UCLA CENTER FOR HEALTH POLICY RESEARCH

UCLA CENTER FOR HEALTH POLICY RESEARCH

POLICY NOTE

January 2014

# Disconnected?: Challenges of Communicating Cal MediConnect to Low-Income Older Californians

*Kathryn G. Kietzman, Jacqueline M. Torres, Charlene Chang, Tina Duyen Tran,*
*Anne Soon Choi, and Steven P. Wallace*

**SUMMARY:** More than 450,000 "dual eligible" adults (those insured through both Medicare and Medi-Cal) in eight California counties are slated to be moved from fee for service to managed care starting in April 2014. New data from the UCLA Center for Health Policy Research's HOME project[1] find that those who will be affected by the transition are often confused or concerned about its potential effects on their health care. This vulnerable group of consumers with multiple chronic illnesses and disabilities is unevenly responsive to the program information received, depending in large part on the older adult's physical or mental state and on the availability of family or other supportive resources. Most of these consumers would like to receive information in a more personal and interactive manner than the typical mailed notices. This policy note recommends the implementation of targeted and tailored communication efforts that are responsive to the diverse information needs and preferences of these vulnerable older adults.

One strategy for information assistance is the use of patient navigators, as done during implementation of the Affordable Care Act. Such people would be specifically trained to respond to the needs of the dual eligible population. This approach would be especially helpful for older adults who are less engaged and are likely to benefit from direct support. In addition, collective and collaborative communication efforts initiated by community-based organizations and local government agencies can provide critical point-of-information dissemination and assistance, with multiple pathways used to reach and follow up with those older adults who are most at risk for experiencing gaps in the receipt of essential medical and social care.

## The Coming Change for Dual Eligibles

Beginning in April 2014, as part of California's Coordinated Care Initiative (CCI), more than 450,000 Californians who are insured through both Medicare and Medi-Cal (i.e., "dual eligibles") will be eligible to transition into a new type of managed care demonstration program called Cal MediConnect. Dual eligible adults are a diverse group with complex and often costly health care needs; these individuals generally have lower incomes and are sicker than those covered by either Medicare or Medi-Cal alone.[2, 3] To date, the delivery systems charged with providing medical and social services to this population have been fragmented, and the daunting task of bridging acute medical and social care services has largely been left to consumers and, when they are available, their family members.

## The HOME Project

This policy note presents new data from the **H**elping **O**lder-adults **M**aintain independenc**E** (HOME) project, a longitudinal and qualitative study following a typical set of dual eligible seniors (i.e., those insured through both Medicare and Medi-Cal) in California since 2010, with support from The SCAN Foundation. Most participants in the first phase of the study were managing multiple chronic conditions, such as diabetes, arthritis, heart disease, and depression. More than two-thirds of participants needed assistance with at least one activity of daily living (ADLs), such as bathing or dressing. All reported needing assistance with at least two instrumental activities of daily living (IADLs), such as cooking or doing laundry. The HOME project documented the experiences of these individuals as they weathered a series of reductions and changes in available services and supports due to state budget cuts. The study revealed that most of these older adults are managing a complex and fragile web of formal and informal supports, and that all share a common determination to stay in their homes and maintain their independence. Many are struggling with increasing disability and have physical and mental health needs that are unpredictable.

During the second phase of the HOME project, the In-Home Supportive Services (IHSS) programs in four of California's eight Coordinated Care Initiative (CCI) demonstration counties (San Diego, Orange, Los Angeles, and Santa Clara) recruited 37 cases of dual eligible adults, ages 65 to 94, who depend on long-term services and supports (LTSS). To date, two in-depth interviews with each older adult and with her or his paid caregiver and/or an unpaid family member, when available,[4] have been conducted.

Cal MediConnect, through selected managed care health plans in eight counties,[5] is 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 (LTSS). These plans will receive a fixed (capitated) payment from both Medicare and Medi-Cal for each enrollee. This approach to financing care is expected to facilitate the coordination of care, reduce unmet needs, improve quality of care, and diminish costs by integrating the provision of medical and social services into a more seamless service delivery system. If successful, the ultimate goal is to transition all of California's 1.1 million dual eligibles into similar managed health care plans in the coming years.

Adults age 65 and older represent 61 percent of dual eligibles in California[6] and more than 75 percent of dual eligibles in the eight demonstration counties.[7] This is an especially fragile group, more likely than their younger counterparts to have multiple chronic conditions and to have both physical and mental/cognitive conditions.[8] Older dual eligibles in California have experienced a lot of uncertainty in recent years as programs and services that they rely upon have undergone cuts or changes in benefits or eligibility criteria due to state budget deficits.[9] The impending transition to managed care represents yet another change in the organization and delivery of their health and social services.

There are a series of important consumer decision points involved in the rollout of the Coordinated Care Initiative. While all services provided through Medi-Cal will be offered through the new managed care programs, the integration with Medicare-covered services through Cal MediConnect plans is "voluntary." 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. Some counties will have more than one managed care health plan providing Cal MediConnect services, so consumers in these counties will have to decide which health plan to choose. Then, within a specific health plan, consumers may also have to select a primary care provider and/or specialists. Those who do not actively make a choice will be automatically assigned a plan based on records of their past provider use. There are also ways in which consumers can request that they continue for a limited time with existing providers who are not in the assigned managed care network.

While many in the dual eligible population stand to benefit from Cal MediConnect, whether care is better coordinated will depend in large part on the extent to which consumers are well informed about their options and actively engaged in the decision-making process within the new system of care. It will also depend on consumers' having additional support available when the time comes for them to take action and make the choices that will serve their best interests, such as selecting the most appropriate managed care plan or provider. The level of consumer engagement in the transition to managed care will likely make a difference in the success and impact of this significant policy and program change.

This policy note examines how dual eligible older adults receive and respond to program-related information, what information this group needs, and how dual eligible older adults would prefer to receive information about services and benefits. These data can be used to inform outreach and education efforts by indicating who should be targeted, how information should be disseminated, and what resources will be needed.

## No Consistent Source of Information on Benefits and Services

HOME study participants find out about changes to their medical and supportive benefits and services from numerous sources, including mail, media (newspapers and television), the Internet, community meetings, health care and social service providers, and word of mouth. Many report that they receive a lot of information in incidental ways, such as while speaking with other residents of their housing complex, while using transportation services, or while attending a community meeting or event.

Wilma, 85, describes the purely accidental way in which she found out about changes to one of her benefits: "*The changes were March 1, [2013], and the only way I [found out] was going downstairs to a meeting, which I didn't know what it was going to be about. But I stayed there and listened anyway and got the paperwork….*" Even though Wilma feels "pretty good" about her ability to use a computer, the one she has is so old that it is always breaking down, and she cannot rely on it to obtain the information she needs.

Participants also perceive that service and benefit changes sometimes occur without any notification, giving them little or no opportunity to respond. Margaret, 79, describes changes to Medi-Cal policies and copayments for prescription coverage that she was unaware of: *"You learn about [changes to copayments under Medi-Cal] when you've been paying one fee and you go in and you pick it up and it's more. No, you don't know."*

## Different Engagement Levels with Information

How HOME study participants are getting their information is just one piece of the puzzle. There is also great variance in what they do with the information. Some older adult consumers are actively engaged and tend to be proactive with the information they receive, following up with members of their social or LTSS networks to ensure that they understand information about available services and changes to existing benefits. For example, Gladys, an 81-year-old woman with respiratory disease, joint problems, and chronic fatigue, talks about using the local Health Insurance Counseling and Advocacy Program (HICAP) and other resources after being charged for prescriptions that had previously been free.

Paul, now 65, has been living with a disability since he was a young adult. He receives 283 hours of personal care per month at home, the maximum number of allowable hours funded through In-Home Supportive Services (IHSS). To stay informed, Paul actively searches for information on the Internet and also relies on information his IHSS caregiver gets from the IHSS provider union. Paul also feels comfortable talking with his primary care provider or reaching out to his social worker if he has any problems with services or benefits.

Other consumers are less proactive than Gladys and Paul but have the support of family or other caregivers who actively seek and interpret information on their behalf. This is especially important when the older person must overcome barriers to getting the necessary information, such as visual or cognitive impairments or limited English language proficiency.

Angie, 77, is a monolingual Spanish speaker who has Parkinson's disease. Angie relies entirely on her daughter Julia for management of all information about medical and IHSS benefits. They both report that the information is received primarily by mail and is usually in English. Julia wishes the information were in Spanish and in a larger print size so that her mother could read the information herself and be more directly engaged in coordinating her own care. What is notable in this case is that most official notices in their county are available in Spanish, but neither the consumer nor the family caregiver are aware of how to request Spanish materials from the variety of agencies with which they interact.

Some consumers cannot identify anyone to help them sift through the information about changes to benefits and services. For these individuals, the effort of following up after changes have already been made seems futile. For example, Fran, 86, who has no advocate, seems resigned to the news she receives about cuts to her benefits: "*I don't call them if they cut. If they cut, I don't want to go through a battle…. They don't tell you, they don't give you a reason or something. That's okay, because everybody can hear all of the budget cuts, everybody can give you that answer. So, I don't bother…. Tell me how much I get, that's good enough for me."*

Although this may be an adaptive strategy for Fran, who faces multiple challenges around coordinating her medical and in-home care, many of our participants are put at risk by some cuts or changes to their current level of services. This group includes consumers like Paul, mentioned above, who must rely on 24-hour care and continuous access to assistive medical equipment in order to survive.

Others who have previously been active in managing their own care have become weary after receiving repeated notices about possible or actual changes to benefits. Several report having received a flurry of solicitations to change health insurance providers or prescription drug coverage. Some report having had changes made to their benefits that they do not remember signing up for.

In the past, Wilma has usually responded to the information she receives. However, she has recently been suffering from a great deal of pain and depression following a hospitalization and diagnosis of diabetes, and as a result she has begun delegating the task of dealing with health services information to family members. As she describes it: "*Medicare is always sending me paperwork on what...group I want to go to and what drugstore I want to deal with, all that. I just can't handle it right now, and I'm giving it to my son and granddaughter and see what they decide…. I can call HICAP, I think it is, and talk to someone there and get some information. But I haven't been feeling good enough to do that…. I don't have enough energy to go to the next building."*

Given the high levels of disability and multiple chronic conditions among dual eligible older adults, a significant number are likely to be in Wilma's situation of chronic pain, mental distress, and/or cognitive impairment, significantly reducing their ability to seek out and process complicated information about their benefits. Many are receiving program-related information from multiple sources, which only increases confusion about what is being offered and why, who is providing the particular service, and what actions might need to be taken. In the absence of help from a family member, caregiver, or other advocate, the constant barrage of complex information can be overwhelming, especially for those who are coping with physical or mental obstacles or distress.

## Proposed Changes Evoke Anxiety and Concern

Participants who have heard about the proposed changes to the service delivery system are concerned about the potential effects on their health care. Many are concerned about keeping their current primary care provider or specialist(s). Those who rely on multiple physicians for their health care are especially worried about the prospect of changes being made to a network of providers that, for some, has taken much time and effort to construct.

Others are concerned about the continued provision of supportive services such as medical equipment. By the time of our second interview, Paul had learned about the upcoming transition to managed care through a letter sent from his ventilator company. He is unsettled by the proposed changes, which could affect the availability and maintenance of his wheelchair and his ventilator, both of which are essential to his day-to-day mobility and functioning. The ventilator company informed Paul that they were not sure whether they would be able to maintain their contract with Medi-Cal under the new managed care system and so might be unable to continue serving him. Paul depends on his ventilator to help him breathe, and he is afraid that the transition from one company to the other would leave him without a ventilator for a period of time.

Margaret, 79, who is legally blind and suffers from arthritis and heart disease, has put together a strong network of medical and LTSS providers, family, and friends. When she began to hear about possible changes to her medical care, she talked about her concerns with one of her health care providers: "*I'm a little concerned with all the changes that are going on. I have to get my pacemaker checked [regularly], and I asked if this would make a difference in my care.… I have heard that if you have both Medicare and Medi-Cal, and you do not have an accompanying insurance policy, you will be dropped.*"

Liz, 75, is a polio survivor who has advocated for her own health and care needs throughout her life. Diagnosed with terminal breast cancer about a year ago, she remains very active in monitoring emerging changes to her medical care and LTSS. She has heard that some major changes are coming and articulates her concerns: "*They want to shove us on managed care, and we would have no choice [about] who would come into our homes and be taking care of us…. To have someone step in, you know, and say 'This is what we are going to do,' forget it. Just put me in an institution. That's how strongly I feel about it.*" This case also illustrates how misinformation spreads or how accurate information can be misinterpreted, since no changes are being proposed in how home care hours or supervision occur for existing IHSS recipients in the initial implementation of Cal MediConnect.

Julia expresses concerns about possible changes to her mother, Angie's, medical and nonmedical benefits for her Parkinson's disease, diabetes, heart disease, arthritis, and osteoporosis: "*We are worried because there will be a change, I think in 2013 or 2014, for Medicare patients, which [means] we will go onto health plans. I'm worried that because of her condition she needs to go to the physician, especially the hospital doctors. Some doctors don't have any health plan, so I'm worried now…. [I found out through] some letters from Medi-Cal, and also I was receiving brochures from the health nurses. I think it's the following year [when], they need to be assigned a plan…. [The information is] just in English.*"

## Most Seniors Prefer to Receive Information in a More Personal and Interactive Manner

While several participants of the HOME study regularly use computers and are able to obtain information from the Internet, most prefer printed information in hard copies and personal assistance – whether by phone or in person – when applying for or learning about changes to benefits or services. Fran explains: "*No, I never even tried to get [information about benefits] from the computer. I don't – it's not necessary. I don't want to go fool around with that…. You know the Section 8 housing forms you can get from the computer, or some [other] things you can get from the computer. But I don't like it. Sometimes my printer is not working or my computer is not working. So, I always just go call them and have them send me the forms if I need [them], or I have somebody take me to the office to get the forms.*"

Gladys also discusses her preference for going to the office to discuss her benefits in person: "*I want to be mentally able to know what's happening, and I want to make sure I know what's going on… and the [written materials] can be hard to read. I need a PhD to read those!*"

Finally, Carlos, 75, a diabetic with ulcerated feet and limited mobility, said that he uses the Internet for general information and political news. When asked how he would like to learn about changes to his benefits, however, he said that he would simply "prefer to talk to someone."

## Discussion

The latest findings from the HOME project highlight the importance of implementing a variety of targeted and tailored communication efforts when instituting changes to the network of medical and social care for a fragile elderly population. This major transition to managed care requires careful attention to those who are least likely to benefit from information that is provided in the standard format. Some of these seniors are already weary from the fits and starts around policy and program changes that they have faced in recent years. In a climate of repeated budget cuts and ongoing uncertainty, compounded by complicated information from multiple sources, some of these individuals may be reluctant to do anything until they confront actual changes in the services they receive.

While the effective dissemination of information will play a critical role in the success of the transition to managed care, it is not sufficient to ensure continuity of care for many in this vulnerable and diverse population. Consumers who are highly engaged with information about changes to their benefits, or who are fortunate enough to have engaged family members or other advocates, will be the best equipped to navigate the changes resulting from the transition to managed care and to make well-informed choices. Those who are not as engaged, perhaps as the result of current health conditions, social or geographical isolation, or the lack of supportive family members or other advocates, will be the least able to ensure that their medical and social care is well coordinated and proceeds without gaps throughout the transition period.

Information about the impending service delivery system changes needs to be targeted, especially to those most at risk, and it needs to be disseminated broadly through multiple venues and in multiple formats. Efforts must be made to effectively communicate the full range of options that consumers have and to facilitate their exercise of informed choice. Early outreach efforts are only one part of the process; strategies are also warranted for assisting consumers who, for a variety of reasons, do not engage with or respond to the information they receive.

## Policy Recommendations

Recognizing the magnitude of this transition for dual eligibles in the demonstration counties, the state of California has taken extraordinary measures to involve a full range of stakeholders in the planning and implementation of CCI and Cal MediConnect. In its efforts to respond to stakeholders' concerns, the state has created a website (www.calduals.org), produced numerous reports, sponsored webinars, convened stakeholder and special workgroup meetings, and solicited public comment.

One critical issue stakeholders have raised repeatedly is that of ensuring that older adult consumers have enough information, together with sufficient time and support, to make informed decisions that serve their needs, preferences, and best interests. The model of patient navigators adopted for the implementation of the Affordable Care Act provides an instructive template for the impending transition to managed care. Community health workers or other navigators who are trained to respond to the specific needs of the dual eligible population can target consumers who do not actively select a new primary care provider once they have been enrolled. Those who are passively enrolled might not be fully informed about their options under the new plan, or they may be struggling with physical or mental health conditions that prevent them from fully engaging with critical information about changes to their medical care.

Others who are also deemed "at risk" -- for example, those with the highest acuity of physical/mental health care needs, those who are monolingual and non-English speaking, and those who are otherwise socially or geographically isolated -- should also be targeted for in-person follow-up visits from knowledgeable advocates to ensure that they are successfully engaged with the new managed care plan and are not experiencing any gaps in care.

Many of our respondents used the telephone to obtain needed information. It is also important, therefore, that the HICAPs that are being tasked with providing consumer information are appropriately resourced so that they can be both adequately staffed in appropriate languages and clearly labeled in all communications as an information source. In addition, other community-based organizations and local government agencies serving dual eligible older adults and their caregivers can assist with the efforts to disseminate information effectively. By initiating collective and collaborative communication efforts and using multiple pathways to reach and follow up with those most at risk for experiencing gaps in medical and social care services, these entities can provide critical point-of-information dissemination and assistance.

## Conclusion

HOME study participants generally fall along a continuum of active to passive information seekers, and engaged to disengaged information users. The result is a typology of seniors that highlights the likely result of standard outreach methods used to inform dual eligibles of upcoming changes in the organization of their care:

**Typology of Seniors' Responses to Information Received**

| | Active information seekers | Passive information seekers |
|---|---|---|
| Engaged information users | successful | misinformed |
| Disengaged information users | discouraged | unsuccessful |

This range of responses to information suggests that targeted strategies are important to: better support those who have accurate information but lack the physical or emotional health, or social support, to act on it; provide better outreach to those who are likely to receive incomplete or inaccurate information second or third hand; and inform those who standard dissemination approaches may not reach and who need support to take action on that information.

## Author Information

Kathryn G. Kietzman, PhD, is a research scientist and director of the HOME study. Jacqueline M. Torres, MPH, Charlene Chang, MA, and Tina Duyen Tran, BA, are graduate student researchers at the UCLA Center for Health Policy Research. Anne Soon Choi, PhD, is a faculty associate at the UCLA Center for Health Policy Research. Steven P. Wallace, PhD, is associate director of the UCLA Center for Health Policy Research and professor and chair of Community Health Sciences at the UCLA Fielding School of Public Health.

## Funder Information

THE scan FOUNDATION This policy note was supported by a grant from The SCAN Foundation, advancing a coordinated and easily navigated system of high-quality services for older adults that preserve dignity and independence.  For more information, visit www.TheSCANFoundation.org.

## Acknowledgments

The authors thank Jack Hailey, Janet Heinritz-Canterbury, Randi Bardeaux, Aileen Harper, A.E. Benjamin, and Carolyn Mendez-Luck for their helpful reviews. We also express our gratitude to our advisory board and to our recruitment partners at San Diego County HHSA Aging & Independence Services, and to IHSS Public Authority, Social Services Agency of Orange County, Los Angeles County Department of Public Social Services, and Santa Clara COA Public Authority Services.

## Suggested Citation

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.

## Case Studies

For more information about 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. *www.healthpolicy.ucla.edu/HOMEstudy*
2. Disability Rights Education and Defense Fund (DRDEF) & National Senior Citizens Law Center (NSCLC). *Advocate's Guide to California's Coordinated Care Initiative, Version 2*. September 2013. Adults ages 65 and older represent more than three-quarters of the "dual eligible" population in California's eight demonstration counties (76 percent, per the NSCLC report). As such, they represent the largest group to be affected by this policy change. Women represent a majority of the dual eligible population (59 percent). English is not the primary language of more than half (55 percent) of the total dual eligible population in the pilot demonstration counties. *http://www.nsclc.org/wp-content/uploads/2013/09/CCI-Advocates-Guide-Sept.-20132.pdf*
3. Reaves EL, Musumeci M, Jacobson G, Perry M, Mulligan Kolb N, and Saulsberry L. *Faces of Dually Eligible Beneficiaries: Profiles of People with Medicare and Medicaid Coverage*, Kaiser Family Foundation**,** July 2013. *http://kff.org/medicaid/issue-brief/faces-of-dually-eligible-beneficiaries-profiles-of-people-with-medicare-and-medicaid-coverage/*
4. 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*.
5. Alameda, Los Angeles, Orange, Riverside, San Bernardino, San Diego, San Mateo, and Santa Clara counties. *http://www.dhcs.ca.gov/provgovpart/Pages/CoordinatedCareIntiatiave.aspx*
6. Young K, Garfield R, Musumeci M, Clemans-Cope L, and Lawton E. *Medicaid's Role for Dual-Eligible Beneficiaries*. Kaiser Family Foundation, August 2013. *http://www.kff.org/medicaid/issue-brief/medicaids-role-for-dual-eligible-beneficiaries/*
7. California Department of Health Care Services. *Medi-Cal's Coordinated Care Initiative (CCI) Population: Combined Medicare and Medi-Cal Cost, Utilization, and Disease Burden.* Sacramento, CA: DHCS Research and Analytic Studies Branch, November 2012. *http://www.dhcs.ca.gov/dataandstats/statistics/Documents/Dual%20Data%20Sets%20Medicare.pdf*
8. Kasper J, O'Malley Watts M, and Lyons B. *Chronic Disease and Co-Morbidity Among Dual Eligibles: Implications for Patterns of Medicaid and Medicare Service Use and Spending*, Kaiser Family Foundation, July 2010. *http://www.kff.org/health-reform/report/chronic-disease-and-co-morbidity-among-dual/*
9. Kietzman KG, Torres JM, Choi AS, and 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. *http://healthpolicy.ucla.edu/publications/search/pages/detail.aspx?PubID=867*