for California and other states.

We examined the roles and implementation of DCSs in California and how the Centers for Medicare and Medicaid Services (CMS) requirements for dementia care coordination are being met. We also assessed the workforce attributes of the DCS role: training, licensure requirements, certification, customary duties, and reimbursement for services.

#### ***Methods***

Our data is drawn from key informant interviews (n = 17) with a variety of professionals at nine health plans (five counties) and non-profit organizations (Alzheimer's organizations) that utilize DCSs in California. Interviews were semi-structured and conducted with health plan administrators, clinical leaders, care coordinators, and DCSs, between January and March 2017. We used thematic analysis to identify themes and explore issues related to DCS roles, qualifications, training, competencies, and practice.

## **Results**

Across the nine health plans, DCSs were primarily nurse and social worker specialists in care management with training and expertise in dementia care coordination. Training provided by Alzheimer's organizations for all DCSs included: Overview of ADRD and how to administer a validated cognitive screen; management of behavioral symptoms; caregiver identification and assessment with a validated tool; and benefits of referral to community-based and LTSS services. The majority of DCSs supported plan members with ongoing care coordination, conducted cognitive screenings, and served on interdisciplinary care teams aimed at developing effective and person- and family-centered care plans. While there were some inconsistencies in dementia care coordination practices, several promising practices were identified and it was clear that there is a growing demand for DCSs as a key component of effective dementia care management.

## **Conclusions and Recommendations**

Further efforts should be directed at translating evidence-based practices for dementia care coordination into health systems and to evaluate promising dementia care management practices. Future research on the impact of policy and workforce training and capability are needed to ensure effective care coordination for individuals with ADRD and their family caregivers.

**Acknowledgements:** We would like to thank Debra Cherry, PhD and Jennifer Schlesinger, MPH, CHES of Alzheimer's Greater Los Angeles for their feedback and guidance on this report and the overall project findings.

Contact Info: Debra Cherry, Executive Vice President of Alzheimer's Greater Los Angeles. Email: [dcherry@alzgla.org](mailto:dcherry@alzgla.org)

## **Dementia Care Specialist Workforce: Scope of Practice, Training, and Demand**

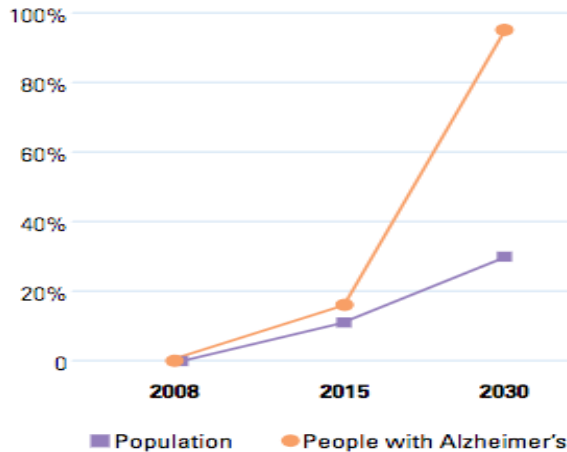
### **Background**

Over five million older adults in the U.S. are currently living with Alzheimer's disease and related dementia (ADRD), a number that is expected to rise to 16 million people by 2050.<sup>1</sup> Dementia care represents a substantial cost to healthcare organizations and society, including costs for formal and informal caregiving services. Effective dementia care coordination and timely referral to services and support for patients with ADRD and their caregivers can help to decrease unnecessary medical services utilization and care costs, delay institutionalization, and improve quality of life of patients and caregivers.<sup>2-4</sup>

In 2015, dementia care in the United States resulted in over \$226 billion in health care costs.<sup>5,6</sup> About 70% of these costs or \$153 billion was covered by Medicare and Medicaid.<sup>1</sup> The U.S. is also experiencing a major shortage of physicians, nurses, social workers, and other health professionals trained to care for older adults with dementia.<sup>7</sup> To offset rising costs for care and meet the care needs of individuals with ADRD and their families, a workforce prepared to provide dementia care that is inter-professional, high quality, engages caregivers and families, and provides cost savings to healthcare organizations is urgently needed.

In California, over 630,000 adults aged  $\geq 55$  years are currently living with ADRD.<sup>5</sup> It is estimated that this number will grow to over 1.1 million by 2030. This will create a tremendous burden for caregivers of people with ADRD. Over a million Californians are caring for a person with ADRD, which represents about 11% of the U.S.'s caregivers.<sup>8</sup> Families in California provide almost three-quarters of both the informal (unpaid) and formal care for persons with ADRD, over \$73 billion of the estimated total cost of \$104 billion.<sup>8,9</sup> This exerts pressure on Medi-Cal, California's Medicaid program for lower income individuals, as benefit expenditures for individuals with ADRD are 2.5 times greater than those without ADRD.<sup>1,5</sup> This population also has greater demand and expenses for long-term care as well as other medical and social services.

**Figure 1. Percent Increase in the Population of California and in Californians with Alzheimer’s**



Source: State of California, Department of Finance Race/Ethnic, Population with Age Sex Detail, 2000–2050. Sacramento, CA, July 2007, accessible at [http://www.dof.ca.gov/html/DEMOGRAP/Data/RaceEthnic/Population-00-50/RaceData\\_2000-2050.php](http://www.dof.ca.gov/html/DEMOGRAP/Data/RaceEthnic/Population-00-50/RaceData_2000-2050.php). See Appendix F for methodology used to estimate California Alzheimer’s disease prevalence.

To address increasing costs and develop more integrated care delivery systems in California, health plans have been encouraged to combine all Medicare and Medi-Cal benefits and services into a single, capitated health program, Cal MediConnect, serving those who are dually eligible for Medicare and Medi-Cal. This includes both health care and long-term services and supports such as in-home, adult day and nursing home care. It is estimated that about 13% of enrolled individuals in Cal MediConnect have a formal diagnosis of ADRD and an additional 13% are undiagnosed.<sup>10</sup> Individuals with ADRD rank in the top five for per capita health care costs in California. This includes costing Medicare three times more and Medicaid 23 times more than other beneficiaries of the same age.

In California, a Dementia Care Specialist Training Program was created as part of the Dementia Cal MediConnect project, a four and half-year grant (2013-2018) funded by the federal Administration on Aging to the California Department of Aging and managed by Alzheimer’s Greater Los Angeles in partnership with the Alzheimer’s Association, Northern California and Northern Nevada Chapter, and the California Department of Health Services (CA DHCS).<sup>10,11</sup> The purpose of the DCS Training Program was to increase dementia-specific capacity of health plan care managers in six counties in

California. Specific requirements of the DCS Training Program are described below.

Following the conclusion of DCS Training Program, we conducted an examination of this newly trained workforce in California, Dementia Care Specialists (DCSs), and how the Centers for Medicare and Medicaid Services (CMS) requirements for dementia care coordination are being met in this large state's population of residents with ADRD. We also focused on the qualifications, training, dementia care coordination practices, and demand, including recruitment and retention, for DCSs in California.

## **Methods**

### ***Key Informant Interviews***

To gain a more in-depth understanding of the challenges and successes of the DCS role at local health plans in California, we sought key informants with all nine participating health plans in California who were identified as partners by Alzheimer's Greater Los Angeles and the Alzheimer's Association, Northern California and Northern Nevada Chapter, who themselves contributed as key informants. Potential key informants were contacted by email and asked to participate in a one-hour telephone interview. Potential key informants were also asked to identify others at that organization, such as DCSs, to participate in the interview.

After receiving approval from University of California, San Francisco's Committee for Human Research, willing participants were contacted by telephone to schedule interviews. Prior to the start of the interview, the interviewer obtained verbal informed consent and reviewed the measures in place to protect confidentiality. Interviews lasted 44 minutes on average, with a range of 31 to 90 minutes. A semi-structured interview guided was utilized. Topics included background and description of the DCS position, dementia care coordination practice at the health plans, discussion of a typical case load and services provided by DCSs, whether and what kind of educational training was required for the DCS position, identification of ongoing training needs, systems for evaluating the impact of dementia care coordination, and perceptions of current and future organizational demand for DCSs. All key informant interviews were conducted by telephone and all informants agreed to be audiotaped.



## **Data analysis**

All interviews were transcribed verbatim, and all personal information was described such that participants' confidentiality was maintained. Thematic analysis methods were employed to uncover themes and explore issues related to DCS' roles, qualifications, training, competencies, and practice. Collectively, the research team examined and reached consensus on a thematic coding and data analysis strategy,<sup>12</sup> which involved regular meetings to discuss themes identified from reviewing and coding the transcripts, and then comparing our findings to the literature. An iterative process of reviewing the transcripts continued until key themes emerged.

## **Results**

### **Overview**

A total of 17 key informants of 28 identified agreed to participate. Although none of the 28 identified candidates refused to participate, several had either left their healthcare organization or could not be reached. Key informants ultimately interviewed came from each of the nine health plans or five counties in California, two Alzheimer's organizations, and one individual from an academic institution. A range of healthcare professionals participated, including nine care managers, two supervisors, two directors, two vice presidents, one chief medical officer, and one academic researcher. Of the 17 key informants, six were DCSs and two were DCS Program trainers.

On average, there were three to four trained DCSs at each of the nine health plans, with a range of two to eight DCSs per health plan. It was estimated that 109 DCS were trained during the four and half years of the Dementia Cal MediConnect Project. The proportion of plan members with dementia varied across health plans, ranging from less than 10% of members with dementia to greater than 50%.

### **California's Dementia Care Specialist Training Program**

The DCS Training Program in California was created to meet a need to comply with three-way contracts developed between the Centers for Medicare and Medicaid (CMS), CA DHCS, and each of the participating health plans. All health plans were required to have trained DCSs.<sup>13</sup> The contract also stipulated that each health plan must have a system of care constituted

with care managers able to assist individuals with dementia and their caregivers to obtain needed care, including acute, primary, and behavioral health, and long-term services and supports.

### ***Meeting Dementia Care Specialist CMS Requirements***

CMS stipulated five requirements for dementia care coordination for health plans participating in Cal MediConnect. Specifically, DCSs should have an understanding and skills in the following areas: 1) global features of dementia; 2) symptoms and disease progression; 3) ability to manage challenging behaviors and communication problems; 4) contributors to caregiver stress and how to manage caregiver needs; and 5) ability to refer members and caregivers to community resources.<sup>13</sup>

Leveraging these contractual requirements, the Dementia Cal MediConnect Project developed the DCS Training Program for health plans in California. The DCSs Training Program was informed by a previous program, Alzheimer's Disease Coordinated Care for San Diego Seniors, or ACCESS,<sup>14</sup> an evidence-based, dementia disease management program aimed at improving the quality of care and outcomes for individuals with dementia. ACCESS had four main components: 1) a steering committee that guided consensus on care goals and designed the care coordination protocols, 2) care managers, 3) targeted provider education, and 4) a web-based communication and decision support system and collaboration with community-based organizations.<sup>15</sup> It provided a range of care management tools, including care management algorithms generating person- and family-centered care plans addressing common care needs and behavioral symptoms, person- and family-centered care plans, self-management materials and resources, and assessment tools for individuals with ADRD and their caregivers. ACCESS was shown to be effective in improving quality of care, use of supportive services, and meeting the needs of individuals with ADRD and their caregivers.<sup>14</sup> California's DCS Program drew on other best practices in dementia care coordination as well, such as symptoms management, best practice care plans, and effective approaches to educate and support caregivers.<sup>16,17</sup> The DCS Program targeted health plan care managers who had direct contact with individuals with ADRD and their families, and was comprised of two tiers of training provided by the Dementia Cal MediConnect Project.

**Tier 1** (8 hours in-person training): Care managers were provided basic and general dementia knowledge and skills. Content (See Table 1) included the causes and risk factors for ADRD, assessment using validated cognitive screening tools (AD8 - an 8-item cognitive screening tool)<sup>18</sup> and an algorithm, guidelines for disease management, how to address challenging behaviors (*IDEA!* Behavior Management Approach), effective communication, safety concerns, elder abuse, hospitalization and discharge planning, caregiver needs, and an overview of community resources.<sup>11</sup> The Tier 1 training also included video clips, facilitated discussions, and activities (problem-based scenarios, role playing, and case studies).

**Tier 2** (Two-day in-person training, about 12 hours): involved advanced-level training for care managers who had completed Tier 1. It aimed to increase knowledge and self-efficacy of care managers in dementia care and in supporting other care managers, health plan members, and families. It also focused on strengthening dementia care coordination systems by encouraging the use of standardized assessments for caregivers and care plans for individuals with ADRD. Content of the training included enhanced skills in conducting cognitive screenings, application of the *IDEA!* Behavior Management Approach, enhanced skills in identifying and meeting the needs of informal and family caregivers, and increased self-efficacy in developing and implementing person and family-centered care plans for individuals with ADRD and their caregivers. This training also included video clips, facilitated discussions, and activities (problem-based scenarios, role playing, and case studies). **Care managers who completed BOTH TIERS of training were considered DCSs and encouraged to participate in an additional 12 hours of training/support through huddle calls.**

After DCSs completed the Tier 2 training, they were invited to participate in monthly, 1-hour “huddle” calls for six months. DCSs were also invited to participate in six huddles following the Tier 1 training. Thus, DCSs were offered an up to 12 hours of training/support in dementia care coordination. The huddle calls provided DCSs with an opportunity to share experiences, challenges, and opportunities for guidance and problem solving around difficult cases. The huddle call structure involved 20-minutes of discussion on a dementia-related topic that reinforced key training messages, with the remaining 40-minutes focused on real-world scenarios and opportunities to ask questions and share solutions.

### ***Dementia Care Specialist – Qualifications***

The healthcare professionals chosen by the health plans to undertake DCS training were either registered nurses (Bachelor's or Master's prepared) or social workers (licensed clinical social worker or Master's prepared). The majority had been at their respective health plan for several years, with  $\geq 3$  years of experience providing direct service and care management, and often they were a supervisor or senior staff member. Several DCSs had previous experience in case management with older adults. In addition, previous knowledge of assessment, treatment, discharge and aftercare planning processes and guidelines were said to be especially helpful. For instance, key informants observed:

*"We tried to select staff that came from a variety of backgrounds, so we included some nurses and social workers. [The DCS] previously worked at a health plan that specialized in older adults so that's really her background and specialty."*

*"I'm sure the minimum is about three years as a case manager with a background, we wouldn't want to select someone who is brand new. To have some sort of a framework there, that would be the minimum. It's a mix ... based on their interests and their background. .... We would do most likely a nurse again, and someone with a social work background. If someone is really passionate about this population, and based on their level of interest, that's definitely something we would want to consider as well."*

To be considered a DCS, care managers had to complete both Tier 1 and 2 trainings, and were encouraged to participate in the monthly huddle calls. However, there were some differences in the types of care managers that were chosen to participate in the DCS Training Program. Since health plans were asked to nominate care managers who had previously completed the Tier 1 training to participate in the DCS Training Program, sometimes more junior care managers were selected. For instance, some of key informants had the following to say about selecting staff for Tier 2 training:

*"There wasn't any sort of specific qualification on our end in terms of who was selected and why we, I pretty much opened it up to the team and said, basically, 'If you're interested, please let me know.'"*

*"I have one person that's more senior and one that's a little more junior, but both would do well with that."*

## **Dementia Care Specialist – Role and Practice**

### DCS Role and Scope of Work

The DCS role and utilization at health plans varied. Some health plans utilized DCSs in a formal way, such as having them serve on an Interdisciplinary Care Teams (ICTs) and consult on a member's dementia-related care coordination needs. Other health plans utilized DCSs in less formal ways and in informal consultant roles, such as to provide education or advice to other care managers and staff who sought out support for dementia-related cases.

For example, key informants stated the following:

*"We are more like a consultant. We provide consultation to other case managers who need support with care coordination for members with dementia and their caregivers." (DCS, RN)*

*" During the ICT (interdisciplinary care team) ...we discuss the presenting issues and goals for the individuals. When an individual presents with memory issues, we emphasize there are tools we can use and make the recommendations during the ICTs." (DCS, MSW)*

However, this consultative role required care managers and other staff to be aware of the availability of DCSs at their organization and their expertise in dementia care coordination. This was not always the case. Several DCSs mentioned that they were underutilized because the health plans did not adequately advertise their availability to colleagues on the frontlines of care.

In addition, several DCSs and directors mentioned that members with dementia were not specifically assigned to care managers who were DCSs.

### Case Loads

There were differences in the number of members with dementia that were assigned to DCSs (case loads), as described by managers:

*"We might be actively working with like 20 or 30 patients, actively working on placement, discharge planning from the hospital. However, we might be managing a total of 100, of maybe we'll be in touch with them once a month, because we're waiting for a social program to get in place."*

*"Caseloads are roughly 15-20. I would say over 50% are with dementia."*

*"On average our social workers have a caseload of about 50 members, which about two to five are maybe diagnosed with dementia. And if not officially diagnosed, may have some early signs of some potential signs and symptoms of dementia."*

Varying case loads may be related to health plans' care management delivery mode. Delivery modes included telephonic, in-person, in-home, and collaborating with social service agencies and long-term care organizations. Most of the plans provided care management primarily by telephone. Only a few provided care management in the home or at community sites (e.g., adult day health centers). The duration of care coordination also varied (e.g., 3 to 6 months vs. more than 1 year).

### ***Dementia Care Specialist - Knowledge***

#### *Utility of the Tier 1 and Tier 2 Training*

The majority of DCSs and care management supervisors and directors felt that the Tier 1 and Tier 2 trainings provided them with useful and relevant knowledge of dementia care coordination. The knowledge they gained included a greater understanding of the causes and risk factors for dementia, understanding how to conduct cognitive screenings, particularly the AD8, best practices in dementia care coordination, person- and family-centered care plans, disease management guidelines, caregiver stress and support

strategies, and how to address challenging behaviors using the “*IDEA!* Behavior Management Approach.”

Several DCSs highlighted the value of the training and informational resources, including utilizing the training materials to coach other care managers, and reviewing the educational materials and behavior management strategies when working with more challenging dementia-related cases.

*“We were resources in that, one of the things that I really liked about the training is that you get a whole binder full of resources to go back to your office, with tangible tools. I would have conversations with other care managers about care planning ideas. Even today when new staff come on and maybe they haven't worked with people with dementia before or are interested in learning more, if there wasn't a training readily available, I'll share and go through some of the helpful flyers or documents that were in that Tier 2 training binder.”*

Another aspect of the training that was considered helpful was the ability to conduct cognitive screening. The most common cognitive screen utilized by DCSs was the AD8, a validated tool that could be administered over the telephone to either the patient or an informed caregiver. This tool was a part of both the Tier 1 and 2 trainings, and the Tier 2 training included skills-based scenarios and hands-on application. Moreover, Tier 2 trainings specifically focused on increasing skills and self-efficacy in conducting cognitive screenings using the AD8 tool.

However, there were also several issues that resulted in inconsistencies with the administration of cognitive screenings, such as care management system infrastructure (e.g., decision support tools were not integrated), variability in the type of cognitive screening tools utilized by health plans, and differing views on who was responsible for administering cognitive screenings (e.g., should screenings be conducted by DCS vs. physician). The majority of health plans utilized the AD8, but some plans relied on responses to either their health risk assessment, the Saint Louis University Mental Status Exam (SLUMS), or the Montreal Cognitive Assessment (MoCA). These differences in the use of cognitive screening tools may make it difficult to draw comparisons on the severity and extent of cognitive impairment among members across health plan populations, as well as potential issues as to whether the tools are appropriate for the care management delivery mode

(e.g., phone vs. in-person), evidence-based for dementia screening, or well-validated in the populations being served by the health plans.

There was also variability in the completion of cognitive screenings for members with dementia. This may have been due to members with dementia not being specifically assigned to a DCS. Compared to DCSs, other care managers often had less experience working with members with dementia. In addition, some health plans left cognitive screening up to medical providers or specialists. Rather than doing a screening, DCSs would review the member's medical record to determine whether neurological exams, diagnostic tests, or other documentation of cognitive and/or mental status were included. If there was no documentation, they might do a cognitive screening or make a referral to a physician.

For several health plans, care management system infrastructure created a barrier to conducting cognitive screenings. When care management systems included process flows, decision support tools, and embedded cognitive screenings tools, members were much more likely to receive a cognitive screening via the AD8 or another tool. Several plans mentioned that these tools were being incorporated into their systems, but that it was challenging and time consuming for programming, testing, and approval. Currently, three health plans have integrated a cognitive screen into their electronic medical management systems.

### ***Dementia Care Specialist – Caregiver Support***

Several DCSs also highlighted how the Training Program increased their ability support caregivers of persons with ADRD. DCSs reported that they were in regular contact with caregivers and worked with them to develop and implement a person- and family-centered care plan for members with ADRD. These care plans might address caregiving demands and stressors, such as referrals to respite services, encourage the use of informal supports (e.g., other family members and support networks), and involve an assessment of caregiver stress. It was quite common for DCSs to be in regular contact and to frequently communicate about care plans with caregivers. Caregiver support was not necessarily covered by or billable to Cal MediConnect based on existing CMS reimbursement models. While training in working with caregivers was required by the CMS guidelines, working with caregivers was not billable. However, DCSs said it was an important way of ensuring appropriate care coordination for members with ADRD. For instance, a key informant noted:



*"In the health risk assessment, we identify caregivers and family that the member would like to be included in their care. That's the initial place where we try to identify a family member as a caregiver. Another opportunity is just a monthly call that we might have with the person a member identifies a caregiver. The care manager's able to document that and talk about the member's preferences as far as involving the caregiver in their care. If the member gives consent, of course we would include the family as their caregiver in any discussions, or call them forward to any care team meetings."*

Similar to the system infrastructure issues that created a barrier to conducting cognitive screenings (e.g., lack of decision support tools and integration into care management systems), infrastructure issues were a common reason cited for not conducting a caregiver assessment. Only a few plans assessed caregiver burden or stress even though this was a part of Tier 1 and 2 trainings and CMS requirements. Very few had made steps to integrate caregiver assessments into their care management systems. Those that did conduct assessments were doing so informally and there was no system in place for tracking, assessing changes or improvements, or determining the impact of dementia care coordination on caregiver stress and burden. Currently, only two health plans have integrated caregiver identification and assessment into their electronic medical management systems.

### ***Dementia Care Specialist – Referral to Community Resources***

A key role of DCSs was to educate and refer members and their caregivers to long-term services and supports in the community. Referrals might involve coordinating access to a specific service, such as Adult Day Care; linking members to programs and supportive resources available through local Alzheimer's organizations; and coordinating a hospital discharge, or placement in a nursing home or hospice care. The majority of DCSs said this was a regular component of their care plans and an important component of care coordination for members with ADRD.

The most common referrals included Alzheimer's organizations, caregiver support services (e.g., support groups, educational classes, board and care services, and respite services), placement in assisted living or hospice care, and assistance with scheduling medical appointments and specialist visits. A key informant had the following to say about providing referral services:

*"One of the things was really connecting the family to the Alzheimer's support, caregiver support. We do educational classes, but we don't really provide that long, ongoing caregiver support, like being part of a support group."*

### **Dementia Care Specialist – Future Demand**

The majority of directors, managers, and supervisors at health plans highlighted the growing need for care managers with expertise in dementia care coordination. Many also highlighted that they have been increasingly seeing members with ADRD or cognitive challenges, providing anecdotal evidence of the epidemiologic trends that have been reported. They mentioned that there will not be enough care managers, caregivers, or long-term care facilities to meet this growing demand.

*"It's very important. Ideally, we would like to have all our care coordinators to be very well trained in this area [be]cause I think we're going to see more and more people affected with cognitive impairment. [They] [m]ay not have a diagnosis of dementia, but there's going to be some level of a cognitive impairment that needs to be properly assessed and addressed."*

*"What I know is going to happen, people my age and the baby boomers, there's not enough caregivers, there's not enough facilities, there's just not .... There's got to be more in the future, because this population is going to have a huge explosion in the future, and I don't see that we are preparing or doing anything to begin to even prepare for that."*

Health plans also highlighted that there was a growing number of members with dementia who also have multiple chronic conditions. These complex cases often required greater supervision, and extensive, well-integrated person- and family-centered care plans and care coordination. As described by one DCSs:

*"Currently in my new position, we are rolling out dementia care management to the entire system. We have noticed that members have a lot of complex health concerns and it is made much harder when they have Alzheimer's disease."*

## **Facilitators and Challenges**

There were several facilitators and challenges to the training and practice of DCSs that may have impacted their ability to provide effective dementia care coordination. The CMS contract was a huge driver to participation in training DCSs for the health plans participating in the Cal MediConnect Project. Existing relationships with Alzheimer's organizations also helped to drive health plan buy-in. In addition, support directly from the health plan's senior leadership was pivotal to getting health plans to participate in the DCSs training as well as being in compliance with the CMS contract guidelines. In fact, some of the health plans even paid for the Alzheimer's organizations to provide the Tier 1 and 2 trainings to their care managers. Others provided time and allowed their care managers to participate in trainings offered by community organizations.

An additional facilitator to the training was health plans' concerns about costs and the potential cost savings of having care managers specialized in dementia care coordination. Health plan directors and supervisors acknowledged that members with ADRD often had higher costs for health care and required more time from care managers and much more extensive and ongoing care coordination. Finally, health plans and DCSs acknowledged that the DCS Training Program was customized to their needs, staff's availability, and that it was convenient because of nearby or local trainings.

One of the major challenges to the training and practice of DCSs was the lack of system infrastructure (e.g., a lack of decision support tools for dementia care coordination and integrating cognitive screenings into medical care systems and for record-keeping) and the inability to track the effectiveness of dementia care coordination, potential cost savings, and health outcomes for members with dementia and their caregivers. While health plans were starting to integrate dementia care coordination best practices into care management systems, it was a slow and challenging process.

Reimbursement for dementia care coordination was also limited based on current CMS reimbursement models, especially for the additional support of caregivers. Typically, billing was a part of health plans' standard care management reimbursements from CMS and there was no mechanism for covering the additional costs of specialized dementia care coordination. For example, since the system is capitated, health plans receive a per person monthly rate as part of their standard reimbursement, but there is no additional reimbursement for more challenging or time-consuming cases.

While the trainings were rated highly and there were limited challenges for completion, participation in the six-month “huddle” calls was a challenge. There was often a decline over time in participation. This resulted in a low turnout for the “huddle” calls and a missed opportunity for DCSs to gain additional hands-on training and real-world problem solving skills. This likely had to do with health plans not providing protected time for DCSs to attend the additional training provided in the “huddle” calls.

Another challenge for health plans in maintaining effective dementia care coordination was high DCS turnover. In the first three years of the project, nearly 30% of trained DCSs (n = 29) had left their health plans and about 10% were either promoted or had a change in their role (e.g., moved to a different department). Reasons for turnover included the DCSs moving to another local health plan for advancement or more competitive wages. However, turnover sometimes resulted in other health plans gaining a DCS or a DCS moving into a senior leadership position. Having DCSs in senior leadership positions may aid in future systems changes that may be supportive of effective dementia care coordination.

A final challenge was the lack of acknowledgement of DCSs’ level of expertise and inconsistency in how their roles were carried out in providing dementia care coordination and on the ICTs. None of the health plans reported that they directly assigned members with AD/DRD to a DCS. It has been suggested that assigning DCSs to people with two or more conditions and dementia or using some other criterias may led to better allocation of care and lower costs. In addition, DCSs mentioned that there was variability in how they were utilized. For instance, some health plans had DCSs serve on ICTs while other plans used them less formally, such as being available to consult on difficult cases or train newly hired care managers. Skill level and scope of practice also varied given that some care managers were nurses, social workers, or another healthcare professional (e.g., Masters prepared in healthcare administration or MHA). Finally, health plans sometimes assigned more experienced care managers to complete the Tier 1 and 2 trainings, while others relied on care managers volunteering to participate. These inconsistencies may result in variability in the scope and effectiveness of dementia care coordination across these local health plans. There is a need for a more structured implementation plan, adoption of consistent processes for dementia care coordination, and standardized assessment of health outcomes and cost savings for members and health plans. Future efforts

aimed at providing a formal certification to highlight proficiency in dementia care and encouraging on-going continuing education should be considered.

## **Discussion, Policy Implications and Future Directions**

There is a need for greater support and resources for family or unpaid caregivers. Additional care needs of persons with ADRD are typically covered by unpaid caregivers, of which 83% comes from family members, friends or other unpaid caregivers.<sup>5</sup> In 2016, this accounted for an estimated 18.2 billion hours of unpaid care and an economic value of \$230.1 billion. It has also been estimated that there will likely be a decrease in the number of family caregivers that can provide care to persons with ADRD in the future.<sup>19</sup> In addition, policies aimed at reducing LTC admissions, rehospitalizations, and length of stay, may increase demands for effective care coordination and family caregivers.<sup>20,21</sup>

These societal and economic burdens highlight the need for effective workforce planning to care for a greater number of persons with ADRD. This includes effective policies aimed at managing health care costs by adopting and translating evidence-based workforce and dementia care coordination practices into health systems, communities, and for caregivers of persons with ADRD.

## **Limitations**

Our study has several limitations. First, the generalizability of findings is limited since all DCSs interviewed were based in California and participated in the state's Financial Realignment Pilot, Cal MediConnect Project, and received training from participating Alzheimer's organizations in the Dementia Cal MediConnect Project. However, key informants from all nine health plans participating in the Dementia Cal MediConnect Project were interviewed. Due to the high turnover of managers and DCSs, our findings may reflect the more promising examples of dementia care coordination and management, adoption of training skills, and other positive perspectives. While findings may not be representative of all dementia care coordination practices, this work can inform future national efforts aimed at providing effective care coordination at health plans and other care management programs, as well as providing support for patients with ADRD and their caregivers.

## Conclusion

There is a need for further efforts aimed at translating evidence-based practices for dementia care coordination into health systems and to evaluate promising dementia care management practices. The Dementia Cal MediConnect Project's training of DCSs is a promising strategy for ensuring a dementia-capable workforce that can institute standardized practices for dementia care management and services to support caregivers. This model has already started to be disseminated across six states and regions, including Georgia, Maryland, North Carolina, Rhode Island, Texas, Virginia, and Washington D.C. This growth is likely due to increasing demand for dementia care and rising health care costs for dementia care management and paid caregiving. Dissemination has been aided by the online, train-the-trainer resources provided by the Dementia Cal MediConnect Project: (<https://www.alzglia.org/professionals/creating-dementia-capable-healthcare-systems/>). Future research is needed on the impact of similar CMS policies in other states and the effectiveness of workforce training and their dementia capability on improving health outcomes and processes while reducing health care costs for individuals living with ADRD and their caregivers.

## **Table 1. Content for the Tier 1 and Tier 2 Dementia Care Specialist Training Program**

Tier 1 - Basic dementia knowledge and skills

Causes and risk factors for Alzheimer's disease and relate dementia

Algorithm for cognitive screening

AD8<sup>18</sup>

Disease management guidelines

Addressing challenging behaviors - *IDEA!* Behavior Management Approach<sup>22</sup>

Community resources

Video clips, facilitated discussions, and activities (problem-based scenarios, role playing, & case studies)

Tier 2 – Advanced-level dementia knowledge and skills

Enhancing cognitive screenings skills

Applying the *IDEA!* Behavior Management Approach

Identification of informal/family caregivers

Identifying needs of informal and family caregivers/caregiver assessment tools

Development and implementation of a care plans

Video clips, facilitated discussions, and activities (problem-based scenarios, role playing, & case studies)

## **Acronyms Used in this Report**

ADRD – Alzheimer’s disease and related dementias

CMS – Centers for Medicare and Medicaid Services

DCS – Dementia Care Specialist

ICT – Interdisciplinary care team

LTC – Long-term Care

MHA - Master of Healthcare Administration

MSW – Master in social work

RN – Registered nurse



## References

1. Alzheimer's Association. 2015 Alzheimer's disease facts and figures. *Alzheimers Dement.* 2015;11(3):332-384.
2. Hollister B, Flatt JD, Chapman SA. Dementia-Capable Care Coordination in Duals Demonstration Programs: Workforce Needs, Promising Practices, and Policy. *The Gerontologist.* 2017.
3. McGurin NE, Budson A, Gosselin E, Patterson B. DEMENTIA CARE COORDINATION: IMPACT ON PATIENT AND CAREGIVER OUTCOMES. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association.* 2016;12(7):P794.
4. Nadash P, Silverstein NM, Porell F. The Dementia Care Coordination Program: Engaging health systems in caregiver supports. *Dementia.* 2017:1471301217697466.
5. Alzheimer's Association. 2017 Alzheimer's disease facts and figures. *Alzheimer's & Dementia.* 2017;13(4):325-373.
6. Alzheimer's Association. 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia.* 2016;12(4):459-509.
7. Cottingham AH, Alder C, Austrom MG, Johnson CS, Boustani MA, Litzelman DK. New workforce development in dementia care: Screening for "caring": Preliminary data. *Journal of the American Geriatrics Society.* 2014;62(7):1364-1368.
8. Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures: Includes a Special Report on the Personal Financial Impact of Alzheimer on Families.* Alzheimer's Association; 2016.
9. Alzheimer's Association. *Alzheimer's Disease Facts and Figures in California.* 2009. <https://www.alz.org/CAdata/FullReport2009.pdf>. Accessed September 9, 2017.
10. Connolly L. California Coordinated Care Initiative: An Opportunity to Improve Access and Services for Persons with Dementia and their Family Caregivers. 2016; <http://www.chhs.ca.gov/Alzheimer/AgendaItem4-DementiaCalMediConnectProjectUpdate.pdf>. Accessed September 9, 2017.
11. Cherry D, Schlesinger, J., Hollister, B. Dementia Cal MediConnect: Project Evolution and Results. *Generations.* 2017;ACL Supplement:63-67.
12. Schensul SL, Schensul JJ, LeCompte MD. *Essential ethnographic methods: Observations, interviews, and questionnaires.* Vol 2: Rowman Altamira; 1999.
13. Contract with California Department of Health Care Services, (2013); <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/CAContractwithoutSub.pdf>. Accessed September 9, 2017.

14. Vickrey BG, Mittman BS, Connor KI, et al. The Effect of a Disease Management Intervention on Quality and Outcomes of Dementia Care: A Randomized, Controlled Trial. *Dementia Care Quality Intervention Trial. Annals of internal medicine.* 2006;145(10):713-726.
15. Chodosh J, Berry E, Lee M, et al. Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of care. *Journal of the American Geriatrics Society.* 2006;54(2):311-317.
16. Clark P, Bass D, Looman W, McCarthy C, Eckert S. Outcomes for patients with dementia from the Cleveland Alzheimer's Managed Care Demonstration. *Aging & mental health.* 2004;8(1):40-51.
17. Borson S, Chodosh J. Developing dementia-capable health care systems: A 12-step program. *Clinics in Geriatric Medicine.* 2014;30(3):395-420.
18. Galvin J, Roe C, Powlishta K, et al. The AD8: A brief informant interview to detect dementia. *Neurology.* 2005;65(4):559-564.
19. National Academies of Sciences, Institute of Medicine. *Families caring for an aging America.* National Academies Press; 2016.
20. Mor V, Zinn J, Gozalo P, Feng Z, Intrator O, Grabowski DC. Prospects for transferring nursing home residents to the community. *Health Affairs.* 2007;26(6):1762-1771.
21. Gaugler JE, Jukowitz E, Peterson C.M. An Overview of Dementia Caregiving in the United States. *Generations.* 2017;ACL Supplement:37-43.
22. Alzheimer's Greater Los Angeles, 2016. *IDEA! Strategy.* <https://www.alzgl.org/wp-content/uploads/2016/01/Dementia-Care-Toolkit-IDEA-strategy.pdf>. Accessed September 9, 2017.