

Building an advocacy model to improve the dementia-capability of health plans in California

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Abstract

Background: Given the high and growing prevalence of Alzheimer's disease and related dementias, and the intensity of this population's care needs, it is imperative that healthcare systems increase their capacity to effectively serve people living with dementia (PLwD). The Dementia Cal MediConnect (Dementia CMC) project proposes an advocacy model that may foster dementia-capable systems change.

Methods: The Dementia CMC project was a 5-year partnership (2013–2018) between local Alzheimer's organizations and 10 managed care health plans (HPs) in California's duals demonstration. It used an advocacy model with the following steps: (1) Identify dementia-capable best practices to set as systems change indicators; (2) Identify and leverage public policies in support of systems change indicators; (3) Identify and engage champions; (4) Develop and advocate for a business case to improve dementia care; (5) Identify gaps in dementia-capable practices; (6) Provide technical assistance, tools, and staff training to address the gaps in dementia-capable practices; and (7) Track systems change. Systems change data were collected through participant observation with HPs and interviews with key informants representing partnering organizations or government entities.

Results: Participating HPs reported making systems changes toward more dementia-capable practices such as: better pathways for detection and diagnosis; better identification, assessment, support, and engagement of caregivers; and improved systems of referral to community-based organizations (CBOs), including Alzheimer's CBOs. Some indicators of systems change were inconclusive due to flawed assumptions around HP's care coordination, and the availability of common electronic health records between HPs and providers.

See related Editorial by Callahan et al.

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Conclusion: The application of this advocacy model in California has led to systems changes that can improve care for PLwD and their caregivers and should be replicated to expand the dementia-capability of other health systems. Continued efforts to refine indicators are needed to capture systems change in complex and changing health systems.

KEYWORDS

Alzheimer's, dementia, dementia-capable care coordination, managed care health plans, systems change

INTRODUCTION

In 2020, more than 5.8 million Americans aged 65+ live with Alzheimer's disease and related dementias, with that number is projected to reach 13.8 million by 2050.¹ However, most healthcare systems are ill-prepared to meet the unique needs of PLwD.¹ Dementia-capable healthcare systems include the expertise and best practices needed to identify and support PLwD and their caregivers by integrating clinical care with long-term services and supports (LTSS). Dementia-capable best care practices are established, though challenging to implement.²⁻⁶ Healthcare reforms have often tasked managed care HPs with providing care although containing costs through risk-based, capitated payments. The motivation of these HPs to innovate and control costs presents an opportunity to advocate for PLwD and make a business case for system change.

The Dementia Cal MediConnect project

In 2013, California initiated an effort to improve care for PLwD within its Financial and Administrative Alignment (duals) demonstration project, Cal MediConnect (CMC), which serves individuals dually eligible for Medicare and Medicaid through managed care HPs. CMC's HPs served as the single point of entry for enrollment and access to medical care, behavioral health, and LTSS. To participate in CMC, HPs were required to incorporate population-based screening, care coordination, and interdisciplinary care teams into their models of care.⁷ While HPs served approximately 110,000–120,000 CMC members during the project period, HP's overall membership was much higher.⁸ Prior to CMC, the participating HPs had little experience working with older adults or addressing LTSS needs. Literature leading up to CMC documented likely challenges with care coordination, LTSS, and serving vulnerable populations.^{9,10} As active participants in their communities, project partners were concerned about the HP's ability to serve individuals with dementia. This article describes a multicomponent advocacy model used to

Key Points

- Health systems lack dementia-capability.
- Advocacy can be used to encourage dementia-capable systems change.
- Indicators can be tracked to monitor dementia-capable systems change.

Why Does this Paper Matter?

Following advocacy, health plans were more dementia-capable according to several indicators.

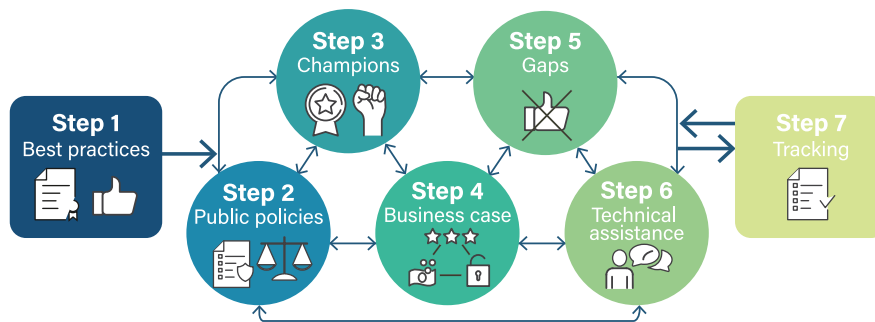
encourage dementia-capable HP system change and presents findings regarding systems change indicators.

The Dementia CMC project was led by the California Department of Aging and Alzheimer's Los Angeles, in partnership with the California Departments of Health Care Services and Public Health; the Alzheimer's Association Northern California and Northern Nevada Chapter; Alzheimer's San Diego; and evaluators at the University of California, San Francisco. The project team met regularly from 2013 to 2018 to coordinate project implementation through monthly meetings, as well as quarterly Steering Group meetings with all project partners.

Creating and evaluating systems change

To create systems change, underlying system dynamics, structures, and conditions need to be examined, questioned, and at times disrupted through advocacy, policy, or both. Prior studies have highlighted challenges to tracking efforts to implement systems changes, and argue that they must consider the dynamics of the situation.^{11,12} Complex conditions and dynamics were considered when evaluating this advocacy model's impact on systems change. Additionally, the model's development was based

FIGURE 1 Key steps of an advocacy model to encourage dementia-capable systems change



on an evolving understanding of systems' norms, resources, operations, and interdependencies,¹³ which allowed the project to course correct and further refine the advocacy model and indicators over time. While literature on theories of change,¹⁴ systems change,¹³ and organizational change¹⁵ are helpful in mapping out how change can be achieved, the inputs or interventions to achieve change (“advocate for ...” or “raise awareness about ...”) are often oversimplified, making replication difficult.

PROCEDURES

The Dementia CMC project's multicomponent advocacy model engaged project partners as well as representatives from 10 CMC HPs and other stakeholders (home care agencies, CBOs), to inform our understanding of CMC and HP system norms, resources, and operations. This allowed the advocacy model to evolve over time, ultimately including the following steps: (1) Identify dementia-capable best practices to set as systems change indicators; (2) Identify and leverage public policies in support of systems change indicators; (3) Identify and engage champions; (4) Develop and advocate for a business case to improve dementia care; (5) Identify gaps in dementia-capable practices; (6) Provide technical assistance, tools, and staff training to address the gaps in dementia-capable practices; and (7) Track systems change (see Figure 1). While the model begins with Step 1 and ends with Step 7, Steps 2–6 are nonlinear, requiring an iterative and sometimes cyclical approach. For example, the order of steps may vary based on HP's readiness to participate. Additionally, depending on the results of Step 7, Steps 2–6 may need to be repeated. A more detailed description of project procedures can be found elsewhere.^{16,17}

Step 1: Identify dementia-capable best practices to set as systems change indicators

Dementia-capable best practices were identified through a review of literature and practice guidelines,^{2–6} as well

as requests for input from the State of California's Alzheimer's Disease Advisory Committee, which includes PLwD and their caregivers. Three primary areas of best practices were identified: (1) better detection and documentation of PLwD; (2) better identification, documentation, assessment, support, and engagement of family/friend caregivers; and (3) better care coordination and connection to CBOs for home and community-based services. Systems change indicators were identified to assess each HPs' dementia-capability (Table 1).

Step 2: Identify and leverage public policies in support of systems change indicators

Dementia-capable policy levers were identified in three-way contracts between the Centers for Medicare and Medicaid Services, the State of California (the State), and HPs; requiring HPs to provide population-based screening and care coordination, and to train Dementia Care Specialists.¹⁸ Project partners also regularly reviewed State guidance documents to identify levers that could be used to encourage the adoption of systems change indicators.^{19–22}

Step 3: Identify and engage champions

HP champions were often HP leaders (upper-level management in care management or LTSS) with personal connections to dementia and/or with knowledge of the needs of PLwD, geriatricians, or neurologists. Champions were usually identified by word of mouth or through introductory meetings about the project with HP leadership. Project staff held regular meetings with HP champions to discuss dementia-capable best practices and provide technical assistance (Step 6). Project staff also regularly engaged with policy champions within State and federal government. These policy champions were asked to serve on the project's steering committee and received updates on project activities. Project staff advocated with these policy champions to expand upon levers of dementia-capable

TABLE 1 Health plan progress toward dementia-capable systems change indicators

Systems change indicators	Baseline	Follow up
Better detection and documentation of people living with dementia		
(1) Assess members for cognitive impairment through an annual health risk assessment	^a	10
(2) Adopt a validated cognitive impairment screening tool	1	6
(3) Integrate the results of cognitive impairment screens into electronic health records	^b	^b
(4) Develop a protocol for follow-up in the case of a positive cognitive impairment screen	1	10
Better identification, documentation, assessment, support, and engagement of caregivers		
(5) Develop a protocol to identify and record the presence of a caregiver in electronic health records	^b	^b
(6) Develop a protocol to assess the stress, strain, and/or burden of caregivers using a validated tool	0	3
(7) Provide respite to caregivers of people living with dementia	0	6
(8) Provide or arrange for education for people living with dementia and their caregivers	1	10
Better care coordination and connection to community-based organizations for home and community-based services		
(9) Develop a protocol to assign members with dementia to Dementia Care Specialists	^b	^b
(10) Adopt a proactive tool to make referrals to Alzheimer's community-based organizations for disease education and support	0	7

^aBaseline data unavailable as indicators were added or revised later in the project.

^bFindings inconclusive or indicator flawed.

system change in policy documents (Step 2) and promote them to HPs.

Step 4: Develop and advocate for a business case to improve dementia care

A central component of the Dementia CMC project was ensuring HP leadership understood and internalized the importance of focusing on dementia-capable systems

changes. To accomplish this, project staff developed a business case statement.²³ Messaging in support of this statement was developed, including:

- Only about 50% of PLwD receive a formal diagnosis and only half of these have it documented in their charts.²⁴ Therefore, PLwD often do not access appropriate care for their dementia or other health conditions.
- Family caregivers are the backbone of our care system for PLwD, yet they are not well-supported by HPs. They need to be identified, assessed for their own needs, and provided with disease education and support.
- Alzheimer's CBOs offer many services beneficial to PLwD and their caregivers, but referrals are not made systematically.

These messages were communicated repeatedly and consistently to HP champions and through meetings with HP leadership at CMC stakeholder meetings, and were even featured in a Dementia Informational Bulletin issued by the State.²²

Step 5: Identify gaps in dementia-capable practices

Based on dementia-capable care practices and systems change indicators identified in Step 1 (Table 1), a checklist was created by project evaluators in collaboration with project partners to identify gaps in dementia-capable practices within the HPs. Through meetings with HP contacts, project partners established a "baseline" for each HP's progress toward the indicators. Usually, this was done through in-depth conversations about the HP's model of care, internal protocols and practices, and established ambitions. This system change checklist was later used to track systems change over time (Step 7).

Step 6: Provide technical assistance, tools, and staff training to address the gaps in dementia-capable practices

A multipronged strategy of technical assistance, promotion of specific tools, and HP staff training was adopted to address gaps in dementia-capable practices and encourage adoption of systems change indicators:

Technical assistance

Project partners offered technical assistance around the adoption of dementia-capable best practices and meeting

systems change indicators. HPs also sought technical assistance on issues such as: screens for cognitive impairment (CI); tools to determine caregiver needs; and content for physician training.

Tools

To facilitate the systems changes recommended by the Dementia CMC project, HPs were provided with tools that were easy to adopt and available online.²⁵ These included: CI trigger questions for Health Risk Assessments (HRAs), validated CI screens,²⁶ validated caregiver assessment tools,^{27,28} best practice dementia care plans,⁶ and a proactive referral tool to Alzheimer's CBOs.

Staff training

Project staff provided training to HP care management, LTSS, and behavioral health staff on using the suggested tools and implementing dementia-capable practices. Curricula are available online.²⁵

Step 7: Tracking systems change (methods)

In line with the literature, the project chose a mixed methods, adaptive evaluation design that could accommodate the evolving systems of care in which we hoped to stimulate change, as well as an approach that would allow us to capture interesting and unpredicted outcomes.¹² To capture evidence of systems change in complex systems, multiple methods of data collection were used: participant observation using a systems change checklist, process evaluation interviews, and systems change confirmation interviews. As noted in the literature on systems change^{11,12} and quality improvement research,²⁹⁻³¹ qualitative and observational designs, despite possible biases or other weaknesses, are preferable in evaluating interventions in complex systems. Ten HPs participated in the Dementia CMC project, eight beginning in 2013 and two in 2016.

Systems change checklist

Project staff from the Alzheimer's CBOs served as participant observers in meetings with the HPs, collecting guided field notes based on each of the indicators identified in Table 1. These were then entered into a shared checklist that created a baseline of gaps in dementia-capable practices (Step 5), and tracked and quantified system change

progress over time. All project partners were instructed on how to complete the checklist and nuances around each indicator were discussed at length. Baseline data were collected early in the relationship with each HP, usually within the first year of their involvement in the project. Baseline values were not available for every indicator, as some indicators were identified or refined later in the project. Efforts were made to complete checklists once a year, each HP completed between 2 and 6 checklists.

Process evaluation and systems change confirmation interviews

Process interviews with project partners ($n = 7$) and HP representatives ($n = 8$) were conducted at the end of 2017. Semistructured interview protocols included questions about systems change, effectiveness, barriers/challenges, sustainability, and replicability. In Fall 2018, systems change confirmation interviews were conducted with representatives from every participating HP ($n = 10$) to validate and expand upon the findings recorded in the systems change checklist. Often more than one HP representative was present for the interview to speak to the range of plan activities and protocols. These interviews were an important step in validating the findings in the checklists; discrepancies between data in the checklists and from the interviews were discussed between the interviewer and project partners. Occasionally, further clarification from the HPs was sought.

Analysis

Given the small sample size, basic descriptive analysis was conducted using quantitative data from the systems change checklist. Both process evaluation and systems change confirmation interviews were transcribed verbatim and thematically analyzed. Data were triangulated according to the systems change indicators.

Human subjects research

The study received human subjects' research exemption from the University of California, San Francisco Institutional Review Board in 2015.

FINDINGS

As a result of implementing this advocacy model, the project demonstrated effectiveness in moving HPs toward

more dementia-capable practices. Findings around each of the systems change indicators are presented in Table 1.

1. Assess members for CI through an annual HRA

Although three-way contracts implied that CMC HPs should include questions about CI in their assessment protocols, project partners found that HPs were uneven in their implementation; leading to increased advocacy with HP and policy champions around this issue, which was added as an indicator later in the project (hence the lack of a baseline values). By the end of the project, all HPs had at least one question in their HRA pertaining to CI. Additionally, in 2017, the State issued guidance mandating the inclusion of a specific CI trigger question in the CMC LTSS assessment protocol.²⁶ Key informants (KIs) reported that this guidance was issued partly because of project advocacy.

2. Adopt a validated CI screening tool

One HP was using a validated CI screen at baseline. By the conclusion of the project, six HPs, including three with national presence, reported adopting a validated screening tool into *at least one* of their assessment protocols. Two HPs reported that they were in process of meeting this indicator. However, KIs reported that HPs did not use the screening tool universally for people whose HRAs suggested CI. Rather, they were used in specific programs like complex care programs or memory clinics.

4. Develop a protocol for follow-up in the case of a positive CI screen

At baseline one HP reported having a formal protocol in place to refer a member with a positive CI screen to a provider for a diagnostic evaluation; by project completion, all plans reported having such a protocol. However, the interpretation of what qualifies as a “protocol” varied by plan. Every plan shared care plans with providers, which would include information about the member’s response to the CI question in the HRA or a positive screen. All HPs also confirmed that their care managers would contact providers to directly inform them of suspected CI. One HP reported that they developed a template letter for care managers to send to providers informing them of a positive CI screen and encouraging a

diagnostic evaluation. KIs reported that this template letter was later shared with all CMC HPs.

6. Develop a protocol to assess the stress and needs of caregivers

At baseline, none of the HPs conducted validated caregiver assessments. By the end of the project, three HPs formally adopted validated caregiver assessment tools and embedded them into their electronic care management records. Two of these HPs also reported implementing an audit process to ensure that the screens are being conducted. Other HPs reported using caregiver assessment tools; however, they had not incorporated them into their data management systems. Three additional HPs reported that they were in process of meeting this indicator.

7. Provide respite to caregivers of PLwD

No HPs provided or arranged for respite at baseline. By the end of the project, six HPs reported offering respite to caregivers, although the number of recipients or hours offered were not available. However, based on data reported by the State,³² one HP delivered respite through its own resources, serving 6–14 members per quarter between 2016 and 2018. The others relied on services paid for and provided by CBOs.

8. Provide or arrange for education for PLwD and their caregivers

One HP offered or arranged for caregiver education at baseline. By the end of the project, all HPs reported some effort to provide education, either through their own education department or referral to Alzheimer’s CBOs.

10. Adopt a proactive tool to make referrals to Alzheimer’s CBOs for disease education and support

At baseline, no HPs had in place formal referral systems to Alzheimer’s CBOs. By the project’s end, seven had such a system, with four integrating a proactive referral tool, ALZ Direct Connect™, into their electronic care management records. KIs indicated that the actual number of referrals from HPs to Alzheimer’s CBOs varied greatly and that barriers remain,

including: perceived privacy restrictions or caregiver resistance to referral.

Insufficient system change indicators

Three systems change indicators were deemed insufficient at capturing meaningful systems change, primarily due to two failed assumptions. First, HP electronic care management records did not “communicate” with provider’s electronic health records as initially assumed. Hence, the results of CI screens (Indicator 3) or the identification of caregivers (Indicator 5) could only be communicated passively through shared care plans. Second, there were unexpected differences in HP care management protocols for use of their Dementia Care Specialists. Dementia Care Specialists were not uniformly assigned to PLwD, but were sometimes used as internal consultants to other care managers who worked with PLwD. Project partners reported that with this knowledge, they have provided guidance to the State on recommended roles and responsibilities of Dementia Care Specialists.

DISCUSSION

As a result of the project’s advocacy model, HPs reported progress in all three categories of dementia-capable best practices.²⁻⁶ However not all indicators were successful in capturing meaningful systems change. These findings support further replication of the proposed advocacy model, though refinement of the systems change indicators is needed. The literature supports the need for and value of the iterative and evolving nature of systems change and quality improvement interventions and research.^{11-13,29-31}

Better detection and documentation of PLwD in healthcare systems

All CMC HPs include at least one CI question in their HRAs. In addition, six HPs reported adopting validated CI screening tools into their assessment protocols. However, these HPs also reported variable assessment protocols; consequently, members with possible CI, who are otherwise healthy and do not require complex care, may not receive the CI screens conducted through complex care programs. Similarly, although all HPs report referring members with suspected CI to PCPs for assessment, this does not indicate that more members with CI are receiving a diagnosis. Providing a letter to providers, as

one HP did with support from the project, may be an effective and formal process to educate providers and encourage diagnosis. Future research could determine the efficacy of these letters by comparing the number of people with a positive CI screen to the number receiving a diagnosis. The lack of shared electronic health records between HPs and providers will continue to pose barriers to communication between HPs and providers. In the future, data from HPs and secondary data may be used as systems change indicators, such as the proportion of members with a dementia diagnosis versus estimated prevalence rates. HPs may also conduct audits of how many members with a positive CI trigger question on the HRA receive a validated CI screening and/or a diagnosis.

Better identification, documentation, assessment, support, and engagement of caregivers

Although we could report some positive systems change in HP’s willingness to offer respite to caregivers, it is uncertain how meaningful, extensive, or lasting this systems change is, as these HPs were often taking advantage of respite services offered by Alzheimer’s CBOs. Previous research shows the HPs tend to offer optional services through existing community resources rather than HP resources.³³ The State should continue to track data from HPs on their delivery of respite services and future replications should adjust indicator 7 to reflect the practice and extent of respite services provided. Future efforts to identify and support caregivers might use HP data to track the number of PLwD with a documented caregiver or the number of PLwD with a caregiver on their interdisciplinary care team.

Better care coordination and connection to CBOs for home and community-based services

Seven HPs showed positive systems changes regarding the adoption of a proactive referral tool to connect PLwD to Alzheimer’s CBOs, though more work is needed to determine the extent of the referrals made. Although our indicator of dementia-capable care coordination being delivered by Dementia Care Specialists was found to be inadequate, this does not reflect the extensive progress toward this goal by the project. Throughout the course of the project, 483 care managers and 105 Dementia Care Specialists were trained and best practice care plans⁶ shared with all 10 participating HPs. Further refinement

of the indicators around the use of Dementia Care Specialists within HPs should be informed by research around how HPs ensure PLwD and their caregivers have access to Dementia Care Specialists.

Limitations

This model was implemented within HPs operating under California's (and later Texas') dual demonstration, which presented some key policy levers that reinforced the adoption of dementia-capable systems changes. However, it remains to be seen if this advocacy model will create similar changes in other health systems. The goal of this project was to assess uptake of dementia-capable care practices within HPs, and not to assess their impact on patient outcomes or healthcare utilization—though this would be a valuable continuation of this work. Lastly, participant observations to track systems change should be conducted more regularly by a single researcher, but this was not possible given the project's structure, geographic reach, and funding.

CONCLUSION

Healthcare systems are increasingly moving toward coordinated, person- and family-centered, value-based approaches to care; creating opportunities to improve care for PLwD and their caregivers. By implementing the proposed advocacy model, the Dementia CMC project achieved systems change within several HPs, expanding their dementia-capability. Our advocacy model required an adaptive approach to tracking systems change through defining and re-defining indicators. Further replication of this advocacy model is recommended, with refinement of systems change indicators based on the findings presented here as well individual health systems' norms, resources, operations, and interdependencies.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to report.

AUTHOR CONTRIBUTIONS

All authors contributed to the design and implementation of the Dementia CMC project; data collection activities; and preparation of the manuscript. Brooke A. Hollister, Jarmin Yeh, and Leslie Ross analyzed and interpreted the data.

SPONSOR'S ROLE

Sponsors were not involved in design, methods, subject recruitment, data collection, analysis, or manuscript preparation.

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