



## *Improving Dementia Care and Identification and Support of Family Caregivers in the Dually-Eligible Population*

One overarching aim and call to action of the Change AGENTS Initiative Dementia Caregiving Network (DCN) was improving the identification, assessment, and support of family caregivers within health care systems. Family caregivers provide the overwhelming majority of care to persons with dementia and are therefore vital partners in all of health and long-term care delivery. The more than 9 million individuals who are covered by both Medicare and Medicaid have complex and often costly health care needs. This dually-eligible population includes an especially vulnerable population of persons with Alzheimer's disease and related disorders (ADRD) who face higher rates of hospitalization and nursing home entry than older adults without ADRD. Likewise, the family caregivers who are vital to helping meet daily care needs of persons with ADRD face significant risks to their own physical and emotional well-being from their lack of training and support for their care responsibilities. Support, education, and training for family caregivers have been shown to improve the quality of life of persons with dementia and the health and well-being of their caregivers. Recent health reform initiatives focus on improving care and controlling costs for people who are dually-eligible beneficiaries and offer the opportunity for health systems to explore new approaches to dementia care and caregiver engagement and support.

The **Dementia Cal MediConnect Project** ([Dementia CMC](#)), co-led by DCN member and Alzheimer's Greater Los Angeles Executive Vice President Debra Cherry and California Department of Aging Director Lora Connolly, presented an opportunity to address the challenges of dementia caregiving with an innovative approach within health care reform. As one of twelve states participating in a Centers for Medicare and Medicaid Services (CMS) demonstration project under the CMS Financial Alignment Initiative (sometimes called a "Duals Pilot"), California has a contract with CMS and with multiple health plans to align administration of services and financing for people dually-eligible for Medicare and Medicaid in six counties. Working with CMS and the health plans, California seeks to blend funding and better coordinate enrollees' medical, behavioral, long-term institutional, and home and community-based services and supports to provide the "right care in the right place at the right time" and thereby avoid unnecessary and costly hospitalizations and institutionalization.

With funding from the Administration for Community Living Alzheimer's Disease Supportive Services Program ([ACL-ADSSP](#)), Dementia CMC has undertaken several activities to advance the capabilities of the health plans and their affiliated providers to identify plan members with cognitive impairment, to identify the members' family caregivers, and to adopt promising practices to meet their needs. The Dementia CMC team has effectively leveraged provisions in the three-way contracts between CMS, California's Department of Health Care Services, and each of the participating health plans requiring that dementia care coordination staff be specially designated and have specific dementia-related knowledge to better serve patients and family caregivers. Further leverage was provided by guidance letters issued to health plans by the state requiring a cognitive screen in health risk assessments and mandating that a caregiver be identified if needed. The Dementia CMC project staff outlined a set of quality goals, including better detection and screening of patients with dementia; identification, assessment, support, and engagement of family caregivers; and improved co-management with community-based organizations. To achieve these goals, the project advocated with the plans, provided them with technical assistance, trained their care managers, delivered caregiver education, and encouraged referral of patients and caregivers to local Alzheimer's organizations. The DCN strategically collaborated with Dementia CMC project leaders to strengthen the value of lessons learned and advance the dissemination and uptake of the tools and resources for health plans, care managers, community-based advocates, and family caregivers.

## **Outcomes of Collaborative Work**

The DCN convened a meeting of key policy stakeholders, advocates, health plan leaders, ACL and CMS staff, and DCN leaders for advancing attention to caregiver identification, assessment, support, and engagement through all avenues: policy, health care systems changes, provider training, and consumer advocacy.

Outcomes from this activity included pursuit of other states with financial alignment demonstration projects in which to replicate promising practices from California, leading to Texas and Rhode Island incorporating these practices in their demonstrations. DCN members with the guidance of the California team helped the State of Texas secure an ACL-ADSSP grant. Activities for the Texas initiative began in October 2016.

## **Additional Activities and Accomplishments of Dementia CMC**

1. Contributed to evaluation of training provided to 289 care managers in nine California health plans.
2. Produced, with guidance from the DCN, the Dementia Care Management Toolkit, including guidance for identifying caregivers, assessing their stress, and determining their needs; standardized care plans for supporting caregivers; and “plain language” fact sheets written at a low reading level for education of caregivers. These materials are available for free as web downloads from [www.alzgia.org/professionals](http://www.alzgia.org/professionals).
3. Developed a training module, “Advocacy with Healthcare Systems,” and supportive documents that were recently used to train 29 advocates from five states, including Rhode Island, Maryland, Texas, California, and Virginia.
4. Supported peer learning by convening teams of leaders from five health plans in Southern California, representatives from CMS and the California Departments of Aging and of Health Care Services, which administers the state's Medicaid program (Medi-Cal), and the team from Alzheimer's Greater Los Angeles to share best practices and inform key policy makers and funders of their system change accomplishments.
5. Saw their work featured prominently in the Geriatric-Competent Care Webinar Series, “Caring for Individuals with Alzheimer's Disease and Related Dementias,” which was developed by the American Geriatrics Society in collaboration with Community Catalyst and The Lewin Group and hosted by the CMS Medicare-Medicaid Coordination Office Integrated Care Resource Center in 2015 and 2016. DCN members contributed to the development and delivery of this series. These [webinars](#) were delivered twice and reached a large number of health professionals from many settings and disciplines, averaging 500 each in 2015 and 300 each in 2016. A new webinar, “Advancing Dementia Care within Integrated Medicare and Medicaid Models,” will be added to this series in 2017.
6. Conceived a comprehensive white paper on lessons learned, which is in production and will be available in 2017 on the website of The Gerontological Society of America.

## **Leadership and Ongoing Work**

Leadership for this extensive array of practice change activities that achieve and disseminate improvements in services, supports, and care for persons with dementia and their family caregivers has involved DCN members, including Debra Cherry at Alzheimer's Greater Los Angeles ([dcherry@alzgia.org](mailto:dcherry@alzgia.org)), Lisa Gwyther at the Duke Family Support Program ([lisa.gwyther@duke.edu](mailto:lisa.gwyther@duke.edu)), Katie Maslow at The Gerontological Society of America ([kmaslow@geron.org](mailto:kmaslow@geron.org)), Nancy Wilson (DCN co-lead) at Baylor College of Medicine and Michael E. DeBakey Veterans Affairs Medical Center ([nwilson@bcm.edu](mailto:nwilson@bcm.edu)), and collaborator Brooke Hollister at the University of California, San Francisco ([Brooke.Hollister@ucsf.edu](mailto:Brooke.Hollister@ucsf.edu)), all of whom continue to advance this work in their states and across the country.

*The Change AGENTS Initiative was a three-year effort dedicated to improving the health of older Americans, their families, and their communities through practice change. The initiative harnessed the collective strengths, resources, and expertise of the John A. Hartford Foundation's interprofessional community of scholars, clinicians, and health system leaders. The initiative was managed by The Gerontological Society of America with support from the John A. Hartford Foundation.*