



One woman's struggle for care in America's South, without Medicaid

— TRANSCRIPT —

Welcome to **Code WACK!**, your podcast on America's broken healthcare system and how Medicare for All could help. I'm your host, **Brenda Gazzar**.

Now that the COVID health emergency is over, our thoughts are with the millions of Americans who are losing their Medicaid coverage. But **we must not forget the nearly two million Americans who would have been eligible for Medicaid back in 2014, thanks to the Affordable Care Act, but never got it** because their state did not adopt the expansion.

As of June 2023, ten states have still not taken advantage of the Affordable Care Act, and two have approved - but not implemented - the expansion. *"What does this mean for the people who live there?"*

To find out, we're revisiting one of our favorite episodes about radio personality and performance artist, **Eliska Hahn**, who was struggling with multiple sclerosis while living in a state that did not accept the ACA's Medicaid expansion. **How did this force her into making some difficult choices to avoid financial ruin?**

As millions of Americans are about to lose their health insurance, ***this oldie but goodie episode is an excellent reminder of why we need Medicare for All in America.***

Welcome to Code WACK!, Eliska.

Q: So tell me about your diagnosis with MS, and how that has affected your life?

Hahn: In 2008, I was working as a skating director of the rink. It's in Morgantown, West Virginia. I remember I skated a performance, a solo performance, in our Christmas show in 2008. As I prepared and definitely as I skated in the show. I'm like, there is something wrong with my body.

Starting in about February of 2009. I started to have some symptomatology that was extremely concerning. And I ended up going to seek help, and going to doctors in West Virginia. They did not properly diagnose me. They did four different exploratory surgeries, which only made things worse. Finally, they kind of gave up on me. They said, "you don't have heart disease or cancer or diabetes, so we don't know what's wrong with you." I kept having (an) inability to walk or feel. I had blurred vision. I had pain. Try showing up at an ER repeatedly with pain and see how you're treated, even if your community knows you as a professional athlete who teaches their kids.

So, I mean, I even had an ER doctor say to me "I think that this is emotional. I think that you need to consider being seen by a psychologist, and a psychiatrist. We believe that you've had some sort of a break."

By the time my birthday rolled around in 2009. I had been bedridden for about six weeks and I was convinced that was my last birthday. I couldn't get to the bathroom. I was incontinent. I couldn't walk. I kept falling down. My vision would blur. My hair would fall out. My gums would bleed. And finally I had, it was actually a chiropractor, that advised me. "Listen, you're going to have to go to a different kind of doctor because regular medicine is not going to serve you well on this."

One time in what seemed like my weekly visit to the ER, I saw a doctor there and he said, "You did not hear this from me but you're not going to get the help you need here. You're going to have to go to an integrative autoimmune specialist type of doctor. We don't know what it is. But, you know, we've checked you head to toe." And so I went back to that chiropractor friend that I spoke to earlier, and he was able to connect me with a doctor in Pittsburgh. And so within a week after my birthday that I thought would be my last, I ended up at an integrative med doctor in Pittsburgh. She was a specialist in autoimmune disorders and systemic infections. That first visit, they took 30 vials of blood and shipped it all over the United States to try to figure out what in the world is going on and that was when I was diagnosed with multiple sclerosis. I was diagnosed with Epstein Barr and mono and I was vitamin deficient and malnourished, which was shocking to me. My body was so inflamed, I wasn't able to absorb food. I had so many things going on and was so, so, so sick. I'm so thankful that I ended up in her hands.

Q: Eliska, did you ever have a problem getting health insurance because you had MS?

Hahn: I didn't have a problem getting private insurance because I was so sick for so long, it depleted my financials so much, that I didn't really try to get private insurance. But what happened is I moved to Wilmington, North Carolina a couple of years ago and I moved there to be with my fiancé and I was not aware at the time that North Carolina is one of the 14 states in the United States that did not adopt Medicaid expansion. So I moved there and after I moved there I then realized, uh oh. I was starting to get better. I had a recent flare. I was starting to get better, but I definitely needed coverage until I could get back on my feet.

And I was not able to get it. I was not able to get it. I ended up going over \$50,000 in debt. I collapsed in my home The day after Christmas, it would have been Christmas of 2019. I had to be rushed to the hospital. I had to be admitted, the common treatment for MS. When it gets that far out of control is almost like a chemo level steroid. They give you an IV steroid called solumedrol. It's extremely powerful. They give you a gram of it -- 1000 milligrams. To put that in perspective, when somebody breaks a bone, they're maybe going to get 100 milligrams as a

treatment for inflammation and pain, and they give you that every day for 3-5 days, to try to get the body again to halt that inflammatory process that is the hallmark of MS.. It's very expensive. And so even though I was only in the hospital for five days and I had a couple of emergency room visits, I was deeply, deeply in debt.

And thankfully, a woman that I believe was a social worker at the hospital, she came up and she saw the situation and he said you need to file for coverage in the state of North Carolina. But the only way that you're going to be able to do that is if the state of North Carolina finds you disabled. Because I thought she was talking about social security disability, I said I tried to file for Social Security Disability when I was really sick and I got denied. I said, I'm going to be better. I'm going to get better. I don't want to be on disability forever and she said just to get on Medicaid. So the fact that I don't have a job, and the financial situation, she said it doesn't matter here. You have to be found disabled by the state. And they have to summon all your medical records and go through this process. There's going to be a hearing. You'll be supplied with a lawyer. It took six and a half months for it to finally come to hearing. But it did and the good state of North Carolina decided that I was disabled.

Q: And the reason you didn't qualify for Medicaid without being designated disabled , did it have something to do with you not having minor children?

Hahn: Right. I don't know how it works in all of the states that did not adopt Medicaid expansion, the few people that I've connected with that have similar situations, I found that if you are a parent of a minor child, you can get Medicaid if you have financial need without being declared disabled. Once your children are not minors anymore -- they're 18 and up -- it doesn't matter what your financial need is. It doesn't matter. And it just blows my mind. I'm like, "what do you mean? AT the time, I just turned 53. And I'm like, What do you mean that that's a disqualifying factor? Yes, that was 100% the reason.

Q: Wow. So, how did you feel when you realized that you had \$50,000 worth of medical bills, and you weren't sure how you're going to pay them?

Hahn: Ahhh. I was a little panicked about it but honestly I got out of the hospital at the beginning of January, or right before. My fiance's birthday is New Year's Eve, so I got out at some point on the 31st. I ended up back in the ER the first week in January. I had driven home because I had not seen my 92-year-old dad in almost a year. I'm like I'm kind of patched together. I've had the treatment. I'm going to drive home and just see my dad. So I come home to West Virginia to visit with my father and I end up collapsing again. So I go back into the hospital for another nine days. So February of last year was my last hospitalization. Now my dad, who is as honest as any person I've ever met in my life-- retired military -- truly my hero.

Um. (Pauses) I'm sorry, just truly the most honorable man I've ever met. He said you're going to use my address and you're going to tell them that you live here because you're not going to allow them to do that to you, to destroy you financially. And so my dad vouched for my citizenship in West Virginia so I can go to the Department of Health and Human (Services.) I called them from my hospital bed and I said, "can you please reinstate ...you know I'm in a critical situation" And they did. They knew I had had West Virginia Medicaid before. They said we will retroactivate you to cover you and they did. So that was a relief. I don't know if it's a good idea to lie about it. I don't mind being honest about that. I did still have a West Virginia driver's license. I had only lived in Wilmington for a little over 10 months at the time and I had been sick for much of that so getting a new residence and an updated driver's license was not high on my list of things to do.

So my Dad lived in my childhood town at home. He said this is your home. It's always been your home. And you're going to use this address and you're going to tell them that you need coverage again. And so that's what they did. My dad was so frustrated. My dad just was always the type of guy that as long as you did the right thing and told the truth that ultimately, things would work out. It was very disillusioning for him to see how I was mishandled over the last 10 years.

And with the relapsing nature of my multiple sclerosis, it didn't do anything to help my case being disabled. And honestly, I didn't want to be considered disabled because I just had the spirit inside of me. I knew I was going to get better, that it was temporary, but it doesn't take too long of a temporary situation to wreck you,

your financial state, if you don't have good coverage or if you're not able to work. It was so frustrating because I'm a pretty smart chick and talented and I could not think my way out of it. And I went to talk to people who were very very smart, and they couldn't figure a way out of it.

I know as somebody who has had a voice publicly for coming on the better part of 35 years, a very public voice nationally, if I am having trouble like this, if I have struggled like this. I can't even imagine the number of people that are out there [who] don't have a way out, or hope. Honestly, that has been the hardest part. The MS is not fun sometimes but honestly, the hardest part of having MS was not having health insurance.

Thank you, Eliska.

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