



No place at the policy table? Failing those most in need.

"So there's just this concern in the disability community that we've totally been left out of all the policy decisions that our elected officials have been making since they decided to end the COVID emergency and all the things that went along with it. A lot of people with disabilities feel abandoned that their needs weren't taken into account."-- 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 challenges do those with disabilities face when it comes to accessing quality health care? To find out, we spoke to **Angela Gardner**, a disability rights advocate who lives in the Los Angeles area. This is the first of two episodes with Angela.

Welcome to Code WACK! Angela.

Gardner: Thank you Brenda. Thanks for having me.

Q: Awww, thanks for being here. Tell us about yourself. Where do you live and how did you become an advocate for people with disabilities?

Gardner: I am a California native, born in Los Angeles. I currently still live in Los Angeles in a city called Whittier. I'm a person with a disability, autism, learning disabilities, and ID – intellectual disability. I became an advocate while working in a special education school.

Q: I love that. Tell us, tell us about your clientele. What kind of disabilities do they have and how do you help them as an advocate?

Gardner: Well, I do not work with individuals. I work with advocacy organizations and on social media by bringing education resources and awareness about issues and needs for people with disabilities.

Q: Got it. Let's talk about health care. What are some of the main challenges you see when it comes to those with disabilities accessing, keeping, or paying for their health care under our current healthcare system?

Gardner: Well, Medi-Cal or Medicaid, as it's called nationwide, but Medi-Cal in the state of California provides healthcare benefits and long-term services and supports like in-home care, an essential service to help with the daily care needs, bathing, dressing, feeding, home cleaning, et cetera, medication and devices that people with disability may use. And currently there are income caps to Medicaid. I'm on Medicaid myself. That causes disabled people to choose between employment and health care and their long-term services and supports. If they make too much money, they could lose their Medi-Cal benefits.

In many states, there are wait lists for in-home care services and the long-term services and supports under Medicaid, and there's also a shortage in in-home care workers due to low wages and benefits. And the other more recent issue is COVID. The COVID health emergency provided individuals in their family access to Medicaid, but when it ended more than a million people were dropped or lost coverage.

Q: Right, right. So how are all these things impacting people with disabilities today?

Gardner: Well, some people are losing their health care. I mean, people are just panicked and scared and they're also fearful of the COVID safety protocols being ended for wearing masks and other protections in public places, faces, businesses, not acquiring masks for employees in gloves or hand sanitizers. There are a lot of people with disabilities who are fearful of getting COVID because they have complex healthcare needs that might require them to be in the hospital, might be

life threatening for them. So those are some of the issues that people with disabilities are dealing with.

Q: Right. And you mentioned, I think, was it wait lists for home care?

Gardner: Yes. In a lot of states, yes.

Q: Okay. So what does that mean for somebody who has disabilities? What do they do when they're on a waitlist and they can't get home care?

Gardner: Some of them are in nursing homes in other states, or they have family caregivers. Some of them have aging family members and there's a concern about how much longer can a parent or a primary caregiver who's older be able to take care of their child or their family member who has disabilities and other health conditions that, you know, they must require in-home care services. So those are some of the issues as far as the waiting lists go.

Q: Got it. Angela. Do you have any specific stories of people who've struggled with our healthcare system that you can share with us?

Gardner: Oh, yes. <Laugh> Some people that I know through the organization Hand in Hand that I worked with were sharing during the COVID in 2020 that their in-home care workers did not feel safe coming to their homes. Some of them couldn't find in-home care providers, so they could not get the care they needed and they ended up going to the emergency room, being hospitalized or being in nursing homes for a short period of time because they just didn't have access to, you know, in-home care. They didn't have access to workers.

We also represent the in-home care workers at Hand in Hand also. And they were sharing the same thing that, you know, there wasn't any safety equipment, you know, they felt you know, they didn't feel safe, you know, and it was difficult for them to provide care during that time.

Q: That's really hard. So it sounds like the in-home care workers themselves didn't feel adequately protected, so they couldn't help and support the people who needed it the most, which are people with disabilities. So I could see how that could be very scary for both sides. So did you know of anyone that wasn't able to find care in this situation?

Gardner: Yeah. Yeah. Some of my members weren't able to find care. Mm-Hmm. <affirmative>, some of them had to go into the hospital. They were hospitalized.

Q: And how long did they have to stay in the hospital for?

Gardner: Sometimes weeks, depending on, you know, the severity of their situation.

Q: Do you know what kinds of disabilities we're talking about?

Gardner: One of our members has cerebral palsy and you know, so yeah, she's in a wheelchair, so she required a lot of support in the home. So, and some of their friends too, they said, were in a similar situation.

Q: Hmm. So, how do you feel about that?

Gardner: Wow. It's tough. You know, my heart goes out to them. I was in shock because I don't have those support needs. So to know that if someone doesn't have in-home care on a daily basis, they could end up in the hospital. That was shocking.

Q: Angela, today, do you think there are enough in-home care workers?

Gardner: No, they're not. There's still shortages in California. There's still shortages. They especially in, you know, rural areas. They really have shortages of in-home care workers.

Mm-Hmm. <affirmative>, why do you think that is?

Gardner: Well, the low wages and benefits. There's not a lot of paid sick leave. Vacation, retirement benefits. You know, that's a real big problem because again, the cost of living in California's extremely expensive. And so a lot of these workers, some of them don't even have health care themselves.

Q: <Affirmative>, Wow that's ironic and sad.

Gardner: Mm-Hmm. <affirmative>.

Q: What other challenges have you noticed when it comes to those with disabilities and healthcare? Are you noticing any trends?

Gardner: Besides COVID and all the challenges that are connected to that. And also with COVID, there's a new group of people that have long-term disabling conditions with long COVID. So there's just this concern, you know, in the disability community that we've totally been left out of all the policy decisions that our elected officials have been making since, you know, they decided to end the COVID emergency and all the things that went along with it. A lot of people with disabilities feel abandoned that, you know, their needs weren't taken into account at all and you know, those are the two biggest things that I've seen a lot recently.

Q: So what would they have liked to have happened? Did they want the government to extend, like the public health emergency and not dropping people from Medi-Cal or Medicaid?

Gardner: Right. And the safety protocols in public places, and especially workplaces, wearing masks, having gloves, having sanitizers, those kinds of things, that keep, you know, people feeling protected from, from you know, possibly getting infected with COVID.

Q: Wow. So do people with disabilities feel, or are they more vulnerable to COVID because of their disabilities?

Gardner: Yes, a lot of them are. A lot of them have respiratory conditions, you know, part of their conditions or respiratory. Some of them might be immunocompromised, chronic illness. So yeah, a lot of people in the disability community, you know, are vulnerable to acquiring COVID and it could be life threatening for them.

Q: Wow. And so the people that Hand in Hand deals with what kind of disabilities do they have? Is it also, is it physical and intellectual?

Gardner: Yes. You know, we welcome anyone with a disability. And we also, again, work with the in-home care workers as well to make sure they get, you know, the proper wages, the proper supports that they need to do their job. That's what makes Hand in Hand unique because organizations deal with one end or the other. What makes Hand in Hand unique is that people with disabilities are included with in-home care workers to advocate.

Q: That's great. So the organization Hand in Hand helps people living with disabilities get the long-term services and support they need. Can you talk about what kinds of services and support are available and how easy or difficult they are to access?

Gardner: Sure. In California, there are long-term care services and supports available, like in-home support services, Medicaid or Medi-Cal is mainly the funder for a lot of these services. Well, also there's another organization called Regional Centers, and they are run by the state of California and they also provide long-term services and supports for people with intellectual and developmental disabilities as well. And their funding comes from the state and Medicaid as well. So the long-term services and supports vary state by state. You know, there's not a national law to make sure that states provide those services and supports. That's what's needed. And there isn't enough funding for these services, even in California, especially with

the regional centers. There's some regional centers that are better funded than others, so everyone doesn't have access to the same services.

Q: And what other barriers to access are there for people with disabilities besides funding of regional centers?

Gardner: Housing, that's a big barrier for people to get access to the long-term services and supports they need. A lot of adults don't get to live independently because housing is so expensive. So that's a big barrier to getting long-term services and supports.

Q: So what do they do? How are they living? And how are they managing with the care that they need?

Gardner: Some of them do still get in-home care services. Some of them live with their parents, live with family, you know. They're just unable to live in their own places. Some live in group homes.

Q: If they're living with other people, is it harder to get in-home care?

Gardner: I don't think so. In California we have the programs, but there's an issue with some – this happened with the COVID emergency also ending is that some family members were paid to care for their kids because their family members, they lost income in some households, even here in California you know, caregivers have to stop working. And so the COVID health emergency, you know, helped pay for families to provide care for their loved ones, and that's no longer available. So that is a hardship. Or if there's a worker shortage, the family has to step in and, you know, they have to lose income and employment and other things to care for their loved one.

Thank you, Angela Gardner. Stay tuned for our next episode when we talk to Angela about what policy solutions are needed to better help people with disabilities get the health care they need.

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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