

*[Music by Molly Joyce 00:00 - 00:14]*

**Bonnie:** Welcome to Included, the disability equity podcast, brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each season digs deep into topics, offering multiple perspectives, and will expand your view of disability. We are your hosts. I'm Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

**Nick:** I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health. On this episode of Included, we sit down with Dr. Diana Cejas to discuss ableism in healthcare and its impact on patients as well as physicians. Dr. Diana Cejas is an assistant professor at the University of North Carolina School of Medicine and pediatric neurologist at the Carolina Institute of Developmental Disabilities.

Her clinical and research interests center upon youth with neurodevelopmental disabilities. She is particularly interested in patient-centered care, the transition from pediatric to adult healthcare systems, and improving health outcomes for adolescents and young adults with chronic neurological and neurodevelopmental conditions.

She is also a disability advocate and author. Her work has been published in mainstream outlets such as Stat News and was included in Alice Wong's Disability Visibility book of essays. She is currently writing her own memoir of essays on her experiences with racism and ableism in the healthcare system both as a physician and a patient.

*[Music playing 01:52 - 02:00]*

**Nick:** Dr. Cejas, thank you so much for making time to be our guest today.

**Diana Cejas:** Thank you very much for inviting me.

**Bonnie:** We're so happy to have you on the show. I want to start with talking about an article, a commentary that you recently wrote titled, "'I have a disability too', I told my patient". This was a really powerful essay, and it's all about medical ableism. You also describe your personal experience with medical ableism and the impact it has on patients and doctors. I'm gonna read a quote for our audience from the essay.

You write, "From inappropriate questioning about a disabled person's ability to make decisions about their care to debates about quality of life and which lives are worth saving during the COVID-19 pandemic, ableism and bias are deeply entrenched in our healthcare system. This further prevents this population from receiving the comprehensive, high-quality care they deserve." Can you share with our audience what ableism is? How do you define ableism?

*Diana Cejas:*

Yes. I think one of the simplest ways to describe ableism is just to say that it is discrimination against disabled people. That can look like many different things. It can be interpersonal ableism, which I think, when most people think about discrimination, they tend to think about that interpersonal reaction where maybe someone is calling a disabled person a slur. Maybe someone is, to their face, trying to deny that they are disabled, or doing something else that's just really mean and doing it in a very personal one-on-one kind of way.

It can also look like institutional ableism. It can be structural ableism. It can be things like going to the doctor's office as a wheelchair user and not being able to get up onto the examination table because the table is not made for you. It can be something like thinking about this whole COVID situation and how many restaurants are doing their restaurant thing outside and blocking up sidewalks. That can be a form of institutional and structural kinds of ableism.

I think it's just really anything that you can think of that leads to or contributes to disabled people being discriminated against, and that's no matter what their disability status is, whether they have visible disabilities, invisible disabilities, or what-have-you.

*Nick:*

I appreciate that you included invisible disability in that because I think it's hard sometimes to think, in the healthcare system, about how that leads to ableism. At the crux of the issue, and at the crux of this article, you talk about ableism in patient-centered care and patient care in general. Could you comment on that a little bit?

*Diana Cejas:*

Yes. I think that one of the big problems when it comes to medical ableism is that it is so, so entrenched in the way that we do things. The way that we look disability in medicine is not as if it's a good thing, not as if it's a normal thing, not as if it is something that should be expected as being just part of the regular human condition. It's something that is a problem. It is something that's

pathological. It's something that needs to be fixed. With all of that, I think that there's also this thought that that means that anybody who is disabled, something's wrong with them, quote-unquote. They need to be fixed, quote-unquote. They can't possibly have a happy, healthy, quote-unquote, normal life.

I think, when we're thinking about—that comes from your earliest training in medical school. We spend so much time learning about pathology. We learn so much about physiology and how it is you're supposed to see and treat and manage disease, but we talk about it as if pathology comes without people. We don't talk about what it actually means to be a person who is living with a specific condition and how we could, as physicians, basically just help them live a life that's a little bit easier. Rather than us, as physicians, trying to help our patients live with their conditions, no matter what those conditions are, we can put barriers into place.

That can come even in the form of the care that we provide by assuming that maybe a disabled person doesn't have a good quality of life when they do or assuming that their disability is a problem when it's actually access that's a problem or accessibility and inaccessibility that's a problem. I think that sometimes, whether we mean to or not, as a physician, we end up upholding the ableism that's within medicine and even having these interpersonal conversations with disabled people where we could just—we could really provide better care than we do.

*Bonnie:* Yeah. What you just described is so entrenched in our society. We've talked about this before on other episodes, but it never loses its impact, at least on me, at how hard this is to shift this mindset, right, and how remarkable it is that, for so many people, they feel this viewpoint that people with disabilities are lesser is acceptable, is the right way to think, is—there's no other way. There's sometimes a combativeness when you try to approach that, and it's just striking to me it remains.

*Nick:* I think—

*Bonnie:* Go ahead.

*Nick:* I think what's interesting too on this topic, Bonnie, is, we've had other conversations with researchers, clinicians, and you brought up this interesting idea that people get combative when you tell them they're wrong, right? The interesting thing about disability is, people don't even know it's wrong. I find there's this interesting intersection where we talk about racism where, for the most part, I

hope we're at a point where everybody understands at a societal level that racism is wrong, and they understand the basics of it, right? Whether they adhere to it or not, that's a different story.

The disability side, when we talked with Lisa Iezzoni, she revealed to us a survey where, for the most part, people were reporting at something like the 80th, 90th percentile that they didn't make any accommodations and didn't think people really needed accommodations for disability. That is amazing when you think about survey bias where, if most people fundamentally knew ableism existed, and they knew that this was a problem, they probably wouldn't admit that they were ableist. We're almost like a step behind it where people don't even realize it. It's such an interesting topic. I concur with you wholeheartedly. I wanted to inject that from a previous piece we had talked about.

*Bonnie:*

Yeah. Relatedly, Diana, you write in this amazing article, you write, "Medical ableism doesn't just affect patients. It affects doctors too." Can you share more with our audience about what you meant by that and why you wrote that?

*Diana Cejas:*

I think I'm writing that just so that I can put it out there that, one, doctors with disabilities exist, which I think that a lot of people don't realize, but then also that the reason that I think that a lot of people don't think that disabled doctors exist is because we've had to get used to hiding our disabilities, those of us who can. There is a culture in medicine that it's—and I think it's both from outside society and from people within medicine ourselves. It's like, doctors are expected to be some kind of superhuman figures rather than actual people.

I have so many stories from training where you would hear about someone. You're in training. You're doing 24-hour calls, 36-hour calls, sometimes, longer than that. You're doing it every other day. It's like, it becomes a badge of honor to be exhausted, not sleeping, not eating, not peeing, honestly, or using the restroom or the facilities, and just being able to just power through. People talk about that like it's a great thing. I have so many, I guess, fun stories, I guess you could say, where I would be just sitting around with other residents.

One of them would be talking about that time she got a kidney stone 'cause she couldn't go to the bathroom for so long, and we're laughing and joking about it. If you saw someone who was struggling or who needed to take a break or who maybe just, in some cases, just wanted to have a granola bar or a snack, it's like,

that person is weak. They cannot keep up. They're not gonna be able to handle the pace and the rigor of what medicine is really like. When you think about coming into a field that has that kind of culture—and even though I try to tell pre-meds and even one of my friends who just started in medical school, you don't really know what you're getting into until you get into it.

I think that a lot of people recognize that there is this idea within medicine, you're working really long hours. You have to get used to just being at a different level physically. I think that even though you're coming into this culture as a person who has a disability, what is that gonna make you do? Are you gonna be the person—like let's say you have some chronic pain. Let's say that you need some time, like you need to take breaks. You need to eat snacks. You need to be able to go to rest at a specific time.

Are you gonna want to be that one person on the team who says, "Hey, wait a minute. I need a break. Hey, wait a minute. I need to go take my medicine." No. You're gonna want to, if you can, hide the fact that you have all of these issues that you need to take care of because, again, as you go along in your training, all kinds of expectations that you just put your body—you put your body's needs aside. You put your own personal needs aside so that you can focus on the work.

Part of me understands that because it's like, there are gonna be times when you are the only person on call, and you need to be able to get up and answer the patient's question or attend to that person, but sometimes, we do this, and it's just like, it feels like it's for no good reason. It feels like you're just trying to haze trainees into being able to take this horribly damaging physical experience, and if they can't do it, then they can't cut it. I think that disabled physicians get used to hiding what they need pretty quickly. I think if you talk to other—a lot of other physicians who have disabilities, they'll probably talk about in some kind of way how they've had to hide at least one of their symptoms. I know I have.

Then even when you get to a point where maybe you feel a little bit more comfortable about talking about your own issues or disclosure or any of that, it always comes knowing that it could come with a price, knowing that there could be some kind of pushback against it, whether it's, you need to take some time off. Oh, that means the other resident's gonna have to work. Maybe that means that there's gonna be bad relationship between you and that resident. Maybe you're concerned. Maybe you have a mental health condition, and you're worried that that means you're gonna

get reported. That means that people are gonna talk about your fitness.

That means you're gonna have to be doing all kinds of things to jump through hoops to be able to make sure that you can get your license. I think that there—and certainly, as I've been more vocal about my own issues, I've met so many other physicians that have been like, "Hey, I'm disabled too," but unfortunately, most of the time, it's not a, "I'm open and proud about my disability." It's a, I'm whispering, "Hey, I'm disabled too." These are people that still feel like they have to hide their own disabilities because they just don't feel safe.

*Bonnie:* That last statement there, right, that people have come to you and shared, and I'm guessing probably have thanked you for doing things you're doing and saying because they can't—they're not in an environment where they feel empowered to, I certainly get that often even in the research side, right, in public health. That's the thing that I always sit really heavy with is how many people there are that just feel so restricted to be who they are in their work environment. It's heavy, right? That's part of who you are. Yeah. Thank you for sharing that. That, I think, is important.

*Diana Cejas:* Yeah.

*Nick:* I thought that was well said. A lot of what you just said actually harkens back to an article that you were featured in in—I think it was Huff Post. "Disabled doctors were too weak to be in medicine. It's hurting the entire system," is the title. It reflects on what you just spoke about, this grind culture in medicine, and the impact on disabled doctors. I was wondering if you could narrow down a little bit and think about the challenges with accommodations and ableism during your residency and if you're okay with it and if you're comfortable in this space sharing that a little bit.

*Diana Cejas:* Yeah. Part of me is really thankful that I experienced my illness when I did because it was such a learning opportunity. I guess that's the medical nerd coming out of me because you're supposed to take everything and turn it into a learning opportunity. I quickly learned just how difficult it can be to get accommodations even in a setting that you think should be able to provide those kinds of accommodations for you. I had no idea what that would actually look like, and that was because I'd never thought to ask for accommodations for myself before.

I've had migraines since I was a child, and it was certainly something I was dealing with all the way through my training, all the way through medical school. I never even thought that that was something I should ask for accommodations for, ask for help for for anything. It's just because of, again, the culture that I was in and the fact that I had started to internalize some of those messages about migraines and chronic pain not being a big deal, that I just was like, this is something I'm gonna have to deal with it. I'm gonna have to suck it up, do my work, and keep it moving.

I had absolutely no idea how to go about getting accommodations when I first had my illness. Even when I first came back to work, I didn't think to ask for accommodations. I didn't think that it was something I should even want or need. Ultimately, it wasn't me who decided to ask for accommodations at first or who pushed me towards asking for it at first. I had a stroke, and my left hand, I have a permanent sensory loss, meaning I can move it. It's all right. It looks like a—I don't know. It looks like it does pretty well, but I'm really not feeling things in this hand very much at all.

One of the things that physicians do a lot is a lot of typing, a lot of taking notes. I'm in neurology, so my notes are usually pretty long. Even when I was in residency, my notes were pretty long. What I was noticing when I first came back into clinical work is that notes that would take me 30 minutes, maybe 45 minutes, which is still quite a long period of time, were taking me two and three hours and even longer to be able to type. At that time, I was also dealing with—so I was freshly back into work.

I was still dealing with a lot of poststroke fatigue, so I was exhausted and still falling asleep, trying to do notes, staying up until the wee hours of the morning, trying to get my things done. Even then, I was not even thinking accommodations would be something that I should ask for. It took me being in clinic with an attending who was watching me struggle who said, "Let me do the typing. You tell me what to say, and I'll write this down for you."

I remember just, one, being touched because I was like, "That's so kind of you to offer," but then I was like, "Wait a minute. That's not how this is supposed to go at all. You're my attending. I'm the one who's supposed to be taking the notes. It's kind of you to offer, but I need to figure something else out." She started talking with me. She was like, "Why don't you get a scribe? Why don't you try to see if there's some dictation software that you can use? Why aren't you asking to get some help?" I was like, "I didn't know that that was even an option."

That was the first time I really started thinking about accommodations and trying to look things up and find out what might be available to me. I remember going to talk with someone who I really respected, and I still respect them to this day and the work that they're able to do with their own patients. This is someone who I'd worked with for several years at that point. This is someone who knew what had happened.

I guess I have a lot of complicated feelings about where it was that I got my diagnosis and my care. One of the good things, I guess, about getting care in the hospital where I worked was that everybody knew. One of the bad things was that everybody knew. This is a person who had seen me when I was in the ICU on the ventilator, in the bed, not able to move. I'm like, you know what I'm working with here right now.

When I went to them and asked them for help and said that I needed accommodations and the reason why, because I could not get my notes done in a timely fashion, I just remember them asking me, they were like, "Diana, you're going into neurology, right?" I said, "Yes." They said, "Then you know that nerves take a long time to heal." I said, "Yes, I understand." They were like, "Then I think that that just means that you just need to practice a little bit more."

I remember being just so sad in that moment because I was sitting here thinking—I was in occupational therapy at the time. I was also in physical therapy at the time. I was trying to go to work, so I was taking—after I got off work, going to occupational therapy and physical therapy and speech, as a matter of fact. One of my occupational therapist's son was a physician, and she knew how many notes that we had to write, so one of my programs, exercises, was typing. I would go from work to go to OT to practice typing for at least an hour every single time.

Here's this person who has seen everything that I've been through, and they're basically telling me I'm not working hard enough. I'm not doing enough. It was, I think, one of my first—the first time I felt ableism, to know what it was, and to know what that felt like. For to it come from someone who I had such great feelings for, it just—it really hurt. Unfortunately, that wasn't the first time that I had someone respond with a, "You're not working hard enough. You're not trying hard enough."

It's like, I'm trying to be a resident and learn how to navigate a brand-new newly-disabled body. What more do you want from me? What else can I be doing? I think that, for me, luckily, I went to someone else and asked if I could get those accommodations, and they were a little bit more willing to help out, but even then, there was a lot of trial and error. I think one of the things that I expected was that, since I was at a hospital, people would know how to provide accommodations, and they do not. I thought that there was gonna be maybe some policy in place for working with residents with illnesses and disabilities.

There was not. I just expected that there was gonna be more infrastructure around all of this, and it was really a whole lot of people just throwing ideas out there, and we're randomly trying to see what's sticking. I don't know what to do because I've never had cancer before. There was a lot of me trying to figure things out, asking if it was okay. Someone would tell me no. Someone else would tell me yes.

Maybe someone would tell me no in a mean way, and it got to the point where I was just like, you know what? I'm not gonna apologize for the fact that I need these accommodations. I'm trying to do my job. I'm still at least, I think, doing a decent job of taking care of patients. I just need this one accommodation so that I can physically be able to complete the rest of my job with not having to stay up until 3:00 in the morning to be able to do it.

*Bonnie:* Thank you for sharing that very personal story with us. I'm speechless only because I can empathize very much with some of the things you're saying and—

*Diana Cejas:* Yeah.

*Bonnie:* - I think, as someone who is new to disability, newly disabled, there's a lot going on in those moments, right? You're fighting internalization of ableism. You're fighting the external ableism. Chances are, you don't even know that word or know you're doing it. You're trying to just figure life out with this new setup, the new protocols, and you've got a lot of people who now, all of a sudden, treat you very differently. You have to challenge your inner belief system because you can fall into that trap of thinking, they might be on to something, and that—they're not. Let me be clear. They are not on to something.

*Diana Cejas:* Right.

*Bonnie:*

It is just so—those are some hard moments, so thank you for sharing that. I hope that our audience deeply can understand this after you describing that. The challenges around getting accommodations are so important, are not new, but as your perspective as someone with a disability, as a doctor who cares for patients with disabilities, from what you just shared with us around the challenges and the barriers to getting accommodations, particularly in a healthcare setting, what do you think the problems are? Where do you think these—what's holding us back, basically, from doing better?

*Diana Cejas:*

I think one of the things that frustrates me the most is that people seem to see accommodations as some kind of special treatment, or you're getting by, or you're getting something out of this that you shouldn't be getting. I'm thinking about a patient that I saw within the last few weeks who is a patient with mobility issues. They're young. They're in their teens. One of the things that they've really been wanting, which is one of the things their parents also want, is a mobility aid, a scooter, a wheelchair, something.

Because they are ambulatory—they're able to walk around and walk around their house—but when it comes to longer distances, they really, really struggle. They have received so much pushback from other physicians about getting a mobility aid because it's like, I don't want you to use that as, quote, unquote, a crutch. When you talk to this person, all they want to be able to do is walk their dog. They want to be able to go to the grocery store with their parent.

They want to be able to—ultimately, they want to be able to go to college, and they want to be able to just have a normal tooling around the quad, being able to go between classes without being extremely exhausted and having a lot of pain at the end of the day. It makes no sense to me because I'm like, I'm never gonna be able to fix this person's underlying medical condition. They were born with it. They're gonna keep it. That's how it is. They are ambulatory.

Yes, I want them to be able to be ambulatory for as long as they possibly can be, knowing that when they're in their 30s, 40s, 50s, 60s, they might lose that completely, but until then, I feel like it's just my job to be able to help them live as happy and healthy and, quote-unquote, normal a life as possible. How am I going to say as a physician that, by giving you an aid that will help you just be able to go to the grocery store—the grocery store—I'm doing something that's gonna impede you in some way?

I think that there is a lot of that backwards thinking in medicine. I've seen it a lot with mobility aids, but I've also seen it with my patients who use AAC, assistive and augmentative communication devices where—sometimes, it's parents. Sometimes, it's other physicians who will be like, "Oh, if they start using this, then they'll never talk." It's like, who says that they need to talk? Who says that they're—maybe this is the way that they prefer to communicate. Maybe this is what's easier for them, even if they have the ability to engage in vocal communication.

I think that some of this comes from—again, it goes back to our thinking in medicine that disability is just inherently wrong, and we need to do something to correct it. If I'm giving this person a wheelchair, that means I'm not fixing the problem. Then again, I keep going back to the fact that so many of the patients that I work with in particular, I'm not gonna be able to cure their cerebral palsy. I'm not gonna be able to fix the fact they have autism. I'm not going to change their underlying neurogenetic condition. It's just not gonna happen.

What, again, I feel like I should be doing and what we should be doing as physicians is just not focusing necessarily on that—those pathologies. Let's try to focus on what we can do to make things easier for these patients to just be people. That's one of the things I get so irritated with, and I'm sure probably some of my colleagues get irritated with me because I'll see patients who have been seeing various physicians and will be like, they've been told multiple times, "You can't have this. You can't have that."

I see it sometimes with disability placards for cars or people wanting to take—go on FMLA or something like that. I know that there is certainly things you have to think about when you're considering filling out that paperwork and doing all that stuff for a patient, but then it's like, is what I do—if I give this person a disability placard so that they can park their car in front of the store, is that really that bad? Am I really gonna be doing something that's gonna be contributing to their pathology? No.

I'm just gonna do something that maybe makes it a little easier for them to go to Target. I think that sometimes we focus too much on minutiae, and we're not seeing the fact that this—whatever treatment we're trying to do in medicine is really just trying—the patient has to live with that treatment. They have to have a life with whatever that is. I feel like too many of us physicians gatekeep around accessibility, and it's really not right.

*Nick:* Thank you so much for that insight. As you were talking, I was just thinking about the tunnel vision we see in healthcare constantly where, not only is there an ableism going on where we're treating disability instead of considering disability part of the person and the individual, there's also a tunnel vision where, I think in healthcare in general actually, this applies across so many broad areas, we don't necessarily align what we care about with what the patient cares about.

I think it's unfortunately really hard for many people, allied health physicians across the entire system, administrators, to just remember, sometimes, that patient, all they want to do is go to their grandkid's birthday party. That's it. They don't care about how they get there, and that's okay. We can adjust plans to work on that. I don't know. I thought that was phenomenal. I'm curious though about—you've laid all this out for us. What do you think we can do as a next step to address the barriers?

*Diana Cejas:* I think, when it comes to those of us in medicine, it's gonna have to start from the bottom. It's gonna have to start from the way that we educate medical students and trainees. I don't want to say that I'm completely giving up on my older colleagues because there are still a lot of practicing physicians who could also do with some improved cultural competence around disability, but really, we've got to look at the next generation of physicians and those currently in training to figure out, what are we actually teaching people about disability? Not just pathology.

What are we teaching people about what it means to be disabled, disability identity, disability rights, even just laws related to disability? I think I've said—I can't remember if it was that essay that we talked about earlier or one of the other ones that I wrote—we don't really spend a lot of time learning about that in medical school. I really didn't get any kind of training on disability until my last year of training when I went into the LEND program, the Illinois Leadership Education in Neurodevelopmental and Related Disabilities. I think I always get that wrong, which is terrible because I'm a LEND trainee and LEND faculty. I'll have to apologize to everyone.

That was the first time that I was in a space that was really disability-focused where we had disabled self-advocates, we had people from medicine, from allied health, family advocates and everybody in the same room learning about the same topics, but each contributing in a different way and talking about what our experiences meant around that. I think that if I would have had that

kind of experience earlier in my training, that would have only been beneficial to me just because it gives you the chance to, again, get out of the silo, like take a look at the fact that your— here's your patient. I can say, "Go over there. Go to physical therapy."

Maybe I as a physician—not me, but maybe I don't have the context for what that actually means, what that means for your life, your day, your routine, all that kind of stuff. Maybe I can say as a physician, "Oh, okay. You need to be able to go to therapy. You need to be able to go get transportation, your Medicaid transportation."

If I don't have that context, I need to be able to speak with someone, engage with someone who does have that kind of context and to do it in a way where we're all on a level playing field because I think that sometimes physicians forget about how much power we have over the patients, and that, sometimes, even our patients who might have that experience might want to tell us things and teach us things don't feel comfortable in sharing that information. I think if there is a way for us to be able to get that education into people when they're earlier in their careers, we can really make a difference in the way that we address how we want to take care of patients.

For me personally, one of the things that I'm trying to do with my own residents is, every time we have a patient where accommodations come up, or we need to talk about educational stuff because we talk about schools a lot since I'm in pediatrics, I will try to give additional context. I try to say like, let's think about what we can be doing for this patient from a holistic perspective.

Let's not just focus on—yes, I want to control his seizures. I absolutely need to control his seizures and give him the medication that he needs, but if I'm not—if I'm only throwing Keppra at him and not addressing all the rest of the things that could be causing him to not have a great outcome or to keep his seizures under control in the first place, then I'm not really taking care of that patient.

I think, again, if we could just try to see if we can't implement that education sooner, that would be great. Then, of course, admitting more disabled people into medicine is gonna be something else that's really gonna make a big change because I think, or I like to think, that a lot of my colleagues have learned about this stuff just by the fact that they work with me, and I fuss at them and make

them listen to some of these things sometimes.

*Nick:* Dr. Cejas, I think Bonnie and I are so thankful for you coming in here and not only talking about structural ableism in healthcare, but feeling safe enough to tell us your own experiences and lay that out for our audience. I think that this is such an amazing chance for our audience to get an inside view of what it's like from a patient and physician perspective. Thank you so much.

*Diana Cejas:* Yeah. Thank you so much for inviting me. This has been a nice talk.

*Bonnie:* You have been listening to Included, the disability equity podcast, brought to you by the Johns Hopkins Disability Health Research Center.

*Nick:* Thank you to our Included podcast team and everyone that made this podcast possible, especially Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Johns Hopkins Ten by Twenty challenge grant.

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