



## Penny wise, pound foolish? How our long-term care policies fail us

*"All that we ever seem to focus on is how much it will cost, but what we don't talk about is how much it will save..." - Jodi Reid*

*911. What's your emergency?*

*America's healthcare system is broken and people are dying.*

Welcome to **Code WACK!**, where we shine a light on America's callous healthcare system, how it hurts us and what we can do about it. I'm your host, **Brenda Gazzar**.

*(music)*

This time on **Code WACK!** Why is long term care, including in-home health care, in crisis? How come two-thirds of people in California getting in-home health care get it from family members who are often unpaid? And how would universal long term care help? To find out, we spoke to **Jodi Reid**, executive director of **California Alliance for Retired Americans**, California's largest grassroots senior advocacy organization. She has more than four decades of organizing experience on issues ranging from health care to housing. Jodi represents her organization on the

board of **Healthy California Now**, a single-payer advocacy coalition. This is the first of a two-part series with Jodi about long-term care.

***Welcome back to Code WACK! Jodi!***

***Q: So what are long-term services and supports? Is that the same thing as long-term care like nursing homes or assisted living?***

**Reid:** There's a whole spectrum of what we consider long-term services and supports. So starting with health, there are institutional care facilities that range from what people consider traditional nursing homes to smaller board and care facilities that have less residents but are usually homes that care for maybe up to 10, usually less people and a number of licensed, different kinds of licensed facilities. But then there's also a kind of care that can be provided at home called home care. There's publicly subsidized home care for people whose incomes are at Medi-Cal levels. And then there's a share-of-cost program where if you're slightly over, you can pay a small amount for that care. And those are the in-Home Supportive Services program is right now there, there's a public authority that oversees that program in every county and its workforce is represented by labor. So there's SEIU 2015 and United Domestic Workers who bargain with the counties for those workers who provide training and try to win basic benefits.

And for the people who are income eligible for those programs, you get assessed how many hours you need per day or per week, what kind of activities of daily living you need assistance with. So it could be food, it could be bathing, it could be medication, it could be transport to providers, it could be bandage care, you know, wound care dressing. I mean, you name it, there's a whole list and you get assessed by a social worker to say, 'here's the things you'll need and here's how many hours we're able to assign to you of a worker for this many days.' And it could be that you need an hour or two a day or 24/7 care and you get care based on this assessment. But for people who are over that income, they have to go to

the private marketplace if they wanna stay at home.

And so there are home care agencies that you pay hourly for service. There are co-ops, domestic worker co-ops where you can get access like a registry. But two thirds of the people in California get that home care from family members, family caregivers who often are unpaid. Now if the person who you're caring for is eligible for IHSS, many times a family member becomes your official worker and gets paid at least for the hours that you've been assigned by the IHSS system. They get paid for those hours to care for you. Often you don't get as many hours paid for as you might need and so all the extra hours are donated, if you will, by the family caregiver and that takes a huge toll on families, who may be also raising children working, many have to give up their jobs because their family member needs more care and they can't manage the jobs, which puts their family into a stressful financial situation.

Their kids may not get as much of their family members' time. It's a whole spiral. And there's not a lot of support training or respite for those family caregivers. This is a huge, huge area that needs to be investigated.

***Right. It's a major burden on families.***

**Reid:** But the truth is, most people who need some level of care wanna try to stay home. The other thing is that the institutional care is very expensive. So there's assisted living and independent living and some of the newer buildings that are being developed for older folks, you move through the levels of care. So you might start in an independent environment and then as your needs increase, you may become eligible for, you know, so many hours and they provide staff to help you. You know, you may move into congregate meal programs, et cetera and it moves some now have memory care and Alzheimer's units. So you move within this facility to different levels of care. It's super expensive.

***Q: How expensive?***

**Reid:** Oh, it can be \$10,000 or more a month.

***Wow.***

**Reid:** So people have to sell their home obviously as they need more care and can't... One way or another, what often winds up happening, unless you're fairly well off, is that you have to spend so much money on care that you no longer have any savings and your income may be fixed even though you might have had savings or some, you know, whatever assets that you could sell and eventually become Medi-Cal eligible for those who are not wealthy. I mean, so a working family, middle class incomes. And the truth is, there are not enough facilities like nursing homes and boarding care facilities. There's not enough beds for all the people who might need them. And we're not necessarily spending money on building more nursing homes 'cause that's not where people wanna be.

But also it's like A Catch 22, you know, the state doesn't wanna pay for more access to home care services – another issue we're working on to try and get a universal long-term care benefit for everybody regardless of income that is affordable and that we all kind of chip in for kind of like single payer for long-term care, which I'll talk about in a minute. But instead the state says it's gonna cost way, way, way too much money. We can't afford that 'cause long-term care is so expensive. And so then people spend down and wind up becoming Medi-Cal eligible, which the state pays for. So whether they're paying for it on the front end and avoiding the costly expenses of not providing any care so people get worse and more severe, which requires much more expensive care. If we would allow people to stay home and get the small, you know, hourly care that they need so that they can be healthy and independent, it could save a lot of money for the state in the long run.

**Q: *That's a great point, Jodi.***

**Reid:** And it's a similar argument with, you know, a guaranteed unified financing system and single payer. All that we ever seem to focus on is how much it will cost. But what we don't talk about is how much it will save. And that is especially true in the area of long-term care. So since CARA is also a single-payer supporter or a unified financing system advocate, not only are we looking to create this unified financing system and get rid of the expensive privatized corporatized care where we pay for CEO salaries and marketing and administrative fees that we

would save, but we also can advocate for a benefit package that everybody has that includes like vision and dental and long-term care. If we're in one big pot together, all paying into those services so that if we need them, we will have access to them, it would cost a lot less than, and we would save a lot of money from people unnecessarily winding up in the emergency room, for example. Or needing, you know, much more costly medical care than if they were able to eat well and have the care they need at home.

***Yes, addressing preventive medicine and the economic and social conditions that influence people's health.***

**Reid:** So long-term supports and services is really about a whole array of nutrition support and housing support and transportation support and obviously medical support in the home so that people can continue to live independently and with some dignity in the communities that also support the other things, where their friends are, where their families are, where their religious congregations are, where their social networks are, which also is proven to be essential for keeping people healthy and especially brain healthy so that we don't suffer from cognitive impairments because we're isolated and no longer connected. So it's a much more holistic approach and long-term supports and services should be a part of any universal comprehensive healthcare system. Right. So that's what we're fighting for.

***Q: That sounds promising, Jodi. So would you call it a universal long-term care benefit or is it universal long-term supports and services?***

**Reid:** You know, the LTSS, long-term supports and services is kind of the catchphrase these days. I think what most people think of when they think of that is home care.

***Oh, got it. Home care.***

**Reid:** Okay. But it is actually kind of bigger than that.

**Q: Right. So it's all forms of long-term care essentially.**

**Reid: Yeah. Yeah.**

**Q: Got it. What would that look like in terms of if there was a universal long-term care benefit, would that mean that anybody could go into a nursing home and spend as long as they need to there? Anyone could go into assisted living or boarding care, which is a boarding care facility and spend as much time as they need to there without having to pay any kind of part of that. It would be paid through kind of taxes I assume, but at the time of service they wouldn't have to pay for it. Is that right?**

**Reid:** Preferably that kind of care at home. A lot of people don't need to be in a more institutional environment, but there are no other options for them because they can't pay out-of-pocket for that home care. So yeah it would be a continuum of care depending on need. Just like when you go to the hospital, you know, you get various care based on what you need. You know, if it's determined that you need daily care, what is the best environment for you to receive that care? And you have, you would be assessed based on, you know, do you need 24/7 care and where can you best get that? Do you just need a couple hours a day? How would you best get that? You know, so, you know, the whole continuum of care would be covered if it's done through a single-payer healthcare system, then it would be part of the financing of that larger system.

That would be, in my opinion, the best way to finance it. Because everybody's in, everybody's paying in based on, you know, however we determine that a progressive tax structure, for example, and employers paying in, they're already, theoretically many are paying into healthcare for their employees. Instead, they would pay into this system. The state would pay into this, public dollars would be contributed. And the big ticket is federal dollars. You know, part of winning this larger system is releasing the dollars that the federal government spends on healthcare for California residents and we get a waiver to bring that money into our one pot here in California. If we were just talking about creating a universal long-term care benefit, then we have to fund that as an independent benefit.

Everybody would still need to pay into it somehow. But when it's not part of this larger system with all these ways to finance it, it gets trickier on how do you pay for that?

You know, if it's a payroll tax for example, which is a model that other states have been trying, the problem with that model is if you're not working, you're not paying in because you don't have a payroll tax. And so those models are based on vesting into the system for so many years in order to be eligible for some benefit amount, that's usually not enough. But let's just say whatever the benefit is, if you're unable to work or are retired, you are excluded from that model because you're not paying in. So like how does that make sense? So the current population that needs the care won't have access to it in that model because they're not paying payroll taxes. So we need to think about how would you finance a system that's equitable regardless of your income, you know, that you have access to it.

So now Medi-Cal income levels, you get IHSS for example, or nursing home coverage. But if you're over that, how do you get into the system? So it's really complicated. The easiest way is to make that part of the benefit package in a single-payer system, but without that we have to create like another silo of care and financing for this system and so unfortunately CARA is working in both of these spaces, single payer as our ultimate goal with LTSS included as a benefit. But also we're part of the network of groups trying to just deal with this crisis of the lack of LTSS right now while we're fighting to win a transformative healthcare system.

***Q: Well, many thanks to CARA for working on these major issues, Jodi! How is this impacting residents today? You mentioned people that are on Medi-Cal, which is California's version of Medicaid, can go, you know, have Medi-Cal pay for their long-term care, but there's not enough beds. So what does that mean? What are people doing?***

**Reid:** Staying at home and having family members take care of them? I said earlier, two thirds of the providers for home care are unpaid family caregivers in

California. And this has devastating effects on other parts of our economy. For example, earlier we were talking about our state budget. Well, if people are unable to work because they're caring for a family member, they're not paying state income taxes. So all of these things are connected to each other and it's like, you know, we need to get out of this siloed approach of service provision and budget decisions 'cause it is like dominoes. Everything impacts everything. And we need a much more holistic humanistic approach to, you know, health care in general because, you know, we just look at this one small issue of LTSS, but if you also looked at childcare for example, same issue, same problem. People, there's not enough spaces for all of the kids that need childcare, even though it's proven that early childhood education is so helpful in setting you up for your life, but yet we don't put the money in that so parents have to stay home, wind up becoming possibly dependent on welfare of some kind of general assistance or family care programs. Not paying taxes on earnings if they were making a wage and paying state taxes.

So it's not just in the health care arena, but that's kind of what we're focused on now. But it's like, you know, when are we gonna wake up and realize that the decisions we made to put a bandaid on something without really looking at the bigger picture, that bandaid isn't gonna cover the wound for very long and it's gonna explode and it's gonna impact other things. And we need to be much more strategic about how we make these decisions moving forward.

***Thank you, Jodi Reid of California Alliance of Retired Americans.***

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