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Dementia Cal MediConnect: Creating Partnerships Between Health Plans and Alzheimer's Organizations to Improve Care in the Dual Eligibles Pilot

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People who are living with dementia are highly reliant on family and other unpaid caregivers because of their cognitive impairment and inability to manage self-care. Family caregivers are essential members of care teams, as they carry out care plans and facilitate access to support services. Hence, health care for this population is best delivered in active partnership with family caregivers and community-based Alzheimer's organizations. With the innovations inspired by the Affordable Care Act, there have been opportunities to implement more coordinated systems of care that seek to engage unpaid caregivers and community providers in the care process and to improve outcomes while controlling costs. One such opportunity is the Federal Centers for Medicare and Medicaid Services' (CMS) Financial and Administrative Alignment Initiative, a national demonstration program operating in 13 states. This demonstration project (sometimes called the Duals Demonstration) seeks to better coordinate medical care and long-term services and supports (LTSS) for individuals who are dually eligible for Medicare and Medicaid. For dually eligible people living with dementia, these demonstrations have the potential to deliver care in less expensive, community-based settings, which are preferred by most patients and families.

In 2013, the State of California's Department of Aging, in partnership with Alzheimer's Greater Los Angeles, was awarded a grant from the Alzheimer's Disease Supportive Services Program of the federal Administration for Community Living (ACL). The aim was to better the care coordination provided to people with dementia in Cal MediConnect (CMC), California's Financial Alignment Initiative pilot. The project, called Dementia Cal MediConnect (Dementia CMC), built upon the opportunities provided by the federal demonstration's primary objectives: to improve health care outcomes and expand access to health care and LTSS while controlling cost. With a capitated payment for each member served, CMC incentivized plans to provide necessary care in the appropriate environment. It offered an opportunity to strengthen home- and community-based LTSS and to integrate them better with medical care with the hope of improving care processes and reducing hospitalizations and institutionalization (two of the main drivers of medical expenses for the duals population and for people living with dementia).

While the Dementia CMC Project focused on dually eligible health plan members in the CMC pilot, it offered the possibility of improving dementia care more broadly, as it was well known that health plans tend to disseminate

successful innovations within all their lines of business and across geographic locations. Therefore, success within the California pilot could influence care well beyond that provided to enrollees in the state's Financial Alignment pilot. This opportunity was identified and led by Alzheimer's Greater Los Angeles and the California Department of Aging in partnership with the Departments of Health Care Services (the state's Medicaid Agency) and the Department of Public Health, nine CMC health plans, and several community-based Alzheimer's organizations.

Rationale: Why Should Dementia Care be of Concern to Health Care Organizations?

Providing and obtaining high-quality, cost-effective dementia care is an overwhelming challenge for people living with the disease, their families, and the health care systems that serve them. The numbers of people living with dementia are growing, and expected to triple by mid-century (Alzheimer's Association, 2016). The financial burden of care is heavy, both for families and for public programs. These beneficiaries cost Medicare three times more than do other beneficiaries, and they cost Medicaid 19 times more than the cost of care for other Medicare recipients (Bynum, 2009). Dementia not only significantly increases the likelihood and length of hospitalizations but also is recognized as an independent risk factor for nursing home admission (Zhu et al., 2006). Making dually eligible beneficiaries even more vulnerable to admission to institutional care are their high rates of comorbid conditions: 60% have hypertension, 26% have coronary heart disease, 25% have had a stroke, and 23% have diabetes (Bynum, 2009). While these figures are staggering, dementia takes the most dramatic toll on the people who live with it and their family/friend caregivers, many of whom cope with the unrelenting burden of Alzheimer's or a related dementia (ADRD) with little or no direction or support from the health care system.

More than 80% of care for people with ADRD is provided by family and other unpaid caregivers, making them the backbone of dementia LTSS (Schulz & Quittner, 1998). Nationwide, in 2015, 15.9 million family and other unpaid caregivers to people with ADRD surrendered 18.1 billion hours of unpaid care to their loved ones, care estimated to be worth \$221.3 billion (Alzheimer's Association, 2016). The cost to the unpaid caregiver is high: a 63% higher mortality rate than that of peers who are not caregivers and elevated levels of depression, emotional stress, and burnout (Schulz & Beach, 1999).

What Makes a System of Care Dementia Capable?

Borson and Chodosh (2014) describe dementia-capable health care systems, in part, as ones in which there is a focus on detection and care partners are engaged early; clinical care is comprehensive with management of behavioral symptoms

and involvement of caregivers as health care partners; and system changes include formal care coordination and accessible information. As early as 2004, a Kaiser Permanente study in Los Angeles showed that dementia care management, coupled with provider and caregiver education and support provided through partnership with a community-based Alzheimer's organization, could produce dividends: higher levels of caregiver and physician satisfaction with care, higher rates of adherence to practice guidelines, and improvements in family-reported care outcomes (Cherry et al., 2004). Since that time, four randomized controlled trials have examined ways to improve care for this vulnerable population, while controlling costs (Callahan et al., 2006; Clark, Bass, Looman, McCarthy, & Eckert, 2004; Morgan et al., 2015; Vickrey et al., 2006). Each recommended (1) training in dementia care for clinical staff, (2) better collaboration with community-based organizations, and (3) assigning a specialized dementia care manager to patients with ADRD. The Alzheimer's Disease Coordinated Care for San Diego Seniors study, led by Vickrey, further demonstrated that dementia care management and access to community-based organizations for collaborative care management produced cumulative results; together the two interventions were better than use of only dementia care management (Vickrey et al., 2006). More recently, early reports from a CMS Innovation Study performed by the University of California, Los Angeles' Alzheimer's and Dementia Program make similar assertions. In a presentation of preliminary project results, David Reuben, the project director, reported that this intervention, which relies on dementia care management by nurses supplemented by supports from community-based organizations, is improving quality outcomes and decreasing utilization of high-cost medical services (Reuben, 2017).

Unfortunately, despite the literature and evidence behind these dementia-capable care practices, they are not being implemented in most health care systems, and they were not standard practice in the CMC health plans. The Dementia CMC Project focused on building capacity within the health plans to provide dementia care management and to partner with family caregivers and with community-based Alzheimer's organizations. The dementia-capable care practices this project sought to achieve fell into three categories: (1) screening for dementia; (2) caregiver identification, assessment, support, and engagement; and (3) collaboration with community-based Alzheimer's organizations. Table 1 outlines these dementia-capable care processes and the strategies and tools that the Dementia CMC Project utilized to encourage their practice (Galvin et al., 2005; Bass, Noelker, & Reclin, 1996; Vickrey et al., 2006). They are openly accessible on the Alzheimer's Greater Los Angeles website (www.alzglgla.org).

Using Policy Levers to Stimulate Change

To engage the health plans, the Dementia CMC Project staff presented policy levers and opportunities to expand

Table 1. Tools for Dementia-Capable Care Used by Dementia CMC Project

Dementia-Capable Goals	Indicators of Systems Change	Tools ^a
1. Better detection and care management of beneficiaries with dementia	<ul style="list-style-type: none"> • Health risk assessment/other assessments include cognitive impairment • Adoption of AD8 screening tool or other validated cognitive screening tool • Integration of cognitive assessment into e-medical record • Protocol for diagnosis if screen is positive 	<ul style="list-style-type: none"> • Health Risk Assessment Cognitive Impairment Trigger Questions • AD8 (Galvin et al., 2005)
2. Better partnerships between health systems and family/friend caregivers ^b	<ul style="list-style-type: none"> • Ability to identify family/friend caregiver • Documentation of family/friend caregiver in medical record • Family/friend caregiver assessment adopted • Integration of family/friend caregiver education • Adoption of standardized care plans • Respite benefit provided by health plan • Workflow processes established for use of Dementia Care Specialist 	<ul style="list-style-type: none"> • Tool for Identifying an Informal or Family Caregiver • Benjamin Rose Institute Caregiver Strain Instrument (Bass et al., 1996) • Care Needs Assessment Tool • IDEA! Strategy for Managing Challenging Behavioral Symptoms • Plain Language Fact Sheets • Standardized Care Plans (derived from Vickrey et al., 2006)
3. Better partnerships with dementia-specific community-based organizations	<ul style="list-style-type: none"> • Provision of dementia-specific professional training programs and technical assistance • Provision of services and supports to patients and family/informal caregivers • Adoption of ALZ Direct Connect referral program to connect to: <ul style="list-style-type: none"> • Support groups • Caregiver education • Early stage services • Care counseling • Engagement programs 	<ul style="list-style-type: none"> • In-person Dementia Care Manager Tier 1 training • In-person Dementia Care Specialist Tier 2 training • Web-based training modules for care managers • ALZ Direct Connect referral program

^a Tools are available on Alzheimer's Greater Los Angeles website (www.alzgl.org/professionals).

^b The term caregiver refers to any family member, friend, or neighbor who cares full-time or part-time for someone with dementia.

adoption of dementia-capable care practices to nine participating California health plans. With a capitated payment structure and a mandate to integrate the full spectrum of care for their members, CMC plans were forced to explore more efficient and better coordinated systems of care. When serving members with dementia and their caregivers, they faced the daunting task of ensuring that their staffs were prepared to provide dementia-capable care coordination. Operating within a capitated payment system, the stakes of failing in this task were insurmountable financial challenges.

In addition to these financial incentives, further incentives were provided by Dementia CMC staff to improve systems of care through references to the three-way contracts executed between the insurers, the state, and CMS and through "All Plan" letters issued by the state, providing guidance based on the three-way contract. These documents delineated mandates for care coordination and assessment practices, benefits and care plan options, caregiver identification and involvement, workforce qualifications and training, and data reporting and quality metrics that served as policy levers to achieve the Dementia CMC Project's goals. Using these financial, administrative, and

contractual incentives, the Dementia CMC Project endeavored to increase knowledge about dementia, improve care practices, and change systems and protocols within the CMC demonstration.

Advocacy, Training, and Technical Assistance to Advance High-Quality Dementia Care

To affect improved dementia care, the Dementia CMC Project began with and relied upon advocacy at state, stakeholder, and health plan advisory meetings. A five-step process was developed to move the quality dementia care agenda forward (Figure 1). First, the project made the case for addressing dementia care to champions and leaders within the health plans and at the state level, speaking about the potential value proposition behind improving dementia care, describing the CMC policy levers that support it, and explaining the benefits of partnering with family caregivers and with community-based Alzheimer's organizations. Next, project staff asked for help, clearly explaining the need for care manager training, an important step toward improving the system of care for people with dementia and

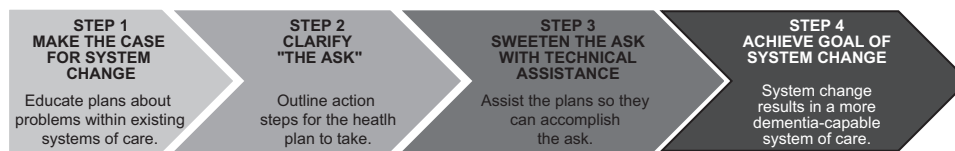


Figure 1. Steps for advocacy.

for caregiver support and education. This was followed by training and technical assistance to build the skills of key health care staff; caregiver education and support (much of which was provided by community-based Alzheimer's organizations); and providing evaluation and feedback to help the plans monitor their progress toward becoming dementia-capable systems of care.

Buying the Case and Answering the Ask

The project's five-step process has generally been met with acceptance and enthusiasm. Within the Dementia CMC Project, more than 300 care managers have participated in an eight-hour training program, with 44 care managers from eight health plans receiving 12 additional hours of training to become Dementia Care Specialists. Additionally, more than 550 family caregivers have engaged in education or support programs. All participating health plans reported making changes to their delivery of care. Three of the plans reported having changed their health risk assessments to include a screening for cognitive impairment, and four that did not have a validated cognitive screening tool in place adopted one and integrated it into their electronic care management system.

All health plans reported that they were systematically identifying family caregivers, and two plans began using measures of caregiver stress and strain (Bass et al., 1996) as part of an assessment of caregivers' needs. While four participating health plans stated that they provided members with respite services as a "care plan option" through California's CMC pilot, in fact many of the plans refer to community-based Alzheimer's organizations for this service rather than paying for it themselves. Similarly, after two and a half years implementing the Dementia CMC Project, six health plans offer caregiver education, either directly or through a referral to a community-based Alzheimer's organization, and four health plans use a proactive referral tool, ALZ Direct Connect, to have the Alzheimer's organizations reach out to specific families with an offer of support, disease education, care counseling and planning, and connection to needed LTSS. Overall, the Dementia CMC Project has perhaps been more successful in convincing health plan staff to refer members and caregivers to the community-based Alzheimer's organizations for caregiver education and support services than in getting the plans to deliver these services themselves. Through community-based organizations, these support services were provided at no cost to beneficiaries, and most services were available

in lower literacy formats and in multiple languages, including English, Spanish, Chinese, and other languages through a translation service.

Encouraging Expansion and Replication

The Dementia CMC Project has leveraged opportunities for system change beyond California's border through engagement across a spectrum of endeavors, including participation in The John A. Hartford Foundation's Change AGENTS Initiative Dementia Caregiving Network, meetings with the CMS Office of Medicare and Medicaid Coordination, participation in the AARP Public Policy Institute's Managed Long-Term Services and Supports Learning Collaborative, and through advocacy with health plans that have a national reach. Additionally, a robust website containing a range of project materials to encourage replication continues to be expanded by Alzheimer's Greater Los Angeles (www.alzpla.org/professionals). Believing in the power of dissemination, the project has posted on the website materials and tools that states, health plans, community-based organizations, and advocates can use to replicate aspects of the Dementia CMC Project.

Outcomes From a Change AGENTS Gathering of Thought Leaders

In January 2016, in collaboration with the Dementia Caregiving Network, the Dementia CMC Project brought together in Washington, D.C., a group of national thought leaders, advocates, and representatives from ACL, CMS, and health plan leaders from the Financial Alignment Initiative. Together this group learned about promising practices from California's Dementia CMC Project and requested strategies for leveraging this project for a broader reach to other health plans and other states. Members identified steps that could be taken to promote improving dementia care within the national pilot. Following this convening, project staff undertook several dissemination and replication activities, which might lead to greater uptake of the project's promising practices:

- In 2016 both Texas and Rhode Island took steps to initiate programs with components derived from the Dementia CMC Project by exploring ACL funding opportunities within their states, both of which participate in the Financial Alignment Initiative. Texas has acquired an ACL grant and is beginning to implement its project.

- The CMS Medicare-Medicaid Coordination Office was approached and subsequently agreed to issue an Informational Bulletin on dementia care, starting with dissemination in California, with possible later dissemination in Texas and other states participating in the duals pilot. The Informational Bulletin makes the case to health plans for improving their dementia care processes and holds them accountable for making recommended improvements to care. Thus, California's participating health plans have reviewed their systems of care and provided updates to the state for its review.
- Furthermore, the CMS Medicare-Medicaid Coordination Office urged the inclusion of promising practices from the Dementia CMC Project in a 2016 Geriatric Competent Care Webinar Series "Caring for Individuals with Alzheimer's Disease and Related Dementias" (https://resourcesforintegratedcare.com/Geriatric_Competent_Care/Webinars/2016). The series, developed by the American Geriatrics Society in collaboration with Community Catalyst and The Lewin Group, brought a much larger audience to the Dementia CMC's work. More than 1400 individuals attended these presentations. An opportunity to build on this audience while reaching a more targeted audience came with the release of a new webinar, which was added to the series in 2017, "Advancing Dementia Care within Integrated Medicare and Medicaid Models." There were more than 500 attendees.
- The AARP Public Policy Institute selected the California effort as a promising practice to highlight in its paper "Family Caregivers and Managed Long-Term Services and Supports" and featured this work in telephone-based learning collaborative meetings on this subject. The calls are attended by staff from health plans and government agencies and by advocates from across the country who are trying to do this work (Reinhard, Fox-Grage, & Feinberg, 2016).
- Other thought leaders also brought promising practices from this work to their constituents through webinars hosted by Justice in Aging and the American Society on Aging.

Dementia Care Management Toolkit

Dementia CMC Project staff have produced a Dementia Care Management Toolkit, a guide to aiding health plans and advocates in their efforts to improve dementia care. It provides tools and strategies both for advocacy and in support of quality dementia health care, including screening tools and other tools for identifying family caregivers and their needs, assessing their stress, and supporting them with standardized care protocols. To support their caregiving education needs, the toolkit provides high-interest, low-reading level fact sheets written in plain language. This toolkit is available online (www.alzgl.org/professionals).

In 2016, advocates from Alzheimer's disease-knowledgeable community-based organizations attended a

web-based training that tracked components of the tool kit. Twenty-nine advocates from five states attended a session on health care system advocacy through a Dementia CMC-authored training module complete with supportive tools. Later, 21 participants from these states also attended a web-based train-the-trainer webinar to master delivery of the care manager training curricula developed through the Dementia CMC Project. Two have since implemented the training in new geographic areas.

Conclusion

This type of system change, which is built upon policy levers, is an iterative process that requires trust and a long-term investment in personal relationships. At each stage of implementation and innovation, the growing relationship between dementia advocates and health care partners is critical in moving toward a dementia-capable system of care. As the process advances, the advocacy approach should adapt accordingly, moving from key messaging statements that are more appropriate to stakeholder meetings, such as "Only 50% of people with Alzheimer's have a formal diagnosis, and only half of these have it documented in their medical records" or "Family caregivers are the backbone of our community-based long-term care system," to more collaborative, one-on-one interactions and supportive technical assistance. For those struggling with ADRD, these reforms to integrate and coordinate care can mean improved screening for cognitive impairment; better trained health care and health plan professionals; newly developed systems to identify, assess, support, and engage family/friend caregivers; and adoption of a referral program that connects families to home and community-based services, including Alzheimer's organizations. For providers and insurers, these changes should mean greater access to specialized training, better coordinated care for individual patients, expanded patient- and family-centered collaborations, and the promise of better long-term cost control.

As California and the country move forward with more integrated systems of care, key components of quality managed care for people with dementia must be in place. The costs of not doing so—to families, to our communities, and to publicly funded health care programs—are too great.

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