

Inclusion, Independence & Dignity: Health care & people with disabilities

"If a person with a disability wants to pursue employment and the, you know, their salaries are too high, basically they'll lose their Medi-Cal, their in-home services and supports, their long-term care." - Angela Gardner

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!** What policy solutions are needed to better help those with disabilities get and keep quality health care - and which policies might be harmful? What would a Medicare for All system mean to this community? To find out, we spoke to **Angela Gardner**, a disability rights advocate who lives in the Los Angeles area. Angela's also a board member of Healthy California Now representing Hand in Hand, which fights for access to home care and disability justice, among other things.

Q: Welcome back to Code WACK! Angela. Last time we spoke about the challenges those with disabilities face when it comes to accessing and keeping quality health care. What legislative or policy solutions do you think we need to better help this community? **Gardner:** Currently there's a bill in Congress called the **Home and Community-Based Services Act** that was introduced I think in March and that would increase Medicaid funding for long-term services and support, provide states with resources for care workers and caregivers to have more training, support, stable quality jobs with a living wage.

Medicare for All also because it would provide access to health care, especially vision, dental, and mental health, which is much more difficult to access and they do not have to worry about the income cap and the income limits to prevent them from getting jobs for higher wages, they'll get to live independently in the community, getting the care at home that they need. Medicare for All would benefit people with disabilities the same as non-disabled people as far as getting access to health care that they're not currently getting or that's difficult to get.

Q: Right, and most Medicare-for-All bills, not all, but also fund long-term care. What would that mean for people with disabilities to have coverage of long-term care?

Gardner: They would be able to live independently in the community. Families will not have the stress of trying to work and provide an income for themselves and their family and take care of a loved one. It would benefit them financially as well and people with disabilities can, you know, pursue employment. They don't have to worry about if they make too much money, you know, will they be able to have health care.

Q: As you said earlier, people are choosing between health care and employment, is that what you said?

Gardner: Yes.

Q: Can you talk a little bit more about that? Why do they have to make that choice?

Gardner: The Medicaid caps, the income cap. So if a person with a disability wants to pursue employment and the salaries are too high, basically they'll lose their Medi-Cal, their in-home services and supports, their long-term care services and supports. They could lose that.

Q: And how would having a single-payer healthcare system – Medicare for All – change your life personally as someone who has autism and learning disabilities?

Gardner: I know I don't have to worry about having health care because I myself had been without health care for many, many years. It wasn't until the Affordable Care Act that had a provision for adults with disabilities with no children that I was able to get Medicaid.

I did not know that.

Gardner: Mm-hmm.

Q: So how did that change your life – finally getting health care after years and years....

Gardner: I didn't have to worry about it.

Q: Right. And what was that like for you to go for so long without having health care?

Gardner: It was stressful. You know it was really hard and so it was a big relief to be able to have health care.

Q: I mean, did you ever get sick and think, 'oh, I can't afford this? I won't go to the doctor, I won't go to the hospital' when you didn't have health care?

Gardner: Yeah, when I didn't have health care, I had some undiagnosed medical conditions and I had to go to have surgery.

Q: And how did you end up paying for the surgery?

Gardner: Well, LA county, I went to the public hospital so they had assistance for people to help pay for their health care.

Q: Did you accrue any debt because of that surgery?

Gardner: No, because I was unemployed.

Q: Okay, got it. So they were able to pay for it like through charity care?

Gardner: The public hospital had funding to help with patients that weren't employed and didn't have access to health care – to pay for health care. Yeah, they had programs for that.

Q: Ok, got it. So I'm curious, when you had undiagnosed medical conditions, did that prevent you from seeing a doctor at first? Were you reluctant to go get care because you didn't have insurance?

Gardner: Yeah, I didn't know where to get health care.

Q: Yep, yep. So what was that like for you?

Gardner: It was hard, you know, because the healthcare system is hard to navigate. So, you know, I didn't know where to go.

Q: And then ultimately, how did you decide to go to the county hospital and figure out that, 'oh, they can pay for this?'

Gardner: It's funny, I saw something that the state of California had a program for people that weren't insured. And I called and they referred me to a clinic, you know, where I lived and then the clinic, once they did the exam and they found some things they were concerned about, they referred me to the county hospital.

Q: Was this like a state funded clinic or a federally funded clinic?

Gardner: It was a state funded clinic.

Q: So what else would you like to tell us, Angela?

Gardner: Well, I think health care is essential for all of us, and I would like to see everyone get covered, everyone have health care and the supports and services that they need.

Q: Where does that leave the communities with disabilities?

Gardner: Well, there's another thing I didn't talk about, and that is the Care Court, the state law that was passed by Gov. (Gavin) Newsom, where homeless individuals with mental health care issues can be taken to court and possibly be put in conservatorships and in institutionalized care, and they don't have the ability to make their own decisions. Disability rights California tried to go to court and block this bill from getting enacted, but they were not successful. That's another issue, you know, that for homeless individuals with disabling mental health conditions are dealing with and that's because there's not access to community-based health care, mental health care, besides housing and, you know, other social services that they may need to, you know, be able to, you know, live in the community again, live in housing and in the community again.

Q: Wow and why is this so concerning, this bill?

Gardner: Because people with disabilities don't have the right to make their own choices and decisions. If you are in an emergency or in a mental health state of crisis, you cannot make decisions for yourself and until, you know, you get stabilized and get treatment. And so a lot of decisions are being made by the court system. It's getting the court system and the legal system involved in making decisions for individuals with disabilities instead of people with disabilities being able to make decisions about what's best for their own care and get access to treatment.

Q: So what's the solution, do you think?

Gardner: What people have been saying is access to more again community-based healthcare at the local level, the county level, the city level, you know, making sure, 'cause those programs, even if you go through the court system, there's a shortage. There's a shortage of facilities, there's a shortage of beds, there's a shortage of treatment providers. So that problem still isn't being addressed. And that needs to be addressed first. Making sure that people have access to treatment, have access to care, and have access to the other supports and services that they need. The other social services, whether it's help getting Medicaid, getting social security, getting housing legal assistance, you know, those things need to be addressed first.

And I know in L.A. County in particular, there's been a coalition, you know, they fought in this budget session with the board of supervisors for a care first policy. You know, where those kinds of, you know what I just said? Those kinds of things are prioritized but I don't know how far that has gotten but yeah, they're more and more advocates that are focusing on a Care First policy to help people with disabilities, especially the unhoused and the extremely, extremely poor... Living in extreme poverty 'cause that is extreme poverty being homeless and unhoused.

Q: Did you want to say anything real quick about the lack of access to mental health care right now?

Gardner: Well, I had that issue too until the Affordable Care Act. I couldn't get mental health care, appropriate mental health care for over 10 years. So, yeah. You know, over 10 years or more, I couldn't get, maybe longer than that. I couldn't get access to health care but again, there's still shortages. I mean, I think there was a push in the state of California to prioritize investing in mental health, even though it's not where it needs to be. But that federal funding definitely helped. But again, there's, you know, our elected officials haven't prioritized, you know, investing in mental health care, public health, and even with COVID you know, we realize that our public healthcare system was not equipped to meet the needs of the people.

Q: Right. Would you say that one of the main challenges is that there's a lack of psychiatrists and psychologists right now that there's a shortage?

Gardner: I have heard that, yes, and the state recently, there were peer support counselors and now the state is putting the Department of Healthcare Services put in a rule recently where, 'cause the peer support specialists were kind of filling in the gaps for the shortage of other, you know, mental health professionals. But now, in order for programs to get funding, they need to prioritize those other providers over the peer support specialists. So, and that's really causing a lot of concern because, you know, what if a nonprofit or a provider of mental health care can't find those providers, you know, and they're not allowed to hire peer support specialists to help, you know, to help people that need it. So, you know, that's another, you know, kind of complication in getting mental health care.

Q: And when you said that you had trouble for 10 years, is that because you were uninsured?

Gardner: Part of it. Yes. Yeah.

Q: And what was the other part?

Gardner: You know, when I did have health care under my parents, it wasn't the best and to this day, this healthcare organization still doesn't provide the services and supports and mental health care because the workers have been striking forever to try to push this healthcare organization to provide those services. So they're still not providing, you know, adequate services in mental health.

Q: What kind of organization is it?

Gardner: Kaiser.

Thank you, Angela Gardner.

Do you have a personal story you'd like to share about our 'wack' healthcare system? Contact us through our website at heal-ca.org.

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