

*[Theme music by Molly Joyce 00:00 - 00:15]*

*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're sitting down again with Dr. Diana Cejas to discuss the intersection of race and ableism during the time of COVID. Dr. Cejas is an assistant professor at the University of North Carolina School of Medicine and a pediatric neurologist at the Carolina Institute for Developmental Disabilities. Her clinical and research interests center upon youth with neurodevelopmental disabilities. She's 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's also a disability advocate and author. Her work has been published in mainstream outlets, including Stat News, and her essays were included in Alice Wong's Disability Visibility book of essays. She's also currently writing her own book, a Memoir of essays on her experiences with racism and ableism in the healthcare system, both as a physician and a patient.

*[Theme music playing 01:49 - 01:57]*

*Nick:* Dr. Cejas, thank you so much for joining us again.

*Diana Cejas:* Yeah, thank you.

*Bonnie:* Dr. Cejas, last July, you wrote another fantastic article titled *To Thrive, Black and Latinx Physicians Need Their Communities*. You wrote this, and this was published in Stat News. In this essay, you described your experience as a black Latina in medicine. In this article, you state, "To put it simply, black and Latinx doctors are good for black and Latinx patients." What I really liked about this article is your focus on the value and the importance of community. You talk about how physicians need community to thrive. My question to you is, what are your thoughts around the disability community in this space? You have all of these

intersecting identities and experiences. What is your experience for finding community and the value of that?

*Diana Cejas:*

Well, I feel incredibly lucky that I've been able to find the communities that I've been able to find. When it comes to the disability community, I just wish that I had found a connection with people sooner. I think that when I first was dealing with my illness, I had internalized a lot of messaging around trying to be strong, trying to be resilient, whatever that means, and thinking that I could handle everything by myself and take care of it by myself. Actually, one of the first essays that I wrote was about celebrating anniversaries. I talked about, in that essay, how I didn't really deal with the focus groups or not focus groups with support groups. I couldn't really be around other people like that.

I completely changed my mind on that subject because I realized that there's so much that you can learn from other people who share, not even the exact same experience as you, but at least who are dealing with some of the same issues that you're dealing with and moving about the world and trying to figure things out together. I think that when it came to making a connection with the disability community, some of the first things that I realized was that I had so much in common with my patients. I think that that's one of the things that really got me to start talking about all this in the first place. When I was first dealing with my illness, I just remember feeling so alone. My cancer is pretty rare. No one had ever had it, or at least none of the people in any of the support groups that I attempted to maybe connect with have had my kind of cancer. Also, most of the people diagnosed with that kind of cancer are usually in their 60s, 70s, 80s.

I had absolutely nothing in common, I thought, with that particular group of people. I would try to talk about my experience as a stroke survivor, and again, most of the people were decades-old from where I was. It just felt like no one knew or understood what I was going through until one of my attendings, who was also a stroke survivor, and had his stroke about the same age that I was when I had mine, just randomly decided to share his experience with me. I remember that was the first time I felt a connection with anyone and the first time I thought that anybody got it and knew how I felt. I'm lucky in that I have a really great support system in my family and friends, but they just couldn't understand some of the things that I was feeling.

Then when I started to be a little bit more vocal about things and started meeting those other physicians who were like, "Hey, I have

a chronic illness too,” or “hey, I have this disability too,” I just felt even more like I has this connection with other people. I don’t think I really related it being related to the disability community until I started spending more time with disabled self-advocates who could say, “I’m disabled.” It’s not I’m disabled. I’m whispering about it. It’s I’m disabled. I’m open. I’m proud about it. Let’s talk about what this means.

I really started to feel more confident in myself, feel more comfortable in saying that I was disabled. I still remember the first time I said it out loud and this relief that I felt. I think that physicians don’t recognize that sometimes. I think sometimes we’re like if I give you a diagnosis, that means it’s always gonna be a sad thing, a bad thing, but it’s not. I had these things that have happened, but the idea that I could identify with this group of people, and they’re just like, “Oh, hey, welcome. Come on over. Let’s talk about things. Let’s talk about how we can support each other mutually,” has just been so beneficial.

Also, luckily, for me, it’s not just that I’ve met these people in my real life, if you wanna call it, but also, I’ve make these connections with people through social media. I think one of the things that’s been most transformative for me personally is that randomly, and against my better judgment, initially, I decided to sign up for a writing group that’s specifically for young adult cancer survivors. The first time I went, I was really like, I don’t know how I feel about this. It’s all through Zoom. If I can shut out the program, it’s called Lacuna Loft. I suggest that anybody who’s an adolescent or young adult cancer survivor look into their programs.

I just remember immediately feeling like I was welcome there. They would take me however I was. If I was having a chronic pain day, and I couldn’t really do very much of anything, that was fine. If I was really angry and just wanted to write about what I was angry about, that’s fine. If I wanted to share something I was happy about, that’s fine. I didn’t have to explain how I felt. I didn’t have to say why I was wanting certain things done certain ways. Everybody just got it. It was like I was just accepted. That was just so helpful to me and helped me really work through some difficult anxiety and post-traumatic issues that I had years after the fact.

I think that just every time I’ve been able to make connections with other disabled people, all it has done is helped me personally in trying to figure out what disability and survivorship looks like for me. Then I feel like it also helps just to make those other connections because, again, you never know who’s out there or

who might be hiding something about themselves who might be dealing with something like this about themselves. Then I just fully credit anything that I know with disability to all of these people who have been so patient and loving, and supportive of me and helped me figure out what I need to learn, what sources I need to look at, what resources I have. I really feel like not only is it a personal connection and strengthening that I've had but also professionally. The course of my career, I think, at this point, is pretty changed. I owe it to my disabled community.

*Bonnie:*

Yeah, listening to you share that, and thank you for doing that, for sharing that. I think so many of us who have a disability that happened later in life or perhaps even in childhood remember the first time they met someone else like them, right? Remember the first time they used that language if they're at that space or place or they do use that kind of language. I certainly do. Some of the really important points you made are around how in the healthcare setting, there's just a lack of nuanced understanding. Disability identity is fluid. It changes. Even if you're born with a disability, it changes over time, and that's okay. That should be welcomed. It's not a fixed state of identity or of being.

The other thing that just really hit home for me is the affiliation with the term disability and being disabled, right? I don't think it is a bad word. I don't have any bad feelings towards that word, but I wasn't always there, right? I wasn't like you. I wasn't always at that space in life. I am now. Now that I'm on this side, and literally before we started this podcast, I was sharing with Nick, I can't go back now. I don't want to. I can't undo this feeling. When I am in a situation where someone has a reaction or uses certain kinds of language, I do now have a response I may have not had before. It's just who I am now, right? I want people to accept me. I think right now in the healthcare system, there's just that lack of understanding that that's part of who we are. Thank you for sharing that. I just really wanted to highlight those critical points.

*Nick:*

For the record, I like who you are now. I didn't know old Bonnie, but.

*Bonnie:*

Thanks. Dr. Cejas, this is so insightful that you're sharing this and so personal. All I keep thinking about is how do we leverage human experiences like yours with community, which is a basic human value and trait, and do better at supporting intersexual inclusion in the medical setting or even beyond? How do we leverage community to a certain extent? Do you have thoughts on that?

*Diana Cejas:*

The first thing I think is it's gonna be difficult because I know physicians. I think a lot of that is gonna have to come down to letting people own their expertise. I think there's a lot of discussion about what lived expertise is and what it means in medicine and elsewhere. Unfortunately, I feel like depending on the field that you're in within medicine, sometimes lived expertise is seen as a great thing. Sometimes it's like, "No, that's terrible. I don't wanna have anything to do with it." I think if we could just recognize, yes, you are an expert in whichever field it is that you are in because you have spent this time learning and doing research and working with patients, and, of course, you have this practical expertise. Also, just because you have 20 years of experience researching a disease does not mean that you have the same kind of expertise as someone who's had 20 years of living with it.

I think that if we really wanna work with communities and engage with community, one of the first things, which would be probably one of the most difficult things to do, would be just to get physicians to own that, accept that, know that your patient might know more about their disease than you do. I think that that's something I have to think about a lot because I work with a lot of kids with rare conditions. Even my own condition, I've had physicians tell me, they're like, "Well, you know more about this tumor than I do." I'm like, "Well, that's comforting." I have complicated feelings about that. Sometimes it's not the thing that I wanna hear.

We have to recognize that patients are coming in, and they've been doing research too. They've been looking into the literature too. If we just say, "Hey, rather than this being a paternalistic relationship where is I as the physician am making decisions, and I say everything, why don't we have it be more of a partnership where we say, you know what, here's my clinical expertise? Here's your lived expertise. How can we use these two things and work together to really get you to whatever goal it is that we together are tryin' to come up with?" Then I think that if we can do that on a personal level, maybe we can start doing that on a broader level, like the healthcare system actually trying to engage with the communities that it says that it's trying to help.

We have all of this discussion about underrepresented patients, underserved groups, underserved communities, but it still feels like a lot of the time when we're talking about underserved communities, we are not talking to the people in those groups. We are not including them in our research. We are not working with

them when it comes to making the plans for interventions. We are just coming in and saying, “This is what I as the experts think is going to work, and this is how it’s going to be,” and then wondering why our interventions don’t work. It’s like, well, that’s because we don’t really have buy-in from the people that we’re supposed to be trying to help. How about for five seconds, we just say, “All right, listen, I’m gonna put my ego aside. I’m gonna listen to what it is that you as a community are telling me, even if it’s things that are hard for us to hear, like the fact that sometimes traditionally medicine has hurt a lot of people.”

Why don’t we just listen to what these communities are saying? Then not just listen, and say, “I hear you. I see you.” Let’s listen to what people are actually trying to say, then taking what they’re saying and implementing it in our interventions. Let’s work with people to designing the interventions in the first place.

Let’s make sure that we got collaboration, not just from the most well-resourced or well-connected person in the group. Let’s find the most marginalized person in that group. Go to them. Ask them what they need. Let’s try and see if we can’t get those patients more involved. I think that maybe if we could do all that, and that is definitely a tall order, then we could really do a lot to improve relationships between medicine and the groups that we’re supposed to be serving.

*Bonnie:*

Yeah, I wholeheartedly agree for so many reasons, very well prioritized. I think, in so many ways, that has to be a priority. I think, from my perspective, some of these efforts, though, are focused compartmentally. What I mean is they’re maybe focused on racial and ethnic minorities, right, the BIPOC communities, maybe some on the disability community. Obviously, we know that there are health care inequities, health inequities for all of these groups, and these groups intersect.

The experience of a black disabled woman is most certainly going to be different than a white disabled man in a healthcare system, right? We know this. Can you talk a little bit from your perspective on what we could do or should be doing to perhaps get us more towards thinking about intersecting communities, bringing them into this space, making them feel included, including them in all the things that you just discussed? How do we get there? I just don’t feel like I’ve seen enough of that.

*Diana Cejas:*

Yeah, I agree. I think that this is an ongoing problem. I was in a meeting earlier today, where we were talking about some of that

related to recruitment for studies and how so many of the studies that we're doing, the population of participants we're able to attract are largely white, largely coming from higher-income families, largely coming from certain areas of the state. It's like, well, what does that say? Even if we're able to come up with this research, even if we find statistically significant results in whatever kind of study we're trying to do, is that generalizable? Is that something that's gonna be true for the patient who is down east, who is maybe from a displaced family, or maybe English is not their first language? Maybe it's from someone who's over closer to the mountains, who is an agricultural kind of a family.

If we're not taking a look at the fact that our studies, and the way that we're conducting research, and the people that we're trying to approach for research, it's not representative, then we're not gonna be able to really try to get those people involved. I think one of the things that comes to mind is I hate the term women and people of color because it implies that you can't be a person of color and be a woman. Now every time I see, and I see that so often in some scientific literature, even when people are well-meaning, they are really trying to get these participants involved in their studies. It's like, "Yes, we're looking for women and people of color. I'm like, "Okay, well, specifically, who are you looking for? Are you looking for, and when you're saying women, are you saying that white women are the default, and then people of color are all in this group? Are you looking at the differences between experiences between, let's say, an Asian man and an Asian woman? Let's say an Asian man and an Asian woman from two different areas, so two different places, even within the same country.

I think that one of the things that we have to do is recognize that if we're not practicing from an intersectional lens, if we're not delivering care through an intersectional lens, if we're not trying to engage with communities through an intersectional lens, we're not really doing any kind of work. I think that one of the things that we're gonna have to do is really just from the bottom when it comes to research, make sure that intersection is inclusion. Intersection is part of the study design. If you're not specifically saying in your methods section of your grant proposal, "I am going to be trying to get this number of people from these racial-ethnic backgrounds. I'm gonna be trying to get these various gender identities. I'm gonna try and make sure that I can include people who, at least in this area, like the most common languages that are spoken, then what are you really doing?"

Unfortunately, you probably attract the people that tend to be traditionally included in these kind of research studies. I think when it comes to care delivery, if you're looking at the patients who are coming into your clinic, and you're noticing, again, that these are higher income, more well-resourced families, what does that say about your clinic? What does that say about your clinical for outreach? I think when it comes down to if you're trying to advertise that you're gonna be offering certain services, you need to make it clear from the outset that it's not just certain people who are welcome here. You need to make it so that more people feel like they are able to come and that they are able to get care there.

I think that it also makes a difference if we're thinking back around the research thing. Your research study team is gonna make a difference. Because if you come in there, and you're like, "Okay, I'm working in a group. Everybody I'm trying to work with is black and low-income," but I'm coming in with, let's say, an all-white study team that's gonna look a way. Who is it that you're trying to include on your study teams? Who is it that's gonna be your research assistant? Who is going to be maybe your call investigators?

If you don't have a person who belongs to that community, and you're really trying to do community-based or patient-centered research, then maybe you need to take a look at that, too. I think that whatever it is that we're trying to be doing, even if you're thinking about education, it's all gotta be the same thing. Who is able to come to the table? Who's making the decisions? If you're looking around, and everybody's that's making decisions looks all the same, what does that mean about what kind of decisions you're really trying to make?

*Bonnie:*

Diana, do you ever feel like you don't have the power to, and I'm projecting here, the power to include the people you wanna include in the work? I'm saying that because I'm admitting I'm at this place sometimes. What do I mean by power? The structures outside of what I can control, the money to support those structures, the data. I don't know. I feel like this has never been thought deeply about, but we have these structures that perpetuate exactly what you just described. We also don't have people who maybe can challenge them with the extra bit that is needed to take those things down. I don't know if you have thoughts about that.

*Diana Cejas:*

Yes, I'm definitely dealing with these thoughts right now. I recently got a little bit of funding for this project that I've been trying to do for years but only partially have gotten some funding

for it. Honestly, what I'm trying to do, it's an all-around healthcare transition. I'm trying to go to parents and patients, the patients particularly since sometimes there's a lot of parent proxy studies. I wanna go to the kids themselves and find out what are we doing really well when it comes to health care transitions for kids with neurodevelopmental disabilities. What are we doing badly? What do we need to change?

Then, hopefully, taking that data and working with a group of collaborators who, again, will identify as being a person with an intellectual or neurodevelopmental disability, or maybe a parent of a person with an intellectual neurodevelopmental disability who is a young adult, and saying, "You know what, this is the data that I've been collecting. This is what I'm hearing from people. This is the kind of program we have developed around healthcare transition here, right now. How do we take this and make it more functional for y'all and also functional for us as clinicians?" Then, hopefully, at some point, being able to pilot whatever kind of program we come up with together.

Geez, three or four years, I've been trying to get a little bit of funding for this study. I've been specifically saying that I want to include racial-ethnic minorities. I would love to be able to include people who are not cisgender heterosexual. I wanna make sure that I'm having gender minorities and other people of the LGBTQA+ community included in this work. I wanna make sure that I'm including people with intellectual disabilities as participants and consultants. Because, again, I'm thinking about I'm trying to develop this program for this patient population, but I'm not a person with an intellectual disability. I don't have that expertise. I need someone to help me out. Trying to get funders and other people to recognize any of that and the importance of it, it's been challenging, to say the least.

I've had some people who were like, "Well, why can't you just do it with the parents?" When it comes to the parents, it's like, "Well, why do you specifically need to say that you're gonna try to recruit people from these racial-ethnic groups?" It's like, "Because if I didn't specifically say it, I feel like I know what the outcome would be." Then again, it even comes to my recruiting sources. I'm thinking about those as well, some subject registries that we work with and some other sources that we have that we traditionally recruited from. I'm looking even in those pools and seeing that a lot of the patients that I'm trying to attract aren't there. It's really making me think about how do I find the people that I want to work with? Because I know they're there because they're showing

up in my clinic. How do I find those patients and have them want to engage in this research?

Then the other thing that I'm thinking about for this particular project is I would absolutely love—when we're thinking about research assistants, I need someone. I like to say that my Spanish is just good enough for my grandparents to be angry about it. I need to try to see if I can find some multilingual or bilingual research assistant. I would also love to try to see if I could find someone who could be a research assistant who is autistic because I am not autistic. Since I'm working with a patient population, and I can imagine that would be the vast majority of my participants, why don't I have that right from the outset as part of the team? Even when I'm thinking about getting those funds to support that person, it's like, well, I've been told, it's like, "Well, how are you gonna even find that person? I don't know if that person exists."

It's like, "Well, I actually know a research assistant who is autistic and queer and also a person of color. I know them. They're out there." I just feel like sometimes there's a lot of pushback. It's like, "Well, things have never been done this way, so why should we do things this way?" Unfortunately, I feel like that is just going to hamper search efforts, and particularly for those of us who are interested in doing more work through an intersectional framework.

*Nick:*

There's so much to unpack there. That was amazing. I hear inclusion matters, opportunities matter, the messenger matters, and representation matters. It's from multiple angles. It's from multiple sides. The barriers of that's not the way it's been done is just not good enough. It's so frustrating. I hear what both of you are saying, from my own experiences, bringing in patient population to my study teams, and people going, "What do you mean? That person isn't a researcher." It doesn't matter. They know, in my case, hearing loss better than I know it, and that matters.

That was so amazing. I almost don't wanna derail the conversation too much, but I wanna bring in COVID and this pandemic that's been this overarching thing in the background of everything lately. The COVID-19 pandemic has certainly elevated historical health care inequities for racial and ethnic minority groups, as well as for people with disabilities. Certainly, there is an intersection too between those groups. Can you talk about if or how approaches to improving health care for these populations can take an intersectional approach?

*Diana Cejas:*

Yeah, I think you're absolutely right. COVID has just really exposed a lot of issues within medicine and our healthcare system. I don't think it honestly was that much of a surprise. Maybe that's surprising to hear and to say. Back in last spring, when the first data started coming out, that showed that mostly the people who were hardest hit happened to be people of color, happened to be people with disabilities. People with or without disabilities, who are also people of color, tend to be the hardest hit. I certainly wasn't surprised by it. I don't think that a lot of people who were honest with themselves would say that they were surprised by it because we can look at the state of health inequities that exist for those populations already.

Now you're putting populations that are already under stress, already not getting the care that they need, already not having great access to certain medical services, already dealing with other kinds of challenges that are affecting their health. A lot of them as a result of structural and institutional, and environmental racism. Of course, it makes sense that these are gonna be the patients that are dealing with COVID and are the hardest hit and dealing with the aftermaths now. Although, it's weird to say after 'cause we're still actively in this pandemic. I think that when it comes to intersectionality, and even COVID care, again, I don't think that what happened with the race and who's most affected, who's getting sick, who's dying from COVID is a surprise to anyone. That's meaning a surprise to anyone within those communities or a surprise to anyone within medicine.

I think, though, that we have had opportunities to really try to engage these communities, and we have been doing a terrible job at that. I think one of the things that we have to recognize is that again, unfortunately, even though a lot of us who go into medicine do so because we wanna help people, we go in with these altruistic motives. We are like, "I wanna come in, and I want to change the world. I wanna make everything better. I wanna make everybody healthy." Medicine is not and has not been the kind of field that is always good for people. Medicine has caused serious harm to groups, particularly people of color, particularly people of color with disabilities, particularly the disabled community. It's like, which community do you wanna talk about? If they have belonged to a marginalized group, medicine has done something to harm them.

I think that one of the things that we have tried to do with COVID, especially last year and in the summer and the spring, I think that some of us in medicine saw the inequity, and we're like, "All right,

let's do somethin' about this. Let's go in there. Let's talk to people about social distancing." Then when the vaccine came out, it was like, "Well, everybody needs to go get the vaccine. We'll just make sure that everybody gets the vaccine." We're not addressing the issues that medicine has. We're not addressing the concerns that these communities have with medicine. We're not addressing the fact that there is an issue of distrust and mistrust.

I think that even when we bring that up, if we're specifically talking about the black community, for instance, we're like, "Oh, there is a mistrust, and it's because of Tuskegee. Oh, there is a mistrust, and it's because of the fact that there were involuntary sterilizations back in like the 1920s, and things like that." It's like, "No, wait a minute. This is not something that is historical. Medicine is ongoing, right now, doing things that hurts people of color. Medicine is right now doing things that hurts people with disabilities."

We know it. None of it is a secret if you ask people. I could go around asking my cousins, how has medicine hurt you? Everybody's gonna have a story. Everybody's gonna have a story that's a little bit different, but it's no less true. I have my own story of not being believed by physicians for years and then finding out that I had cancer. This is something that is an ongoing issue. Of course, it makes sense to me that you're gonna have people in these minoritized groups who are not gonna trust the healthcare system. Why should they? We haven't given them any reason to, even when we come in saying that we're gonna do something that's good. We come in and steamroll the community and say, "We're gonna do what we think is good, not what necessarily you think is good."

I think, when it comes to COVID, especially when it comes to vaccine access and things like that, we're like, "Well, everybody has access to the vaccine. Everybody can get the vaccine right now," not recognizing that that's not always true. I'm thinking about my patients who were in more rural communities. I'm thinking about people who maybe don't have consistent access to transportations. I'm thinking about people who maybe can't take the time off work to be able to go get the vaccine. It's not, I think in every case, it's that people who are unvaccinated don't wanna be vaccinated. It's that maybe they cannot get access to the vaccine, and we're not thinking about it.

We're thinking, "Oh, because it's there at the hospital, that means everyone has access." Well, no, it doesn't. We need to be actually

thinking about how to reach out to communities that need these services the most. Ask them what it is that they need. Then actually give it to them the way that they say that it needs to be given to them. I think when it comes to even spreading health information and talking to people who were hesitant about the vaccines or have questions about it. Maybe we shouldn't just label everybody as being an anti-vaxxer, which there are certainly anti-vaxxers out there. That's a whole different conversation.

Let's look at why people are hesitant. I think about again, within my own family, I have cousins who are were and still are hesitant about getting the vaccine. They weren't sure about it. They weren't sure if they wanted to do it. If you actually just treat them as if they have the ability to make their own decisions about their own care, and you treat them as if they have a point of view that needs to be listened to. Ask them questions about why it is that they're hesitant. It's not that they are coming up with some weird conspiracy theories 9 times out of 10. It's because they're like, "Well, I have heard this, and I wanna know if this is safe. I wanna know if it's okay for me to get this vaccine because I have epilepsy. I wanna know if it's okay for me to get this vaccine because am I going to be really sick after the fact?"

Then, of course, there is the contingent of people who just don't trust the healthcare system, and they're like, "I don't wanna get this vaccine because I don't know what it's gonna do to me because I don't know what the rest the—I'm thinking about all these other atrocities that have happened." I think if we're really serious in medicine about the fact that we wanna take care of people. We wanna help people. We wanna help the people who are most affected by COVID. We have to go to the people who are most affected by COVID and say, "How can we help?" Not say, "This is what I'm gonna do to help you."

We also need to look at structural barriers that might be preventing vaccine access. If you're saying you can go get that vaccine over there at Walgreens, but the nearest Walgreens is 20 minutes away from a community that doesn't have reliable bus transportation or services, what do we really doing? We're not really doing anything to make sure that those people have the access to the vaccine that they need. Then there's all kinds of other just institutional and structural factors that you're thinking of. We're thinking about mask mandates. We're thinking about the fact that so many essential workers are the ones who were coming down with COVID and continue to come down with COVID and so how so many of those workers disproportionately belong to racial-ethnic

minority groups. Then wanna blame people for getting COVID as if that was their choice to do.

We just have so many opportunities where we in medicine and public health could just really try to do a more grassroots approach to educating about COVID, to helping people feel like the vaccine is something that is safe and that it is something that they can have access to, legitimate access to. It's not just gonna be a one-time here's your COVID vaccine, finally. Fantastic, you've done it, and that's it. Because it's not just that these people need better care related to COVID, it's better care generally, better health care for everyone all the time, forever. It can't just be about COVID. We have to look at the fact that we're just not providing good care across the board and figure out what we're gonna do about it.

*Nick:*

You said something just so amazing that I just wanna reiterate for the audience, particularly maybe if we have a hand full of health care workers, physicians, allied health professionals, researchers who do listen to us. When we talk about distrust of the healthcare system, and you brought up, we always go back to Tuskegee. I'm thinking very much through the lens of Baltimore, Henrietta Lacks, or some of the lead-based studies, right? We act like they were decades ago. They did happen a while ago. Granted, hopefully, we have some protections for research in place.

I grew up with a family that owned a fish market, literally in the shadows of Johns Hopkins, in a multi-ethnic neighborhood. At one time, historically black, but it had morphed over the years, and then now it's really gentrified, to be honest with you. There's this premise of distrust in Baltimore among the black community of Johns Hopkins. They place it on the historic aspect. I think you're absolutely right. It's something we need to acknowledge more often that healthcare, in general, is still structurally racist and structurally ablest.

When people don't trust it, it doesn't mean that they're referring to something like Tuskegee. It doesn't mean they're referring to Henrietta Lacks. They're referring to their own experiences, right now, in 2021. That's something that people really, I think, just—I just can't reemphasize what you brought up enough. That's something we need to get through to people, right? I think that when we think historically and when we teach it that way, we actually give people an out.

We let them say, “Oh, it happened forever ago. Sure, they just distrust the system, but it's not my fault.” It is. It's our fault. It's

everybody's fault that deals face-to-face with patients or is in public health or is in research. We're still pushing that structure along. We have to actively push against it. I just couldn't help but reemphasize the point you made there. I thought it was brilliant, and I don't hear it very often. I hadn't even really thought of it that deeply that way, so thank you. Thank you for saying that.

*Bonnie:*

Well, Diana, Dr. Cejas, thank you so much for spending so much time with us. I am so grateful for you for sharing your story and sharing your work and your advocacy. I think the summary is communities matter, communities matter, communities matter. Thank you for all you're doing for putting people back at the center of health care, and thanks for taking time.

*Diana Cejas:*

Yeah, thank you for inviting me.

*Bonnie:*

You have been listening to *Included: The Disability Equity* Podcast, brought to you by the Johns Hopkins Disability Health Research Center.

*Nick:*

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