



CALIFORNIA ADVOCATES FOR NURSING HOME REFORM

1803 6th Street • Berkeley California 94710
(800) 474 - 1116 • www.canhr.org • canhrmail@canhr.org

October 19, 2022

Brooke Hennessy, Chief
Financial Eligibility Unit, Policy Development Branch
Medi-Cal Eligibility Division
Department of Health Care Services
1501 Capitol Ave. MS 4607
Sacramento, 95814

Re: Change of “Share of Cost” Terminology

Dear Ms. Hennessey,

The undersigned advocacy organizations write to express our significant concerns regarding the Department of Health Care Service’s proposal to change the terms used for Share of Cost to “patient liability,” for individuals in Long Term Care, and “spend down of excess income,” for individuals in the Medically Needy program.

We are grateful that DHCS provided a preliminary and limited forum to discuss the proposed changes during our small-group collaboration on the Share of Cost notice insert. However, that limited forum included just three advocacy organizations. For this terminology change that will impact millions of Medi-Cal beneficiaries, the Department must do more before finalizing the new terminology. We do not find these terms are acceptable for use at all, and they are frankly, offensive. We understand that it can be challenging to craft terminology to meet the needs of everyone, but we request that the Department engage with advocates and readability experts to come up with plain language alternatives that make sense. This would ensure consistency with the Department’s commitment to improving Medi-Cal readability broadly through its “Medi-Cal Communications Project” and related efforts.

The existing term, “Share of Cost” can be confusing for beneficiaries, but these suggested terms are not only more confusing, they contain negative connotations that will discourage people to enroll in Medi-Cal.¹ “Share of Cost” has been used for decades, is a term that beneficiaries have become accustomed to, and is used throughout the healthcare system. While we agree that it is time to come up with a better way to describe this concept, the current proposed language is not just confusing, it will make things worse.

¹ For recent findings on how existing Medi-Cal terminology and materials confuse beneficiaries and suggestions for how to improve, see [“Plain and Clear: Making Medi-Cal Communications Easy to Understand”](#) by Beccah Rothschild (Health Engagement Strategies).

We ask that you work with us to get this change right the first time. We ask that you commit to brainstorming alternative terminology with advocates, readability, cultural, and linguistic experts, testing those terminology alternatives with Medi-Cal beneficiaries. Testing findings should be reviewed with advocates, readability, cultural, and linguistic experts before finalizing the new terminology.

“Patient Liability”

First, we have concerns with calling long-term care beneficiaries "patients," as many people who end up in a nursing home are there long term, sometimes for the rest of their lives. For many, the skilled nursing facility is their home, and as such, they should be called “residents.” Use of the term patient may also be confusing as that is commonly the term used for individuals who are in a hospital setting or medical office. Furthermore, the term “liability” has a very negative connotation, with many relating it to debt, and we sincerely believe that the use of this word will discourage people from seeking, or using, long-term care services. Recent testing and research also shows that misunderstanding and fear about Medi-Cal estate recovery means that we should avoid threatening language like “liability” whenever possible.²

We suggest you use plain language, as these terms will be used with consumers who do not work in a medical field, may have limited literacy skills, and may not speak English as a first language. Before we begin the process to select better terms as described above, we initially suggest the consideration of terms such as “nursing home deductible,” or “monthly resident cost.”

“Spend Down of Excess Income”

Referring to a low-income individual’s often limited retirement income as a “spend down of excess income” is an insult to many Medi-Cal beneficiaries. For an older adult or person with a disability who currently lives on \$1,700 per month, it is unlikely that they consider their \$1,100 share of cost as “excess income.” This is incredibly offensive to those who see the share of cost as a real hardship and barrier to medical care.

The use of the term “spend down” is very confusing in this context, as “spend down” has been used for years by beneficiaries and advocates to describe spending down countable income to become eligible for Medi-Cal with no share of cost, or spending down assets to meet the resource limit. Also, in recent user testing of “spend down” in that context, Medi-Cal beneficiaries expressed concerns that the term invited them to deceive the Medi-Cal program in order to qualify; this was perceived as unethical and risky. For example, Medi-Cal beneficiaries had this to say about “spend down” in the asset context:

² The recent “Medi-Cal Maze” report revealed concerns, rumors, and misunderstandings among people who are eligible but not enrolled in Medi-Cal about Medi-Cal estate recovery. See <https://www.chcf.org/wp-content/uploads/2021/09/MediCalMazeWhyManyDontEnroll.pdf> at page 12. It naturally follows that threatening language like “liability” and “spend down” will play right into these rumors and misperceptions.

- "This is interesting. Are they trying to get me to scam Medi-Cal? I'd like more information, but I'd be embarrassed to call and ask. And, wouldn't it raise a red flag on my case if I called and asked?"
- "It's kind of scary. They're talking about lowering your assets when we really don't have much in the first place. This is really sad -- thinking about giving something away just so you can get more Medi-Cal..."
- "I've never heard of this -- of lowering my assets to qualify for Medi-Cal. It's weird. It's like they're saying they're going to help us get away with fraud. If you don't put everything on your monthly forms, you get kicked off, fined, or penalized. So this is like a catch-22. They knew what we had, and now suddenly we have less?"

While other states may be using “spend down” to describe Share of Cost, California has long been a leader in health equity, and we sincerely believe that the use of this term will set back the movement to expand access to affordable healthcare.

Finally, we would like to express our concern with the use of two different terms for the same idea. Applying for Medi-Cal, especially as a result of a life-altering event, is already a complicated undertaking for the applicant and their families. Using two different terms will increase confusion and likely lead people to forgo applying for, or utilizing, Medi-Cal.

We appreciate the difficulty of choosing the right name for what can be a confusing concept to explain in plain language, but we urge you to work with advocates, readability, cultural, and linguistic experts to develop alternatives that work for consumers. Only after this brainstorming and user testing process should the Department determine the new terminology for share of cost.

If you have any questions feel free to contact Maura Gibney, maura@canhr.org, and Pauline Shatara, pauline@canhr.org. We would appreciate your response within the next two weeks as time is of the essence on this issue. We look forward to collaborating with the Department on this important improvement.

Sincerely,

Alliance for Leadership and Education
Alzheimer's Association
Alzheimer's Los Angeles
Alzheimer's Orange County
Bet Tzedek
California Advocates for Nursing Home Reform
California Health Advocates
Center for Elders' Independence
Center for Health Care Rights
Central California Legal Services
Choice in Aging

Collabria Care
Disability Rights California
ElderHelp of San Diego
Health Access California
Healthy Aging Association
Justice In Aging
LeadingAge California
Legal Aid Society of San Mateo County
LIFE ElderCare
LifeLong Medical Care
Maternal and Child Health Access
On Lok
Sacramento Resources for Independent Living
San Diego Senior Alliance
Senior Coalition of Stanislaus County
Seniors Council of Santa Cruz & San Benito Counties
Senior Services Coalition of Alameda County
Western Center on Law & Poverty
Village Movement California