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Smooth Landing?: How California Can Ensure Continuity of Care for Vulnerable Seniors Transitioning to Managed Care

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SUMMARY: On April 1, 2014, the first of an estimated 450,000 “dual eligibles” (adults insured through both Medicare and Medi-Cal) in eight counties¹ were enrolled in a combined Medi-Cal and Medicare managed care program called Cal MediConnect.² Cal MediConnect holds the promise of addressing unmet needs and improving the coordination of their care across a complex array of medical and social support services. However, concerns remain about the transition, and specifically whether it will result in disruptions in care. This policy note documents what continuity of care actually means in the day-to-day lives of older adults affected by the transition. Through interviews with dozens of dual eligible older adults – all of whom are managing multiple chronic conditions and disability – the authors report that continuity of care is best achieved through care that is familiar and responsive, is assured through long-standing relationships with providers, and involves family members, social service providers, and others who are invested and instrumental in meeting their needs. The authors recommend that the state’s definitions and assurances of care continuity³ be expanded to better reflect the broader health and social care needs of consumers. Likewise, the evaluation of quality care should be rooted in the consumer experience, and use metrics that account for the preferences and goals of consumers themselves.

Introduction

The Cal MediConnect program aims to improve the quality of care for individuals who are eligible for both Medicare and Medi-Cal (“dual eligibles”), through the integration of medical and long term services and supports (LTSS) under a capitated model of managed care. One of the premises of this transition to managed care is that the complex care needs of dual eligible individuals will be better coordinated and more efficiently delivered within a closed system of care. Cal MediConnect is a demonstration program that is a product of the Affordable Care Act (ACA) which created the Medicare-Medicaid Coordination Office (MMCO) to more effectively integrate and coordinate dual eligible benefits between the federal government and states to ensure access to quality services.^{4,5}

The rollout of Cal MediConnect has been delayed numerous times. Some of the early delays were due to finalizing the memorandum of understanding (MOU) with CMS. Other delays have resulted from stakeholder pushback due to concerns about consumers having access to understandable information about the new program, clarity about their options, and sufficient time and assistance to make informed decisions. In addition, in some counties, the selected managed care health plans were either not ready, or are not fully qualified to passively enroll new members.⁶ As a result, participating counties now have different timelines for enrollment and only one of the eight counties originally scheduled to launch the program moved forward with passive enrollment as of April 1.⁷

The HOME Project

The HOME (**H**elping **O**lder-adults **M**aintain independence) Project is a longitudinal and qualitative study following a group of dual eligible seniors (i.e., those insured through both Medicare and Medi-Cal) in California since 2010.⁸ It is conducted by the UCLA Center for Health Policy Research with support from The SCAN Foundation. Study participants were recruited with the assistance of In-Home Supportive Services (IHSS) programs in five California counties (San Diego, Orange, Los Angeles, San Francisco and Santa Clara). A total of 54 cases of dual eligible adults, ages 65 to 94, who depend on long-term services and supports (LTSS), were interviewed repeatedly. The majority completed between 4 – 8 interviews over the two phases of the HOME project. When available, paid caregivers and/or unpaid family members were also interviewed.⁹ More than half of the 34 caregivers interviewed were not related to the care recipients. Three-quarters of HOME Project care recipients are female and report English as their primary language. Over half of care recipients are Caucasian, followed by Latino/a (20%), African American (13%), Asian American (7%), and Native American (2%). Most participants are managing multiple chronic conditions, such as diabetes, arthritis, heart disease, and depression. More than two-thirds of participants need assistance with at least one activity of daily living (ADLs), such as bathing or dressing. All report needing assistance with at least one instrumental activity of daily living (IADLs), such as cooking or doing laundry.

This policy note presents new data from the UCLA Center for Health Policy Research’s HOME Project. The HOME Project provides “real time” insights from older adult consumers and their caregivers that can be used to inform and assess the early stages of Cal MediConnect implementation.¹⁰ This is an especially fragile group that is more likely than younger dual eligibles to have multiple chronic conditions and to have both physical and mental/cognitive conditions.^{11,12} Earlier reports from the HOME project have documented the fragmented networks of informal and formal care and unmet needs experienced by many consumers.¹³ These reports have also assessed how consumers manage their own care, adapt to changing health needs, and learn about and respond to changes in the availability of services and supports they rely on to continue to live independently at home.¹⁴ This policy note documents what continuity of care means to consumers as well as the current gaps that disrupt that continuity. Understanding continuity is essential to better-coordinated and person-centered care and to the long-term success of Cal MediConnect.

CONTINUITY OF CARE

Through repeated conversations with consumers about their networks of medical care and long-term services and supports, we learned what aspects of care are most important to them, what providers and services they count on the most, and whether their care is coordinated across sectors. Participants’ own ideas about continuity of care emerged from their descriptions of what is working and not working in their current medical and LTSS networks, providing us with insights on the meaning of continuity of care from a consumer perspective.

Continuity of care is achieved through care that is familiar and responsive

Continuity, for many, means having a long-term relationship with a primary care provider or specialist who is familiar with their medical history and aware of other providers, and available to oversee the bigger picture of their health care. Some Californians eligible for Cal MediConnect have an outside party to help advocate on their behalf – family members, social workers from the Multipurpose Senior Services Program (MSSP), or others. However, it is often the length of the relationship with their healthcare providers that makes consumers feel more confident about the quality and trustworthiness of these relationships. It may also result in minimal gaps in receiving services or referrals.

For example, Wilma’s long-term relationship with her cardiologist means that her medications are prescribed with full knowledge of her medical history, resulting in positive medical outcomes such as pain reduction. This relationship means that she can trust that her concerns about her health are heard and understood:

“[H]e’s been keeping me out of pain for 20 years, so I really appreciate that... He really, uh, knows my chemistry, what medicine I can take and what I can’t take. ... He listens to me... He’s just really patient and he can hear certain words that I say and he knows exactly what’s wrong with me by what I say and it amazes me how he understands so much of it”.

The experience of being heard and understood by a primary care provider is critical to patients’ experience of continuity of care. For example, Margaret describes that her primary care provider of eight years consistently takes the time to ask and listen to her mental and physical health concerns. She says, *“If I go in and I’ve got a problem, whether I come in depressed and I can’t shake the depression, he wants to know. He’ll always ask you how things are going at home... Yesterday I was upset about the [upcoming carpal tunnel surgery], and he took an extra 15 minutes to talk to me about it.”* By taking the time to ask questions and listen to Margaret’s experience, her primary care provider not only was able to make connections between Margaret’s mental and physical health, including her depression and upcoming surgery, but also between her health conditions and “how things are going at home”, which encompassed In-Home Supportive Services (IHSS) and other formal and informal services and supports.

Continuity is often assured through long-standing relationships with providers

Unless dual eligibles “opt out” of Cal MediConnect and elect to stay with their current Medicare providers, most are likely to undergo changes in primary and specialist healthcare providers. While these changes may lead to improved care and care continuity for some, it may raise concerns among those whose long-term relationships with their current providers have helped to ensure continuity of care in a number of ways. Most critically, these providers help consumers connect to a network of doctors that accept their insurance, or otherwise ensure there will be no gaps in their care based on their dual eligible status. For example, Gladys explains that her primary provider is *“well-known for taking most of the Medicare-Medi-Cal patients”*, and has been able to help her find a network of specialists that do the same.

Jill describes that based on referrals from her primary care provider, whom she has known for nearly three decades, she was able to see specialists who do not normally accept dual-eligible patients simply because her doctor referred her. For many years these doctors waived additional fees associated with Jill’s care because of the connection made by her doctor, although she has now started paying out-of-pocket costs that she can ill afford in order to ensure that she can retain these doctors.

Esther, who at 75 is managing multiple chronic conditions including osteoarthritis, describes how her long-term relationship with her doctor meant that her recent request for a referral to an occupational therapist was respected and acted upon. She values being actively involved in directing her own care and says that after seeing her doctor for 38 years, *“She has come to really respect my requests because she trusts that I don’t ever ask her for anything I don’t think I need.”* As a result, Ester received home visits from an occupational therapist to retrain her to eat with her right hand after losing mobility in her left hand.

Continuity involves family members, social service providers, and others

While primary care providers (and specialists in some cases) are critical to a sense of care continuity, there are others who are also instrumental in achieving this objective. Often these individuals are family members, like

Julia, who coordinates all of her mother, Angie's, care. None of Angie's healthcare providers speak Spanish, even though Angie is monolingual Spanish-speaking. For Julia, this means that *"the doctors always call me and give me the update on what is supposed to happen. She has three doctors, and they always call me. I am always there to translate and let her know what's happening..."*

At one point, Julia considered enrolling her mother in a community-based adult services (CBAS) program, to help alleviate her mother's social isolation during the day while Julia was working. Based on Angie's input, however, she decided against the program since it would mean a change from a fee-for-service model to a managed care model of service delivery. The positive result of this transition would include access to CBAS; the negative result would include a potential loss of providers who do not participate in the managed care network. Ideally, she should be able to keep her providers while also benefitting from the important social programs available through CBAS. Julia explains her mother's sentiments: *"She doesn't want to change doctors, especially the oncologist and cardiologist because they know about cancer, and they still see her, and she feels comfortable."*

In other cases, continuous care was facilitated by the efforts of non-family IHSS providers or MSSP social workers who arranged or provided transportation services to medical appointments, communicated directly with doctors, appealed for more hours of IHSS or for assistive equipment. For example, Mildred considers her MSSP social worker to be a liaison between herself and her doctor's office. She says: *"I ask my social worker to call my doctor's office when I need something... She asks how I am, she monitors when I go to the doctors. It helps."*

GAPS IN CARE

We also discovered from our in-depth interviews that, prior to implementation of Cal MediConnect, many consumers are currently lacking certain components of care and support that are essential for their continued health and well-being. Where gaps exist, continuity is not possible.

Some seniors with significant gaps in the continuity of their medical and social care network are managing on their own with very limited resources, without the assistance of a helpful primary care provider, family advocate, or supportive non-family IHSS provider or MSSP social worker.

For example, Henry, a 65-year old man with chronic and severe pain in his feet and back, went for several months without a primary care provider. When he finally found one, he struggled to have his new primary care provider understand his medical needs and care preferences. Henry was determined to keep his existing specialists and told us that his new doctor only agreed to allow him to continue to see his specialists *"after all this yelling and screaming."* Henry did not feel that his new doctor understood the kind of pain that he was in.

Other notable gaps in care are related to access to dental care, mental health services and reliable transportation.

Dental health

Given the state's decision in 2009 to cut dental benefits (i.e., DentiCal) from Medi-Cal, our participants have been without essential dental services almost across the board. It was extremely rare that consumers were able to cover out-of-pocket dental costs. Jill describes that while she has made arrangements to receive regular cleanings from a dentist with whom she has a long-term relationship, all of the teeth on the right side of her mouth have been pulled and she is not able to use this side. While she waits out the possibility of receiving some help with her teeth – something her MSSP social worker is looking into – she says *"I just want the rest of my teeth to hang in there."*

This gap in care persists for Jill even though she has the support of an MSSP social worker and despite the informal arrangements she has made to get dental care with her long-term dentist. Despite Jill's high level of

engagement with her medical care, and the supportive LTSS and medical providers available to her, she continues to experience a significant gap in care, and makes do without teeth on the entire right side of her mouth. Other study participants, most of whom are less proactive than Jill, described similar gaps in dental care and were anxiously awaiting the reinstatement of Medi-Cal dental benefits.

Mental health

Mental health care is another area in which consumers lack access or continuity. Many participants report that their primary care doctors do not ask about their moods or emotions during office visits. While many participants rely on family, friends, and religious beliefs and communities for emotional support, others describe great difficulty accessing formal mental health care. For example, when we asked Wilma about whether she had consulted with her doctor about her recent experience of depression, she told us: *“If I mention to her that I need someone to talk to, I’m sure she would advise me on who to talk to and what not, but I just don’t have the energy to get out there and do it...And I’m sure I can’t afford how much they will charge if they come over to my apartment.”*

Often referrals to mental health care are made when consumers are experiencing profound struggles with depression or other mental health concerns, as well as physical health challenges, and are least able to follow through with referrals on their own. Wilma never received a referral to mental health services from her primary care provider; it was about six months from the time that she revealed the extent of her depression to her primary care provider before she received home-based counseling services, which were located by her newly assigned MSSP social worker.

Consumers with limited English abilities are at the greatest disadvantage in terms of connecting to mental health treatment as they often face additional barriers to gaining information and access to care. Julia says that her mother Angie goes without mental health care in large part due to the limited availability of Spanish-speaking mental health providers. She explains: *“I requested [a therapist], but that doctor doesn’t speak Spanish, so it’s hard to get that... and it’s not possible with my [work] condition. I think the main problem is the Spanish, and also I don’t remember if Medi-Cal does not cover the mental health...I really don’t know.”*

Transportation

A lack of reliable transportation was also cited as a key reason for a breakdown in the continuity of care. For Fran, this meant that she was not able to consistently attend physical therapy sessions that she was referred to, and often had to miss scheduled doctor’s appointments. She said that the service that she attempted to use was *“always last minute, they tell you they cannot make it, and then I have to make [another] appointment. Therapy is supposed to be continuous, every week, so it ended up that I had to quit therapy.”* Given that Fran relies on a patchwork of medical providers at different sites, she says that she has to manage different transportation arrangements for each kind of provider depending on whether or not they offer transportation services. Fran relies heavily on these services because she has few other options for transportation, and the sporadic assistance she gets from her IHSS providers is not nearly enough to close the gap.

Reliable and accessible transportation was also a challenge for Henry, who often had to walk considerable distances and take multiple forms of public transportation to get to doctor’s appointments dispersed throughout the city -- a huge effort, especially while suffering from severe pain in his back and feet and episodes of excruciating muscle spasms. The lack of reliable transportation services meant that Henry could no longer participate in activities at a local senior center; he used to attend at least weekly but it is increasingly too painful for him to walk and ride the bus other than to medical appointments.

DISCUSSION

Data from the HOME study illustrate that our consumer participants value, and typically benefit from, long-standing relationships with primary care providers, specialists, social service providers, and family or other personal caregivers. Given a choice, most would elect to stay with the providers and caregivers they trust, who are familiar with their personal history and health conditions. After weathering years of reductions to their medical and LTSS benefits, these consumers are understandably wary of any additional changes to their health and social care services and benefits.

While the option to remain with all of their current providers might not be possible under Cal MediConnect, the potential for improved care needs to be clearly communicated to these consumers, by addressing their anxieties about change and by assessing and quickly attending to their critical and immediate medical and LTSS needs. Many are so physically, mentally and socially vulnerable that they could not withstand even temporary gaps in care.

Policy Recommendations

Expand definitions of care continuity. To reap the potential for improved care through the Cal MediConnect program, continuity of care must first be realized through the transition period. Many providers are not currently included in the state's continuity of care definitions.³ We recommend that the state's definitions and assurances of care continuity be expanded to include social workers, durable medical equipment providers, incontinence supply providers and other health support personnel not traditionally covered by the definition. A more robust definition of care continuity would embrace a social model of care that emphasizes consumer-directed and community-based options, includes providers, caregivers, services and equipment of all types.

Ensure that dual eligible consumers and providers are well informed of their options and rights. In addition to providing information about service and benefit changes, all communication about Cal MediConnect should include highly visible and easy to understand information about consumer options and rights, and how to exercise them. For some, this might require that additional support is available when the time comes to take action and make the choices that serve their best interests. These materials should highlight the choices and real involvement in decision-making that consumers *do* have. Messaging should emphasize and encourage consumers' continued ability and desire to direct and coordinate aspects of their care based on their own preferences and priorities. Once enrolled in the new program, consumers must also be fully informed about their rights and protections and how to invoke them if needed to redress any problems with access to quality care. Educating providers about continuity of care rights would also help to alleviate the spread of misinformation and the unnecessary disruption of services.

“Real time” monitoring and evaluation of the transition. Ensuring that consumers are well informed, while essential, is not sufficient to ensure continuity of care and achieve the ultimate goal of improved care coordination using a person-centered approach. Other procedures and safeguards also need to be in place to ensure that these goals are reached. As the implementation of Cal MediConnect moves forward, the realization of care continuity and better care outcomes will require careful and continuous monitoring and evaluation. Evaluation measures should include the extent to which consumers are well-informed about their options and can exercise real choice within the new system of care, either by being directly involved or well-represented in the decision-making process. Furthermore, the evaluation of quality care should be rooted in the consumer experience, and use metrics that account for the preferences and goals of consumers themselves. Individual preferences and goals provide the true starting point for “person-centered” care planning and delivery, and represent the core principles which should inform and direct every step of California's CCI and the implementation of Cal MediConnect.

Conclusion

In the quest to better coordinate and provide truly person-centered care, the consumer of care needs to be at the center of decision-making, and provided with the opportunity and support to express his or her preferences and priorities for care to an attentive and responsive audience. This is going to become increasingly important given that new federal regulations have recently been finalized that require a person-centered planning process that solicits and accounts for individual preferences and goals in the delivery of home and community-based services. The final rule provides guidance for states to recognize the consumer as the expert in his or her own care, and to ensure that the consumer remains at the center of the planning and care delivery process.

Author Information

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Case Studies

For more information about Jill, Wilma, Angie and other HOME project participants featured here and in other HOME project publications, please see the in-depth case studies available at: www.healthpolicy.ucla.edu/HOMEstudy.

Notes

1. The original eight demonstration counties include Alameda, Santa Clara, San Mateo, San Bernardino, Riverside, Los Angeles, San Diego and Orange although implementation in Orange County has been put on hold until further notice due to quality concerns of the designated managed care plan.
2. Selected managed care health plans in eight counties are expected to eventually integrate, coordinate and deliver all necessary acute health and social care benefits to this vulnerable population, including behavioral health services and long term services and supports.
3. Health plans must follow existing federal and state laws regarding continuity of care. They must also provide out-of-network access to Medi-Cal doctors for up to 12 months and access to Medicare doctors for up to 6 months, post enrollment.
4. Banach, E., & Bella, M. (2013). What is the focus of the integrated care initiatives aimed at Medicare-Medicaid beneficiaries? *Generations*, 37(2): 6-12.
5. California is one of 26 states that submitted a proposal, and one of 6 states that currently has a Memorandum of Understanding (MOU) with the Center for Medicare and Medicaid Services (CMS) to test different models of managed care with the potential to align service delivery and financing between the Medicare and Medicaid programs. Kaiser Family Foundation. State Demonstration Proposals to Integrate Care and Align Financing and/or Administration for Dual Eligible Beneficiaries. Fact sheet. March 4, 2014. <http://kff.org/medicaid/fact-sheet/state-demonstration-proposals-to-integrate-care-and-align-financing-for-dual-eligible-beneficiaries/>
6. Most eligible individuals will be passively enrolled into Cal MediConnect, meaning that they will have to actively “opt out” if they do not wish to receive their Medicare benefits, such as primary care services, through the new program. While the integration with Medicare services through Cal MediConnect plans is “voluntary”, dual eligibles in the eight demonstration counties will have to enroll in a managed care plan to receive Medi-Cal benefits and services.
7. If successful, the ultimate plan is to transition all of California’s 1.1 million dual eligibles into similar managed health care plans in the near future.
8. www.healthpolicy.ucla.edu/HOMEstudy
9. We are following a uniform set of topics but allowing the respondents to reply in their own words. Interviews are in English and Spanish, as needed; all are transcribed and coded by the research staff. The names and certain other identifying information (e.g., age and/or gender) have been changed to safeguard the confidentiality of study participants. For more in-depth case studies of HOME project participants, see www.healthpolicy.ucla.edu/HOMEstudy.
10. Older adults, ages 65 and older, represent the majority of dual eligibles in California (61%) and more than three-quarters of dual eligibles in the original eight demonstration counties.
11. Kaiser Family Foundation July 2010. See Kaiser Commission on Medicaid and the Uninsured, “Chronic Disease and Co-Morbidity Among Dual Eligibles: Implications for Patterns of Medicaid and Medicare Service Use and Spending,” July 2010, available at: <http://www.kff.org/health-reform/report/chronic-disease-and-co-morbidity-among-dual/>.
12. Older dual eligibles in California have experienced a lot of uncertainty in recent years as, under the duress of state budget deficits, many of the programs and services that they rely upon have undergone cuts or changes in benefits or eligibility criteria. The impending transition to managed care represents yet another change in the organization and delivery of their health and social care services.
13. Kietzman KG, Durazo EM, Torres JM, Choi AS, Wallace SP. *Independence at Risk: Older Californians with Disabilities Struggle to Remain at Home as Public Supports Shrink*. Los Angeles, CA: UCLA Center for Health Policy Research, 2011.
14. Kietzman KG, Torres JM, Chang C, Tran TD, Choi AS, and Wallace SP. *Disconnected?: Challenges of Communicating Cal MediConnect to Low-Income Older Californians*. Los Angeles, CA: UCLA Center for Health Policy Research, 2014.
15. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>