

Improving Medi-Cal Communications for Seniors and People with Disabilities: Explaining the Share of Cost and other Medi-Cal Programs

Project Overview, Goal, Process, Findings, and Recommendations

June 2024

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Background and Project Overview

General Background: Medi-Cal is California’s Medicaid program. It provides health coverage to Californians with low incomes, including families with children, adults, seniors, people with disabilities, pregnant people, and more. In 2023, more than one out of every three Californians (~15 million)* were enrolled in Medi-Cal, a program that the California Department of Health Care Services (DHCS) administers.

Project Overview: At the request of DHCS, the California Health Care Foundation enlisted a team to test and refine written materials with older adults and people with disabilities (or their proxies) currently enrolled in Medi-Cal in the “Aged, Blind, and Disabled (ABD)” aid codes. These aid codes broadly include Medi-Cal enrollees who are age 65+, blind or with low vision (as defined by the Social Security Administration), disabled (also as defined by the Social Security Administration), receiving Supplemental Security Income (SSI), and/or blind or disabled and living in a long-term care facility.

Materials in English, Spanish, and Chinese† were tested with relevant Medi-Cal populations during two project phases.

- **Phase One** focused on documents about Medi-Cal programs for older adults (age 65 or older) and people with disabilities.
- **Phase Two** focused on documents specifically about Medi-Cal with a Share of Cost (SOC). Older adults and people with disabilities whose income is too high to qualify for no-cost Medi-Cal have a SOC that is similar to a deductible. Phase Two materials were tested with Medi-Cal SOC enrollees (or their proxies) who live at home or in long-term care facilities.

* Retrieved from the [DHCS Medi-Cal Enrollment and Renewal dashboard](#) on April 8, 2024.

† DHCS requested the materials to be written in Traditional Chinese. Interviews were conducted in Mandarin ($N = 26$ individuals) and Cantonese ($N = 4$ individuals).

Project Goal and Process

Goal: Assist DHCS in improving their communications to Medi-Cal ABD and SOC enrollees to ensure enrollees can understand and more effectively and efficiently take needed action on topics such as Medi-Cal programs, eligibility, benefits, costs, and the asset test elimination.

Process:

1. Build on lessons learned from previous health communication projects with DHCS, including [Plain and Clear Part One](#) ("Making Medi-Cal Communications Easy to Understand") and [Part Two](#) ("Making the Medi-Cal Rights and Responsibilities Document Easier to Understand for Enrollees").
2. Create initial drafts of Phase One (ABD documents) in English, Spanish, and Chinese.
3. Conduct individual, dyad, and triad user interviews in each language.
4. Make revisions in each language.
5. Solicit subject-matter expert input from DHCS and external stakeholders (i.e., advocacy organizations, county Medi-Cal offices, and non-profit organizations).
6. Make final revisions in each language.
7. Repeat steps 2-6 for Phase Two (SOC documents), incorporating lessons learned from Phase One.

Documents Included in Project

| | Original Document Title | Recommended Revised Document Title |
|---------|---|---|
| Phase 1 | <div>1. Non-MAGI Medi-Cal</div> <div>2. Qualified Medicare Beneficiary (QMB), Specified Low-Income Medicare Beneficiary (SLMB), and Qualifying Individual (QI) Application</div> <div>3. Notice Regarding Standards for Medi-Cal Eligibility</div> | <div>1. Medi-Cal Programs You May Qualify For</div> <div>2. Information and Application to Help You Save Money on Medicare Costs</div> <div>3. Important Medi-Cal Information if You Use Nursing-Facility Care or Get Home Care</div> |
| Phase 2 | <div>1. Denial/Discontinuance of Share of Cost</div> <div>2. Approval of Benefits with a Monthly Cost</div> <div>3. Increase in Monthly Cost</div> <div>4. Change of Benefits</div> <div>5. Ways to Lower or Stop your Medi-Cal Share of Cost</div> | <div>1. Your Medi-Cal Will Be Free</div> <div>2. You Are Approved for Medi-Cal with a “Shared Monthly Cost”</div> <div>3. Your Shared Monthly Cost for Medi-Cal is Increasing</div> <div>4. Your Medi-Cal Costs Have Increased/Decreased*</div> <div>5. Six Ways to Reduce or Eliminate Your Shared Monthly Cost for Medi-Cal</div> |

* Prior to dissemination, DHCS Statewide Automated Welfare System (SAWS) will individualize this title and only use the word “increased” or “decreased,” as applicable.

Methodology

Phase One: Twenty-four (24) interview sessions were conducted in September and October 2023 with English-, Spanish-, Mandarin- and Cantonese-speaking enrollees or caregivers of those enrolled in Medi-Cal under the “aged, blind, and disabled” aid codes. A total of 35 individuals were interviewed in this phase of the study.

Phase Two: Forty-one (41) additional interview sessions were conducted in November and December 2023 in the languages listed above with enrollees or caregivers of those enrolled in Medi-Cal’s “Share of Cost” aid codes. A total of 57 individuals were interviewed in this phase of the study.

Interviews were conducted via Zoom in a combination of **one-on-one, dyad, and triad formats**. Interview moderators for the Spanish, Cantonese, and Mandarin interviews were bilingual and bicultural; they conducted interviews in the respondents’ native/preferred language.

To account and accommodate for cognitive impairment, linguistic differences, and cultural differences — and to gain insights from each document’s actual end user — **healthcare proxies were frequently interviewed in lieu of or in conjunction with enrollees**. Healthcare proxies for both phases included family members and caregivers. For Phase Two only, social workers and staff at nursing facilities also participated as proxies, and specifically so for interviews conducted in Spanish and Mandarin. Of the 92 individuals interviewed in Phases One and Two, 64 were Medi-Cal enrollees and 28 were proxies.

The qualitative nature of these interviews means that this project’s findings offer insights into people’s **feelings and beliefs**. For this reason, and because of the small sample size, findings should be considered **directional rather than absolute**.

Participant Profiles and Demographics

| | | English Speakers | Spanish Speakers | Chinese Speakers* |
|--|----------------|---------------------|---------------------|----------------------|
| Total Participants | | 33 | 29 | 30 |
| Age | Range | 28–81 | 29–74 | 26–96 |
| | Average age | 57 | 52 | 61 |
| Gender† | Male | 13 | 7 | 10 |
| | Female | 20 | 22 | 20 |
| California Region | NorCal | 10 | 3 | 18 |
| | SoCal | 20 | 22 | 5 |
| | Valley/Central | 3 | 4 | 7 |
| Enrollee w/ disability or their proxy | Yes | 14 | 10 | 6 |
| Caregiver | Yes | 13 | 12 | 3 |
| Education‡ | High School | 7 | 13 | 18 |
| | Grad or Lower | | | |

* 26 individuals were interviewed in Mandarin; four individuals were interviewed in Cantonese.

† A nonbinary option was offered in the gender question. No participants selected this option.

‡ Data were collected on several levels of education. Reporting here is limited to only showing the “mid-point” of educational attainment data to help illustrate literacy and comprehension levels.

Key Finding #1: Medi-Cal enrollees are confused, frustrated, insulted, and intimidated when they see words, phrases, and jargon that are unclear, unfamiliar, or overly complicated.

“It’s unclear what ‘250% Working Disabled Program’ means. Are you working 250% of the time? I’m not sure what that means. I’d have to figure that out, and that’s a problem.” – Family caregiver for son (English-language preferred Medi-Cal enrollee in the ABD population without a SOC in Northern CA)

“The ‘personal needs allowance.’ It’s like a child getting their allowance ... It’s heartbreaking. It’s like you’re a bad child.” – Family caregiver for mother (English-language preferred Medi-Cal enrollee in the ABD population with a SOC in Southern CA)

“‘Monthly Maintenance Need’ is the most confusing phrase. It’s like, ‘where did this come from, what does it mean, and who determines this?’ It’s a confusing phrase ... who figures out what I need?” – Medi-Cal enrollee with disability and Share of Cost; English-language preferred white woman, mid-30s, completed some college, lives in Southern CA

Recommendation #1: Use common, everyday words and phrases. Explain programs or concepts before providing their official name. When words or phrases cannot be modified for legal- or policy-related reasons, define them. Update corresponding documents so that revised words and phrases are universal.

Examples

| Original Phrase | Recommended Phrase |
|-------------------------------|--|
| Gross Monthly Income | Total Monthly Income |
| Countable Monthly Income | The only part of your total monthly income that the Medi-Cal program can use to determine your eligibility. |
| Monthly Maintenance Need | Your monthly amount for living expenses. It is based on your household size and not your actual living expenses. California state law sets the amount. |
| 250% Working Disabled Program | The program that provides free Medi-Cal to certain people who are disabled and working at least one hour each month. |

Key Finding #2: Medi-Cal enrollees want specific and relevant details of how any changes will or will not impact them, including examples. They do not want to wade through information that does not pertain to their personal situation or seek out details in other mailings or documentation to get complete information.

“When you see that your Medi-Cal will be free, you think, ‘what am I losing out on?’ ... Say that your benefits have not changed. You need to put that in there or you’d wonder what you’re losing out on.” – Medi-Cal enrollee with a disability, in a long-term care facility, with a SOC; English-language preferred white man, low-30s, completed some college, lives in Southern CA

“You’re going to send another letter with more details? Save the trees! If you’re already sending this out, just add more detail rather than another letter ... I have unopened mail from Medi-Cal from months ago ... instead of another letter, if you want us to read it, have it all there in that one notification!” – Medi-Cal enrollee with a SOC; English-language preferred biracial woman (Black/white), upper-20s, completed high school, lives in Southern CA

Recommendation #2: Include specific details that are relevant and reassuring. Write in a logical flow to minimize the burden on the reader. Streamline the number of mailings sent to enrollees.

Examples

Original Phrase

Recommended Phrase

“You are now responsible for paying a monthly resident cost.”

“You are now responsible for paying a monthly resident cost. It will cover your healthcare, medicine, medical equipment, and personal care; room and board, including meals; physical and occupational therapy; laundry; and social and recreational activities. You will continue to receive all of the same Medi-Cal benefits that you previously had.”

“Beginning on (date) you no longer have a monthly cost ... Your Medi-Cal eligibility is not ending. You will receive another notice about your continuing Medi-Cal eligibility.”

“Your Medi-Cal will be free starting on (date) ... You will get full scope Medi-Cal without a Shared Monthly Cost.

“You only have to pay (your monthly cost) if you get medical care ... Once you have met your monthly cost, Medi-Cal will pay for the rest of your services in that month that are covered by Medi-Cal. If you do not receive healthcare services or benefits in a month, you do not have to pay anything.”

“You are responsible for paying up to \$X,XXX in the months that you use Medi-Cal services. In the months that you use Medi-Cal services that cost less than \$X,XXX, you will only pay that smaller amount. Once you have paid your ‘share,’ Medi-Cal will pay for all of your other covered benefits that month. You do not need to pay anything in the months when you do not use Medi-Cal services.”

Key Finding #3: Medi-Cal enrollees want to see how their Share of Cost is calculated. This will instill confidence that the math was done correctly and provide documentation for enrollees requesting state hearings.

“I want to understand the math ... I’d like it to be super clear. I’ve been [getting this paperwork] for 1 ½ years now, and it’s all high alert. Everything is an alert ... I’d like to see the math ... otherwise, I’m calling that 1-800 number and will be on hold a couple of hours.” – Family caregiver for father (English-language preferred Medi-Cal Enrollee in the ABD population with a SOC and in a long-term care facility in Southern CA)

“Show the breakdown ... you need a line saying ‘this minus that ...’ a simple math problem. Then you see out of my total income how it works. Otherwise, it’s a little confusing.” – Family caregiver for mother (English-language preferred Medi-Cal enrollee in the ABD population with a SOC and in a long-term care facility in Southern CA)

Recommendation #3: Create a simple and understandable graphic that includes all of the pertinent dollar amounts used to determine each enrollee’s Share of Cost. Use plain language to explain what each dollar amount means.

Example

| Numbers Used to Calculate Your Shared Monthly Cost | |
|--|------------|
| Your total monthly income This is the income you reported to Medi-Cal. It's also called your "gross income." | \$ 1,945 |
| Your countable monthly income This is the only part of your total monthly income that the Medi-Cal program can use to determine your eligibility. | \$ 1,760 |
| Your monthly amount for living expenses California state law sets this amount. It's based on your household size and not on your actual living expenses. It's also called your "Maintenance Need." | – \$ 600 |
| Your Maximum Monthly Cost to Use Medi-Cal This is your Shared Monthly Cost (formerly known as your "Share of Cost"). It's the most you will pay in a month to use Medi-Cal. You will not pay anything in the months that you do not use Medi-Cal services. | = \$ 1,160 |

Key Finding #4: Medi-Cal enrollees without a Share of Cost (SOC) thought that the phrase could be clearer. Enrollees with a SOC were familiar with it, mainly understood it, and had mixed feelings about it.

“Share of Cost is another terminology you have to remember ... it’s giving you an idea that you can get some relief from high medical costs ... you need to have ‘monthly’ and ‘cost’ in there, though. – Medi-Cal enrollee in the ABD population without a SOC; English-language preferred Black woman, mid-70s, graduated from college, lives in Southern CA

“Maybe there could be another way of explaining it. ‘Medi-Cal with Share of Cost.’ What does it mean, that they pay 20%?” –Medi-Cal enrollee in the ABD population without a SOC; Spanish-language preferred Hispanic woman, early 70s, some college, lives in Southern CA

“Share of Cost sounds like terminology ... if you want to eliminate jargon, say ‘monthly cost...’ When you add the word ‘shared,’ that’s a good heads up that [they’re] paying everything else and [we’re] not on our own here. It indicates that [they] will not drop [me] on [my] butt and that [they’ll] pay everything else.” –Medi-Cal enrollee with a disability and a SOC; English-language preferred white woman, upper-50s, graduated from college, lives in Southern CA

“I’m used to the term Share of Cost after seven years of calling and figuring it out. But if I didn’t know it ...” –Family caregiver for brother (English-language preferred Medi-Cal enrollee with a SOC and in a long-term care facility in Central CA)

Recommendation #4: Change the phrase “Share of Cost” to “Shared Monthly Cost” for all Medi-Cal populations.

| Sample of Tested Phrases | Reactions from Medi-Cal Enrollees and/or Proxies |
|------------------------------|--|
| Share of Cost | <i>“I would much rather have it changed from Share of Cost to [Shared] Monthly Cost. That way, if my daughters have to step in and take care of this paperwork if I were not capable, it would be more clear to them. With the term ‘Share of Cost,’ you need to call in and find out what that means.”</i> –Family caregiver for husband (English-language preferred Medi-Cal Enrollee, in the ABD population with a SOC in a long-term care facility in Southern CA) |
| Monthly Fee to Use Medi-Cal | <i>“[Monthly] Fee to use Medi-Cal ... that’s direct. This leads me to believe if I don’t use it, I don’t have to pay it. I like this better than Share of Cost.”</i> –Medi-Cal enrollee in the ABD population without a SOC; English-language preferred biracial (Hispanic/Native American), upper-50s, completed some college, lives in Southern CA |
| Monthly Cost to Use Medi-Cal | <i>“Monthly Cost is better because Share of Cost sounds so overwhelming ... a monthly [cost] sounds better. When I heard I had to pay a Share of Cost, I had an anxiety attack right away.”</i> –Medi-Cal enrollee with a SOC; English-language preferred biracial woman (Black/white), upper-20s, completed high school, lives in Southern CA |
| Monthly Contribution | <i>“Monthly Contribution says you may not have a fee if you don’t use it ... it’s like, ‘I’m contributing to my health.’ This is a runner up to ‘monthly cost to use Medi-Cal.’”</i> –Medi-Cal enrollee in the ABD population without a SOC; English-language preferred white woman, low-80s, completed some college, lives in Northern CA |
| Monthly Deductible | <i>“I’m not crazy about ‘deductible’ ... It puts me in a different place, mentally. It scares me. There’s gotta be a way that’s more gentle and accurate.”</i> –Family caregiver for mother (English-language preferred Medi-Cal enrollee with a SOC in Southern CA) |
| Beneficiary Contribution | <i>“Argh! That’s too voluntary. A contribution is what you give to your church. And, what’s a ‘beneficiary’? It doesn’t make sense. It’s too sophisticated.”</i> –Family caregiver for son (English-language preferred Medi-Cal enrollee in the ABD population without a SOC in Northern CA) |
| Shared Monthly Cost | <i>“This defines it as per month and that it’s your contribution.”</i> –Family caregiver for parents (English-language preferred Medi-Cal enrollees in the ABD population without a SOC in Southern CA) |

Key Finding #5: While enrollees across all language groups expressed some common points of confusion, those whose preferred language is Spanish, Mandarin, or Cantonese had additional needs for clarification not shared by native English speakers, including:

- **The way a word or phrase is translated.**

“(For people with a disability), don’t be so specific and [only] say ‘older people’ (hogar de ancianos). Use ‘home for people who need specific care.’ What’s important to highlight is that it’s a place where older people and people with a disability can be cared for.” –Medi-Cal enrollee in the ABD population without a SOC; Spanish-language preferred Hispanic woman, late 60s, completed technical/vocational/trade school, lives in Southern CA

- **The sequencing, presentation, or layout of information.**

“The Chinese translation should not use the English explanation method. In the Chinese context, the most important content should be put at the top.” –Social worker, Mandarin-language preferred Chinese woman, early 30s, vocational school, lives in Northern CA

- **The need for further explanation of concepts that may be more familiar to English speakers.**

“The Chinese expression of ‘Personal Needs Allowance’ may lead to ambiguity ... I feel like (with) this term, Medi-Cal is telling me that I need to give \$35.” –Social worker, Mandarin-language preferred Chinese woman, mid 20s, graduate school, lives in Northern CA

Recommendation #5: For all future materials, conduct user interviews in all threshold languages. Then, make individualized translations and adaptations for each language. Update corresponding documents so that revised words, phrases, and concepts are used universally.

Examples

| Original Phrase | Spanish-Language Recommendation |
|--|---|
| Nursing Home | Nursing Home (for older adults) and Specialized Care Facility (for people with disabilities) |
| Worker | Social worker |
| “We are writing to tell you...”/“We have approved your application...”/“We looked at your income...” | “This letter is to inform you...” / “Your application has been approved...” / “Your income was evaluated...” <i>(This was a recommendation from both Spanish- and Chinese-language preferred participants for more formal, official language, without using the word “we.”)</i> |
| Personal/Monthly Maintenance | Add “amount determined by law.” |
| SOC: “You will need to pay \$1,160.” | “You will need to pay a maximum of \$1,160” <i>(This recommendation was so beneficial that it was carried over into all languages, in various iterations.)</i> |
| Options to Eliminate or Reduce SOC | Start approach with “If this situation applies to you...,” followed by actions to be taken. |

Recommendation #5: (Continued from previous slide, but with Chinese-language examples.)

Examples

| Original Phrase | Chinese-Language Recommendation |
|---|--|
| Nursing Facility/Assisted Living Facility | Skilled Nursing Facility |
| Medi-Cal | Also reference the “white card” (to distinguish from Medicare’s “blue and red card”). |
| “Keep using your same Medi-Cal card. Bring it with you...” | “Keep using your same Medi-Cal card for all your doctors’ appointments...” |
| “You have a ‘Share of Cost’ because your income is over the limit for free Medi-Cal.” | “Because your income is over the limit for free Medi-Cal, you will have a ‘Share of Cost.’” [Provide the cause (reason) first, followed by effect (outcome).] |
| “Find your county office here.” | “County office contact information.” [Provide the most important information first.] |
| Monthly Resident Cost | Nursing Home Deductible |

Contact Information and Acknowledgements

Questions?

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Acknowledgments:

Health Engagement Strategies led the English-language revision process and design process for each document, conducted all interviews in English, and collaborated with DHCS and stakeholders.

Culture IQ conducted recruitment for user interviews in all three languages, conducted interviews in Spanish and Chinese, and translated and adapted all documents in Spanish and Chinese.

Terri Shaw assisted with project design and management.

The Medi-Cal Eligibility Department at the California Department of Health Care Services (DHCS), Medi-Cal enrollees, stakeholders, and advocates provided guidance and insight.