

# Disability Visibility Podcast

## Episode 94: Healthcare Rationing

Guest: Britney Wilson

Host: Alice Wong

Transcript by [Cheryl Green](#)

For more information: [DisabilityVisibilityProject.com/podcast](https://DisabilityVisibilityProject.com/podcast)

### Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Heyyyy ho! Happy New Year? Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host, Alice Wong. It's been over eleven months since the pandemic emerged in the United States and things are worse than ever. Hospitals across the country have reached full capacity and are utilizing crisis standards of care: guidelines used when there's a shortage of resources and care. Today's episode is about healthcare allocation in the time of COVID with Britney Wilson, a civil rights attorney with the National Center for Law and Economic Justice. This center, along with three other disability rights organizations, filed a class action complaint in October 2020 against the State of New York. The lawsuit alleges discrimination in a current state plan that would ration ventilators and allow hospitals to reallocate ventilators from people who use them in the community. Britney will talk about her role in the case and how the case came about, how these existing guidelines are ableist and harm disabled people, and the goals are from the lawsuit. Please note we talked in November 2020, and I included a short update at the end of this episode. Are you ready?!

[electronic beeping] Away. We. Go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: So, Britney, welcome to my podcast today!

BRITNEY WILSON: Thank you so much for having me.

ALICE: And Britney, would you mind, I guess, introducing yourself and sharing a little bit about your background?

BRITNEY: Sure. My name is Britney Wilson. I'm a civil rights attorney from Brooklyn, New York. I have cerebral palsy. I'm very proud of being a Black disabled civil rights attorney and advocate. And I'm currently a staff attorney at the National Center for Law and Economic Justice in New York.

### Feelings about the recent election

ALICE: I just wanna take a moment and comment that, here we are. We're speaking today November 13th, 2020, 10 days after Election Day in the United States. How are you feeling with the results and the potential coup or obstruction by the person currently occupying the White House?

BRITNEY: I think I'm feeling tired. Just sort of the whole news cycle and the stress of it all has been, I think, all-consuming in a lot of ways, both as an advocate, as a civil rights attorney, and as a person, as a citizen. I'm hoping that Trump accepts defeat and that we have a smooth transition of power. But I'm also, like everyone else, remaining vigilant. So, I feel relieved, but also, I feel tired. I think that's the best way I could sum it up.

ALICE: Yeah, I agree. And I think while I was super excited to see voter turnout in such huge numbers, but the fact that this election was such a close election, that was very disheartening, that there were still almost, you know, half the country, half of the voters total almost, roughly, that supported a fascist.

BRITNEY: I'm at the point, sadly, where it takes a lot to surprise me. So, I think I definitely was saddened by that, but not surprised. But I'm glad that people turned out so that that wasn't the case, so that we don't have at least as much of a fight as we could've had, had the outcome been closer than that.

ALICE: I agree. I mean, it's just a very sad indictment of our country, of white supremacy, so. Yeah, that, to me, is not surprising. But just the fact that one would think that after these four years, the deliberate harm is so apparent, it's just yeah, I just don't get it.

BRITNEY: Yeah, I agree.

[lounge music break]

### What it's like for Britney living in New York City

ALICE: We're a good nine months into the coronavirus pandemic, with things progressively becoming worse just day by day. As someone who lives in New York City, one of the hardest hit cities at the very beginning, what was it like for you as a New Yorker when it all started and where we are now?

BRITNEY: It was scary, to say the least. I actually, I lost my aunt to COVID, my great aunt. She was actually in a nursing home. So, she's one of the many nursing home residents who got COVID and passed away. So, that was difficult. Grieving during COVID has been difficult because, you know, none of the rituals that we would usually follow, we couldn't participate in those. As I mentioned, I'm disabled. So, I've been pretty much in my house since March, trying everything I can to avoid COVID and the possibility of getting it in any way or coronavirus. Hoping the same for my family and friends.

You know, I've worried about the people in my family who have been helping to take care of me and get me things that I need and stuff like that, because they're at greater exposure and also risk for COVID as people of color, as people with underlying conditions. So, while I try to take care of myself, I'm also concerned about their well-being and thinking about what would happen if, God forbid, something were to happen to one of them or if I had to seek medical care because of all the things that we're gonna talk about today, just the realities of being disabled and being a person of color and being a disabled person of color and seeking healthcare. And if in the middle of an epidemic, you might have to seek that care on your own and your family members might not be there to help advocate for you or to speak for you or even just to be there to comfort you, the realities of that, so scary. It was scary. And people were dying by 700 people were dying at one point.

It seems like people have forgotten that, which is so weird to me. [chuckles] I think people have sort of trusted the narrative of like, "Oh, you know, it's out West now, or it's Midwest. It's in other

parts of the country. We got it under control.” But we see that the numbers are going up as we speak right now. Today in New York City, they’re talking about potentially closing the public schools again on Monday because the numbers are going back up. So, it’s all very scary. And I feel like we’re riding a wave.

ALICE: Yeah. And I’m so sorry for your loss and the fact that there are so many people in grief and in mourning and really experiencing a lot of trauma right now. I feel like this is gonna be cumulative, and it’s gonna be really scary in the next few years. Because there’s so much to work through. If we do come out of this, there will be a lot of trauma and a need to mourn and a need to take time to process everything.

BRITNEY: Right.

ALICE: ‘Cause I don’t think we’re there yet.

BRITNEY: I also think we’re gonna see a lot of potential long-term health effects associated with COVID-19 even from the people who survived that we haven’t begun to really think about or plan for yet.

ALICE: Agreed.

[lounge music break]

### Healthcare rationing, administrative complaints, and the lawsuit against New York State

ALICE: So, today’s episode is about healthcare rationing. And for people who don’t know what that is, can you describe what’s been happening across different states, and in particular, in New York, as so many hospitals and healthcare systems contend with just huge strains on their resources and workforces?

BRITNEY: Yeah. So, several states around the country have, basically, rationing policies or guidelines which describe what they should do or how they should allocate care or decide who gets treatment or care in the event that there is a shortage of resources: be that a shortage of people who can receive care because the hospitals are so overcrowded or a shortage of equipment that people might need in order to receive care, like ventilators. Several states around the country have filed OCR complaints, complaints with the—that’s the Office of Civil Rights for the federal Department of Health and Human Services—challenging the existence of these guidelines and rationing plans, many of which say things like they rank people’s ability to receive healthcare according to something called a SOFA score—that stands for Sequential Organ Failure Assessment score—which subtracts points based on the function of certain key organs. Basically, those numbers determine whether or not the hospital thinks you should be allowed to receive care in the event there’s a shortage of resources. So, several administrative complaints have been filed about these sorts of policies with the federal Office of Civil Rights from the Department of Health and Human Services.

Several states have actually made some changes to their policies as a result. They’ve included language explicitly saying, we won’t take your ventilator, or we won’t discriminate against you on the basis of disability, or including language that is intended to include more of a reasonable accommodation framework, as opposed to the strictly point-based framework that I described. Some states have not resolved those OCR complaints, including New York, which is where my office, the National Center for Law and Economic Justice, and Disability Rights New York, have filed a lawsuit.

ALICE: You know, I was really interested when you first told me about the development of this case. And I'd love to hear more about kind of the origins and behind-the-scenes work. Because I know that you were really one of the key people that made this case possible.

BRITNEY: Sure. So, the complaints that I mentioned, the administrative complaints that many different disability rights organizations have filed with the Office of Civil Rights in the Department of Health and Human Services are administrative complaints. So, what that means legally is basically, the government of that state can choose to negotiate with the party that filed the administrative complaint, and they could sit down and agree to change their policies' language, for example. That happened in Alabama. It happened in Tennessee. It happened in Pennsylvania. I believe there might be one more state where it's also happened. New York was also one of the states that filed an OCR complaint over their ventilator allocation guidelines. Disability Rights New York, who's actually our co-counsel on the case, filed such an OCR complaint in New York. They filed a complaint over the New York State Department of Health ventilator allocation guidelines. The talks basically stalled.

They didn't come to any sort of resolution about changing the guidelines, and so we decided to file a lawsuit. Because basically, the sorts of plans were making people afraid to seek healthcare in the middle of a pandemic. Specifically, Disability Rights New York was getting calls and complaints and concerns from personal ventilator users who were afraid of the possibility of having their vents taken from them and given to people who were deemed more likely to survive based on some language in the guidelines and based on the SOFA score that I mentioned. So, there was a lot of fear in the disability community. People had heard about the guidelines on social media, in their friend groups, what have you. And ventilators were the key item of the pandemic. I think people sort of had forgotten. Every day on the news, you heard about ventilators, ventilators, ventilators, how important ventilators were and how we might have a shortage. They were bringing in or trying to bring in ventilators from other places. And they were doing all this planning for a potential shortage.

And so, we specifically filed a lawsuit challenging the New York State Department of Health ventilator allocation guidelines. Specifically, we challenged the portion of the guidelines that contemplate reallocating the personal ventilators of chronic ventilator users who come into a hospital to seek acute medical care during the time of triage. So, that means the guidelines say that if you're a personal vent user and you go to the hospital during COVID, for example, and there's a shortage of ventilators, and you, based on your underlying conditions or whatever (the function of your lungs, for example) have a worse SOFA score than someone else, then theoretically, if they needed your ventilator, it could be reallocated to someone who is determined to have a higher likelihood of survival based on their SOFA score. And so, we sued specifically over that policy, the ventilator reallocation contemplation piece. And that's what we're challenging. The case is called Not Dead Yet v Cuomo.

[lounge music break]

### End goal of the case against New York State and challenges in the case itself

ALICE: Yeah, and what is the end goal in terms of the case, in terms of what you wanna see changed?

BRITNEY: We would like to have the state amend the guidelines to ensure that people's personal ventilators would not be reallocated. We want that language changed 'cause we believe it discriminates against people with disabilities.

ALICE: Mhmm. And as a lawyer for this case, what were some of the challenges of building this case and putting everything together? Because I'd love to hear kind of the behind-the-scenes work because clearly, this took a lot of preparation and research and outreach. So, what was it like just working on this case?

BRITNEY: One of the biggest challenges was how we were going to challenge the policy itself. Because technically, New York state has not had to ration ventilators yet. And so, I should make clear that our lawsuit is challenging the policy itself as being discriminatory against people with disabilities. We're not saying that the state has taken people's ventilators, but we're saying that the policy that says that they can, and that directs hospitals to do so based on that criteria, is in itself discriminatory. So, that was a challenge: challenging the policy on its face as opposed to challenging the actual taking away of someone's ventilator.

I think particularly for me and also for the whole team working on the case, we wanted to make sure that the experiences of people of color with disabilities were represented. That has been difficult. I did a lot of deliberate outreach among ventilator users to try to also find people of color with disabilities, because we know that we have unique experiences as people of color with disabilities and particularly in the healthcare system. But so, there was a lot of outreach that we did to try to make sure our plaintiffs were representative of the community, as representative of the community, as we could. And just a lot of hearing people's stories and figuring out how to get the message across that these policies are dangerous, and these policies are discriminatory. And I think getting people to care about the horror of these policies is just generally difficult.

ALICE: Yeah, I think that even if, let's say, supposedly that this hasn't actually happened yet, the fact that this policy exists and that it stands is a form of violence.

BRITNEY: Exactly.

ALICE: And it's also eugenics. You know, this is what I think some people don't understand is, when people, disabled people, are kind of raising the alarms one response I sometimes get is, "Oh, you're just overreacting. It won't happen to you." And I feel like, wow. You know, you really don't get it because this is about our institutions and our policies. And we're making very explicit that it could happen.

BRITNEY: Right.

ALICE: And without changes, individuals have no way of defending themselves, let's say they are the ICU and they are being discriminated against. They have very little to no recourse or just ways to respond because of these existing guidelines. And I think that's the danger and the fear. And I'm speaking as somebody who uses a non-invasive form of ventilation: it's absolutely real. And I just, I get so annoyed by people who are just like, "Oh, just these have been on the books. This is not unusual. Sometimes you have to make hard choices." And I'm like, wow.

BRITNEY: That's easy to say when you're not the hard choice, right, that has to be "decided upon," quote-unquote.

ALICE: It's really surprising how people are just slowly acknowledging medical racism and ableism, which I think is so bizarre and so overdue.

BRITNEY: Exactly. And I think we have, or we at least, are starting to see real concerns about that happening. We see the story of what happened in Texas. I know that there's ongoing

investigations about that. But Michael Hickson and whether or not he was denied potentially life-saving care because the doctors thought, well, it wouldn't improve his quality of life. It's not worth trying it out on him. Because they already perceived him as having a low quality of life. We know that Utah not too long ago was talking about it might have to start rationing care. So, we know the hospitals in rural communities don't have the same capacity and the same facilities, and these numbers are going up. So, if you have these policies in place that say this is what you should do in an emergency, this is what you should do if you don't have the resources, then who are we to think that hospitals are not gonna follow these policies? Those are the policies that are in place. That's the whole point of our advocacy, is to challenge these policies itself. Because in theory, policies are what become what we're actually experiencing. It's not just a theoretical thing. You put the policy in place for a reason.

[lounge music break]

### New York's lack of responsiveness and how people can support the case

ALICE: So, here's a question that is more speculative. Why do you think New York has been so slow or not even responsive, especially to the previous administrative complaint? Because other states have changed their policies. Do you have any, I guess, completely personal opinions of why this hasn't been changed yet?

BRITNEY: It's hard to say. Honestly, as of the time of this recording, the state, our defendants, are moving to dismiss the complaint. That's when you file a lawsuit in response, one of two things usually happens from the defendant. They file what's called an answer, which usually begins the lawsuit process, or you can come to the table and sort of talk about ways to settle the lawsuit. Or you file a motion to dismiss. As of right now, the state is choosing to move to dismiss our complaint. And we really hoped that in filing the lawsuit, they would realize, oh, OK, this is a horrible policy. We don't really mean that. Let's talk about it. Let's figure out how we can change this language. That's what we were hoping for. That's what we expected. So, the fact that instead, the state is choosing to fight this is really concerning to me.

And they're also, at least as of right now, not denying that that's what the policy contemplates: that it contemplates reallocating people's personal ventilators. So, it's difficult to say. And you would also think that as much praise as the state has garnered for its response to COVID when it was at its peak a few months back, and even though the numbers are now rising, as much praise as it garnered for its initial response, it would wanna continue getting good praise, you would think. So, I would hope that people with disabilities would be included in how it wants to be perceived in terms of handling COVID well. But as of right now, they're choosing to fight.

ALICE: Yeah, and that leads me ask you, if people who're listening who are residents of New York State, if they wanna support this case or support the merits of this case, what can they do as individuals? Is there anything that would be helpful in terms of advocating for this case?

BRITNEY: I think we just really need to get the word out about these policies, about the guidelines, about the fact that they're discriminatory, how horrible they are, and we hope that that word and people understanding that vent users or people with disabilities are afraid to seek medical care and that these guidelines have a real impact on people, we hope that that can help create the change that we wanna see.

ALICE: For people who wanna learn more about the case and also follow the updates about the case, where should they go?



BRITNEY: You can visit my organization's website: the National Center for Law and Economic Justice. Our website is NCLEJ, N as in Nancy, C as in Cat, L as in Lisa, E as in egg, and J as in jam dot org. Or you can go to our co-counsel's website, Disability Rights New York.

[lounge music break]

### How Britney's identity and life experiences shape her work

ALICE: And I wanna end our conversation with, I guess, more of a personal question for you, because, you know, as a disabled lawyer, these issues must be close to your heart. And you've also suffered losses due to COVID. How does this kind of being affected so personally, especially as a disabled person, how does it shape your work and your approach to work?

BRITNEY: It's an integral part of it. I say all the time that this is why I do this work. The body that I was born into, being a Black disabled woman is what makes me an advocate. It's why I'm an advocate. So, for me, there is sort of no separating these issues. I am proud to represent the disability community and to hopefully shed light on these issues. It's also difficult because it's hard to litigate ableism, you know what I mean? And I think sort of trying to figure out how to create change that way while also experiencing things in it and going through it personally myself is difficult. But it also reminds me why I'm doing what I'm doing.

One of our plaintiffs, when we were initially interviewing them and talking to them, was explaining something to me. And I said to them, "Oh, you know, I'm disabled, too." And they said, "Oh, my god. Awesome!" [laughs] And that, to me, was a big reminder of the importance of my doing this work.

ALICE: Yeah, and I think as a final kind of, to wrap this up, are there some folks that you've worked with on this case that you wanna give a shout-out to?

BRITNEY: Sure, absolutely. The whole team, the entire team, at NCLEJ, particularly my colleague Amy, who has, we've basically tag teamed this entire case and getting it done, getting it off the ground. And, of course, everybody at Disability Rights New York. All of our plaintiffs. And we have three of our plaintiffs are organizational plaintiffs. I said the case is called Not Dead Yet v Cuomo. But Not Dead Yet, the organization, is one of our plaintiffs. Also NMD United, which is a great disability peer-led organization that supports people with neuromuscular disabilities, is the plaintiff as well, as well as Disability Rights New York is the Protection and Advocacy Agency for New York. So, they're both co-counsel, and they're also an organization all plaintiffs. So, our plaintiffs as well, the individuals as well as the organizations.

ALICE: Yeah, shout-out to them. And I think each case is a collaboration and partnership, and it's wonderful that you all are working together to fix something that really should've never existed in the first place.

BRITNEY: Right.

ALICE: Well, Britney, I am just so thankful for you, and just wishing you and your colleagues all the best. I really do hope that we will get out of this pandemic together. And hopefully, states will recognize the harm that they've caused and will recognize their discriminatory policies.

BRITNEY: Right. I hope so, too. Thank you so much for having me. Thank you for giving me the opportunity to talk about this case. And I should say that your article, your article in Vox, about being a vent user and your experiences and fears during this pandemic was a big source of inspiration and hope for us in this advocacy. So, thank you for all that you do, always.

[loungue music plays through the next few lines]

ALICE: Well, I'm just doing my part. And I think collectively, we're stronger together. So, we need all kinds of approaches, and the law is definitely one avenue. So, I'm so appreciative of that.

### Wrap-up

ALICE: Since the recording of my interview with Britney, she shared with me this update: the State filed a motion to dismiss the case, and Britney and her colleagues are preparing to file an opposition brief in January 2021.

[hip hop]

This podcast is a production of the *Disability Visibility Project*, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at [DisabilityVisibilityProject.com/Podcast](https://DisabilityVisibilityProject.com/Podcast).

You can also find out more about Britney at my website.

The audio producer for this episode is Cheryl Green. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

Subscribe to our podcast on iTunes, Stitcher, Spotify, Pandora, or Google Podcasts. You can also support our podcast for \$1 a month or more by going to our Patreon page at [Patreon.com/DVP](https://Patreon.com/DVP). That's p-a-t-r-e-o-n dot com, slash DVP.

Thanks for listening! And see you on the Internets! Byeeee!

♪ Rocket to the blast off  
Stop, drop dance off ♪