Adding Perspective:
Conversations with Dual Eligible Beneficiaries

Prepared by Harbage Consulting
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Over the last six months, the Department of Health Care Services has organized numerous opportunities to learn directly from Medicare and Medi-Cal beneficiaries about their health care experiences, needs, preferences and reactions to proposed system changes. This work was part of a broad stakeholder engagement process to inform the design and implementation of California's Dual Eligibles Demonstration Project. This document summarizes key insights gleaned from the beneficiary outreach efforts that included:

- Five public stakeholder meetings, which included beneficiary participation on panels.
- Informal focus groups with dual eligibles in four counties: Sacramento, Alameda, Los Angeles and Orange.
- A Consumer Experience E-Survey, completed by 120 dual eligible beneficiaries.
- Numerous one-on-one telephone and in-person conversations.

This document represents just the beginning of the discussion with consumers on these key issues. A strategy to expand this discussion even further in 2012 is being developed.

Key Themes

From the 2011 consumer outreach effort, several key points can be learned.

1. **Care today rarely is coordinated.** The burden of coordination falls on the beneficiaries and their caregivers. While many are capable of assembling delicate webs of providers and services, others are not. Beneficiaries can pinpoint numerous occasions of poor coordination among their providers that led to extra tests, visits and potential adverse complications. Several people suggested the benefits of a "master record" that listed all their services, providers and medications and could be accessed and updated by all their doctors. Any care management system, however, should be beneficiary-centered and blend the medical and social models. Furthermore, care management should provide strong linkages to community-based organizations that provide key wrap-around services that help people live at home.

2. **Beneficiaries often encounter access challenges at medical offices**. Beneficiaries with mobility disabilities reported that they often couldn't get to the doctor because the doctor's office isn't accessible to people using wheelchairs or those who have other mobility issues. This may lead to delays in needed services.

3. **There is a need for direct, clear communication from Medi-Cal**. Beneficiaries reported they felt overwhelmed by letters from Medicare and Medi-Cal, but moreover the information often was not understandable. People said they learned best through in-person conversations and requested direct outreach through local community resources, such as Centers for Independent Living. Second to one-on-one counseling, people want a hotline number to call to answer their questions. They said they were frequently frustrated because they couldn't find someone knowledgeable to give them answers.

4. **Change can be a cause of concern**. No matter the challenges faced today, the prospect of any system-wide change leads to a sense of anxiety, if not fear, among beneficiaries. Many beneficiaries place a high value on stability and consistency, especially after they've found providers and services that meet their unique needs and situations. In

particular, beneficiaries fear disrupting relationships with their current physicians.

5. **In-Home Support Services are seen as a critical support**. When asked what their most important health service was, respondents most often said IHSS and their doctors. Many beneficiaries remarked that IHSS was the key to their independence. “I can’t get up without it, can’t go to bed without it, and can’t make my food without it,” one woman said. Having experienced many recent rounds of cuts to the program, consumers feared future changes. And a major cause for concern was potentially losing self-direction of care under any new system. Many beneficiaries added that the ability to self-direct their care and manage their workers was an essential component of IHSS working well for them.

6. **Beneficiaries want more supplemental benefits.** Beneficiaries want dental, vision and other supplementary benefits, like they used to receive under the Medi-Cal program. One woman said, “I can’t afford the $3,000 it takes to fix a crack in my tooth so I have to live with the pain. And I saved up money from recycling bottles and cans to get my glasses.”

Lack of coordinated care today

Beneficiaries reported “getting bounced from office to office” to get their needs met. By and large, beneficiaries said their care was not coordinated unless they took the initiative and shared information between providers themselves or requested that certain providers communicate. One wheelchair-bound woman said she was tired of restating her medical history and recounted numerous occasions when complications in her care resulted from miscommunication between her providers. Any care management system, however, must bridge the medical and social models, beneficiaries and their advocates said. Care managers should be familiar with both long-term supportive services and medical services, as well as with local community resources. Care management plans should be beneficiary-centered and allow individuals to decide for themselves “the level of risk they’re ready to take on.”

Community based organizations (CBOs) often are key providers and links to resources that help beneficiaries live at home. A key element of any care management model should be developing formal partnerships with CBOs to provide all the wrap-around services dual eligibles need.

Beneficiaries provided the following insights into their care delivery experiences.

> *“I wish they could have a Medi-Medi city where everyone knew about us and we got all of our services.”*
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> *“We have to tell them everything, and we have to start over with each doctor and often with the same doctor,” said an In-Home Supportive Services (IHSS) attendant. She added, “If I wasn’t there, he wouldn’t get the services he needs.”*
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> *“A professional care coordinator would be useful. That would reduce the stress on me and my doctor.”*
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> *“I think it would be very beneficial if there was a master list of patients’ files that doctors all had access to.”*
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> *“I don’t feel like I have a medical home. I’m always seeing new doctors and nurse practitioners and they don’t talk to each other. Often, they don’t even know my name.”*

Need for accessible services

Beneficiaries in wheelchairs recounted times when inaccessible medical facilities complicated their treatment. One elderly, quadriplegic man recalled a time when he needed an X-ray but the medical office’s machine wasn’t accessible. The office sent him to the county hospital’s emergency department, where he had to wait several hours for an X-ray. Moreover, he can use the county’s paratransit for only one reserved appointment per day and thus spent more than an hour on the bus to the hospital. His IHSS worker did not get paid to accompany him to and from the appointment.

Another woman recalled showing up at a medical office that wasn't accessible for her wheelchair. She had to make an appointment with a different doctor and wait another month to be seen.

Consumer education and clear communication

Beneficiaries recounted receiving confusing information from Medicare, Medi-Cal or a health plan. Automated phone messages and form letters typically were unhelpful, they said. Frequently, these mass messages were deleted, thrown away or forgotten in a pile of papers. People commented:

- *"It is all very confusing. People are afraid to do anything because they don't know how it will affect their services."*

- *"Nobody can answer any questions. The most they say is 'Don't do anything too fast and don't let the due dates run out.' … We're calling social workers, ombudsmen and nobody knows. If you talk to health insurance people, they don't know either."*

- *"How do you know what all the acronyms are?"*

As part of the interviews, beneficiaries were asked about new communication methods. Regarding Public Service Announcements, beneficiaries thought they should be used widely, but they should explain clearly: 1) who are dual eligibles; 2) how they might be affected – mention specific benefits and choices; 3) what managed care is; and 4) and add a toll-free number for more information. These messages need to be explained in language consumers understand. Several people suggested using sample scenarios and examples that people could relate to and compare to their own situation.

Few beneficiaries said they used the Internet. The few who had gone online to answer a question said finding the correct website and page was difficult. Some said once they did reach the correct site, the needed information was outdated. One woman suggested partnering with or building something for Medi-Cal benefits similar to the website www.DisabilityBenefits101.org. "It's a go-to page for me," she said. "It would be very helpful to be able to enter in your zip code and see what specific rules there are for you based on your residence."

Staff at the Dayle McIntosh Center for Independent Living said toolkits to help consumers learn what questions to ask of their providers and eligibility workers would be tremendously helpful. Many consumers, they said, are afraid to ask their providers and thus don’t receive the information or services they need.

Additional communication suggestions included requests to establish:

- A cadre of “choice counselors” to help people get one-on-one information so that they understand their options.
- A single call-in number for questions.
- A website where county social workers and eligibility workers learn and find answers would help them inform dual eligibles. *“Now, they only know Medi-Cal.”*
- Health plans should hold community meetings and forums to inform people of their options.
- Also the State, it was suggested, should work with community organizations, such as Independent Living Centers, to help people understand the changes. The community-based organizations need additional funding to do this work.

Concerns about change

While many dual eligible beneficiaries agreed with the goals of improving coordination and could pinpoint failings in the existing system of Medicare and Medi-Cal services, the following remarks reflect their anxiety about any system change.

> *“There’s always change. Keep things the same. It gets confusing.”*
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> *“If you’re adding another service, people should be able to keep the ones they have now. So if you already have certain specialists, you should be able to go to the same specialists.”*
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> *“Does that mean you have to get in one of those HMO plans?”*
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> *“My grandma is a Medi-Medi and she is afraid that if she joined an HMO that her cancer medications wouldn’t be covered.”*

> *“I don’t want to give up Rancho [rehabilitation hospital]. If you pushed me into a plan and I’d have to go someplace else, that would be a big problem.”*
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> *“In Medicare, I can go to any doctor. I don’t want that to change.”*
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> *“[The changes] are overwhelming and exhausting. I’m already dealing with so much, and so it’s just another layer. Anticipating the disappointment is really hard.”*
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> *“Well, having one insurance card and one program sounds good if you get the reaction from the one card that you do currently from the Medicare card. … Will it coincide with what doctors want? Because they have to be willing to take it.”*

Provision of In-Home Supportive Services

Of all the concerns about change, beneficiaries emphasized the need to maintain adequate IHSS worker hours and the ability to self-direct their care. Virtually everyone interviewed relied on, and preferred to rely on, themselves or a relative/friend to manage their health care services.

> *“Prior, to qualifying for IHSS, I was living in squalor because I physically cannot clean my apartment, leaving a dirty shower, toilet, carpet, floors, kitchen, & very dusty with dirty dishes piling up, and not eating well because I cannot cook. So [medical services] and IHSS are both essential.”*
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> *“Having the power taken away from me to be able to choose and schedule my workers – that would just be a nightmare.”*
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> *“Leave us alone and offer a cafeteria of services.”*
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> *“The system needs to provide for back-up workers and respite time for workers.”*

Sources for this Document: The Consumer Experience Survey

In addition to on-site interviews, Harbage Consulting circulated an electronic consumer experience survey during the fall months of 2011. About 120 Medicare and Medi-Cal beneficiaries completed the survey. Most responders had high health care needs and reported being in fair or poor health. A majority had three or more physicians and took six or more prescription medications. The e-survey best reached younger people living at home. Nearly all survey respondents lived at home and 70% were younger than age 65.

While, as predicted, the number of respondents was too few for a statistical analysis, the exercise provided several useful insights. At least 60 beneficiaries provided their email addresses to receive regular updates on the project. Others provided their phone numbers for one-on-one conversations, and some even volunteered and participated on panel discussions at public stakeholder meetings. Despite their limitations, rapid e-surveys may be a useful tool moving forward to gauge beneficiaries' understanding and impressions on the implementation of the duals demonstration project.

Looking forward: Communication Efforts in 2012

The outreach efforts described here provided several useful lessons to inform further work throughout 2012 to engage beneficiaries and other stakeholders in the planning and implementation of California's Dual Eligibles Demonstration project. There will be more public meetings and a new website that will foster interactive dialogue and serve as a clearinghouse for news and updates on the demonstration project. Additionally, the California Department of Health Care Services intends to announce a workgroup structure that will allow for the interactive development of policy analysis among the Administration, stakeholders, and beneficiaries.

Please find more information and updates at www.CalDuals.org and on Twitter @CalDuals.