Hi, my name is Dan Gomez and this is Mental Health Supra Omnia, mental health above all. We identify and understand mental health issues and the paths for help.

Today we want to talk about ableism in its many forms. We have two guests. First, Laura Mauldin. Laura is a writer, sociologist, and an associate professor in the department of social and critical inquiry at the University of Connecticut. Dr. Mauldin frequently writes on in the context of deafness, chronic illness, and disability. Her writings appear in the Los AngelesReview of Books, Baffler, American Prospect, just to name a few. And she's currently working on a fascinating book, which she gave us a glimpse of, but we haven't been able to read yet.

We also have Erica Burgoon. Erica is a member of the leadership team at Equilibria Psychological and a licensed clinical psychologist with 25 years of experience. She provides clinical services across the lifespan and specializes in working with depression, anxiety, and traa.

Laura, we've met, we've read many of your essays and other publications, and there's a lot of them out there, but we've read almost all of them. And we were fascinated by the concept of ableism, both in its classic form and expanded into how many have those very same feelings about not being tall, pretty, or or handsome. Can you explain for us ableism and its different forms? Sure. Thank you, Dan. Thanks for having me on. I'm happy to be here and to talk about ableism. And I do define it in my upcoming book. I'd be remiss not to tell you the title and uh release date, which is it's called In Sickness and In Health: Love Stories from the Front Lines of America's Caregiving Crisis. And that's published by Harper Collins and out February 10th, 2026. And in that book, I give my definition of ableism, but I am certainly not the first. But my definition is really quite simple and quite broad, which is it's a system of belief that some bodies are worth more than other bodies.

Very simple. Now, many other people have defined this and perhaps in more, you know, granular fashion. , but I really like to think about it on this really broad level so that we can understand that it's everywhere in everything and it often is unmarked because it seems appropriate or reasonable to have certain feelings or assptions about certain bodies. Laura, I'm so glad uh we're able to to be here to talk about this today. the many forms of I would say bias and oppression.

I don't feel like ableism gets nearly as much attention as many other forms and yet with an aging population in this country and we know that there's not a great safety net for people who are chronically ill for a for people who are aging and it is almost astonishing to me that we can you know continue to kind of have the blind spots that we do about this.
Uh I I think that often when there is sort of like a landmark moment and the ADA certainly was one back in the 1990s that we can sort of think that we've addressed these things that they're not, you know, these these are not problematic in the way that they used to be. And yet there continues to just be so many spots that we're just not aware of or that we overlook. And I

guess if you could start by talking about some of the ways that ableism shows up that many of us may simply not be aware of.

I am so glad you raised this connection with the ADA, the Americans with Disabilities Act of 1990. , a lot of people's definition of ableism is discrimination against disabled people, which is of course a huge part of ableism, but it is only one slice of it. But as you mentioned, there has been more attention to things like stigma and bias, particularly in like various health fields, right, where you're learning more culturally competent care and you're thinking about all of these issues like sexism and racism. But like you said, ableism is really overlooked. , I think we don't talk about it in medical education.
, and we also think, well, there was this law about you can't discriminate against disabled people, so it's taken care of, right? Except I've worked in a hospital for over 10 years, and I continue to have to as a a sign language interpreter interpreter for deaf patients. And I still have to educate physicians, particularly residents, when they come in in July and we get the new crop and we have to explain how to use an interpreter, that deaf patients exist, that hospitals must provide interpretation, that you know, there are all these different things that even though this law exists, people don't have the awareness of all the far-reaching tentacles culturally, structurally, environmentally, attitudinally that still affect everything. So what you're bringing up about an aging population who is aging into that category of disability, right? And if we don't have safety nets for disabled people, disabled adults particularly even in these younger years, well people are going to have to then face this in their elder years as well once they age into it. Okay. I forgot the like end of your question, but I wanted to put a fine point on everything that you had mentioned because they were all so good. Sure. Yeah. I I was bringing up that uh you know, in maybe some of the big and obvious ways with the ADA, right? We we have ramps installed in public spaces and and door widths widened. Uh but there's still so many in you know invisibilities in terms of the other ways that people may may face ableism may face obstacles when they're living life with a disability you know or in a body that's that's changed by age illness or injury. Yeah. And I think it's really important too to think about the different levels. Okay. So, I'm going to put on my sociology hat for just a minute because we often think about things in society at the micro level, the messo level, and the macro level, right? So, we we often think about things in that way. And when I think about mental health care and ableism and barriers, I want to start with that sort of macrolevel piece where yes, we may have the ADA, a federal law. Sure, we may have that. But we also have a system in this country of care of health care that is based on employment that is rooted in ableism because ableism means that we devalue certain bodies. Right? So if a body isn't deemed normal, isn't deemed productive, isn't deemed able to work, there's this kind of neglect that is justified because if you don't work, I think just yesterday there was like a town hall where some senator says, "Well, do you want this 28-year-old able-bodied person to still get healthcare and not be working?" you know, and there was this resounding sort of protest from the audience that I was very pleased by that were like, "Yes, we do. We do want that person to still get healthcare." But in this country on this macro level, we have a belief system that the people deserve access to health care, including mental health care. Our only people that can work, have normal bodies, are productive.

This is ironic of course because the more we deny care the more disabling we are for the population right as people don't get access to routine health care for example then that can turn into a catastrophic health problem later and result in disability result in traa result in all of these different things. So the irony right is at this macro level we actually create more disabling conditions while also sort of neglecting a certain part of our population as oh well you don't deserve care so you don't get access to care. so that's a major sort of macro level issue. At the MEZO level, this has to do with things like uh paid leave, uh things like like the FMLA, right? The Family Medical Leave Act. that only covers, I believe, up to 12 weeks or something like this. And a disability doesn't go away in 12 weeks, right? And that's just not something that at that meo sort of employer level can take care of those kinds of things. But we don't have this built-in system or safety net as you've mentioned. We don't have home health care uh for disabled and elderly folks. Well, what we do is atrociously inadequate, but you know, we do have some programs that are really means tested and they're poverty- based programs. , and then I'd like to really kind of home in on the micro level. Yes. because there's something called internalized ableism. And this is something I'm particularly thinking about Kathleen Bogart's work. She's a psychology professor atOregon State University. And one of the things that she writes about is how when someone becomes disabled, if they actually begin to think of themselves as part of a disability community and have a disability identity and come into this sort of knowledge that they aren't bad, that they aren't the problem, that they're part of something bigger than themselves. That is the process of sort of getting over getting through internalized ableism that tells you I'm bad. I am the problem. And it results in copious amounts of shame and avoidance of perhaps getting the care you need. And when we don't know what ableism is, think about becoming disabled. I remember one man that I was talking to, he had a a stroke and lost the use of one side of his body and he was crying and telling me, "I'm useless. I'm worthless. All I do is sit here and take resources. I don't contribute anything. I'm not worth anything." And that is ableism telling him that because you became disabled, you are now worthless.

He has taken that sort of ableism that's in the ether that we just sort of think is appropriate and reasonable. Well, yeah. Uh certainly if you're not worth it if you're not producing something for econ for the economy, well, yeah, you're not worth anything. You're worthless. We easily diminish people. Those kinds of messages get internalized. We all take them in disabled or not. And that I think it's really important to know that ableism affects all of us. You do not have to be disabled to experience it. And I'm certainly not the first person to to say that. , but one of the things that happens then at the mental health care sort of moment is people may not have the language to talk about how they're feeling. They may not have the language for that or to know that they're not bad. That there is a larger sort of systemic thing going on here that has resulted in them internalizing this sense of shame and worthlessness which of course contributes to so many other things,right?

A lack of self-esteem, depression, anxiety. There may be traa associated with how they acquired their disability. There may be just ongoing medical traa related with, you know, ongoing long-term chronic conditions that require a lot of interventions. So that internalized ableism is a really big piece of it that really affects whether or not people seek mental health care or how they can talk about what's going on with them if they're trying to cope with becoming disabled. If if I could interject just a little bit, uh Erica and uh and Laura, part of my issue, if you will, uh on this particular topic is that on on one hand, I completely understand and I have examples where I I personally have internalized ableism and where I felt bad uh because something happened to me like mental health I you know, mental health issues as a result of On the flip side though, we do have a system where we are a product a very productive country and we are, you know, pro arguably the number one country in the world right now,right? We have a system that is kind of a patchwork, right? you do get your many people get their insurance through work, of course. uh we had uh people that paid for insurance and then people that didn't have insurance. ACA the Affordable Care Act tried to solve some of that. When it did, it shifted costs away from the younger that 28-year-old able-bodied person who didn't have insurance who probably could have gotten it on the exchange for 250 bucks. And they made it more expensive for anybody 55 and older to where some of those people are spending as much as 30, you know, $1,800 a month for a gold plan, a top tier gold plan. So this the system may not be perfect but almost feel I almost feel under attack just with the the whole concept of of ableism even though there's times where like I said I have hurt my I've gotten hurt and you know I have mental health issues as a result of of not being like everybody else. It's kind of a sense of worth. Isn't that a han thing? Right. That's where our sense I get a sense of worth for actually doing stuff, for helping people, for creating things, for providing for others. Yeah. So, if I can't do that, I mean, why wouldn't I have mental health problems? Yeah. Absolutely. There are all kinds of ways that we have a s we acquire a sense of selfworth, right? There's so many ways that we do that. And you're right. we have a country that is sort of built on this culture of productivity and contribution, right? To be thinking about contributing to society in this way that is measurable and quantifiable. , and I think what often happens with disabled people, and I'll just, you know, think about some of the just disabled friends I have, disabled people I know who, , may have so much to contribute, but it may not be deemed economically valuable. It may not be, , something that can be well, there's also rampant, you know, sort of discrimination and employment practices. disabled people have really struggled to close the gap in unemployment rates and things like that. So there's these other sort of barriers that can sometimes affect disabled people and not all disabled people are affected equally. So disabled people of color, women, there's lots of different ways that people are affected on these different levels. But what ends up happening is there's these sort of conditions that sort of tell us that what we do have to contribute isn't valuable and it's hard to find self worthin that. at the same time. , and people may not know this, but there's lots of disability communities all over the country, and there is, uh, a movement called disability justice where, , a lot of folks actually operate outside of the state and think about providing long-term care for each other and contributing in a more of a barter system. , referring to that as collective care. So in that regards, people start to contribute in their community with one another. Oh, I can contribute by cooking that meal. I can contribute by sitting with that person in those hours when they're going to need care and there's not a paid person to do that. We don't have money to pay people to do that. So there's these ways to contribute that require sort of getting creative and operating in these other ways that we don't usually or typically think about. But it is absolutely a han experience to need to feel productive and that you're contributing to something. And I think often for disabled people especially as they get older and I know this is part of again generally speaking uh that older people can think oh you know I'm not I'm a retiree I'm not sort of contributing anymore and we tend to minimize their worth or their value as they get older. So there's lots of ways that this comes up and I would just say to your point about the systems those are I think there's the sort of internalized piece that I'm very much talking about that sort of microlevel individual feeling and struggle and how people try to cope with that. But I think what's just necessary to locate is that that internalization comes from a really uh long embedded entrenched history in this culture in this society of how we decide on care policy, how we decide who gets care. Like those like big patchwork systems came from somewhere. Those decisions came from somewhere from some kind of belief system that said, "Oh, we're going to set it up this way." So there's whole histories on how, you know, the fight for Medicaid, the fightfor Medicare, the fight for the ACA, the fight like all of these different things happened not in a vacu, but in a sort of cultural historical moment where we made decisions about who we think should receive care. And so that's and that's we can't necessarily do anything about that right now. I think what especially in my book I'm trying to do is show people that there's this larger thing happening but it affects us individually in these really deep intimate ways how we feel about ourselves and thus how wefeel whether or not we deserve love we deserve care and that means from our partners from our family members or getting mental health care any of those in any of those ways. So it is han, but it is also a very specific flavor of something happening that's connected to a larger history, a larger cultural piece. And we don't necessarily have to have a whole lesson on that, but we do. It is helpful to locate our feelings as part of something bigger than us. So that we don't have to blame ourselvesand our bodies for what they're doing. And when they're just being han, they're just our bodies are meant to decompensate over time. That's what they do. we're just we're fallible and it we have a really hard time accepting that. I think Erica, do we have examples or do you have examples of of where other people's perceptions of a somebody that that perhaps was disabled or was not as quick, not as fast, not as pretty as somebody else. you know were verbally told that theywere an inspiration or that in some way made themsel made those people feel bad even though they didn't mean to. Uh well it sounds to me like one of the areas you may be hitting on here Dan is that uh Laura's been speaking you have been speaking Laura about a lot of cultural narratives that it I think oftent times a hallmark of a cultural narrative is when we're embedded in the culture we kind of it becomes invisible and we adopt it we internalize it and I've noticed that oneof those uh cultural narratives too is this idea that we can overcome all challenges and also a narrow definition of what it means to overcome. And so I'm thinking of some folks I'm familiar with both through my uh professional work as well as in my personal lives where they may be living with a disability and and one of the things that they've shared with me is in essence I didn't sign up to be anyone's inspiration. So, they get these messages like, "Oh, you're so brave," or "You'resuch an inspiration." , and they don't necessarily find that helpful. Uh, and and I don't want to overgeneralize. Other uh people living with a disability may feel differently. Uh, but almost like this uh desire to see them overcome again in a way that's pretty narrowly defined. Uh, and I think about that as a type of ableism, too. Oh, you're so right. And I you also make a really good point and that's why I used specifically the plural disability communities earlier because it's not amonolith, right? I mean disability is just such a huge category. Can be mobility, it can be cognitive, it can be sensory. There's so many different impairments that sort of fall under that. So we can't generalize. You're right. , but I do think that that inspiration piece is absolutely a sort of form of ableism because it betrays the the pity and the low bar of oh, if you just go outside you're you're brave. You know, I've I've been with friends who've told me about peoplecoming up to them and they're a wheelchair user and somebody will say, "I would kill myself if I looked like you." Literally, people strangers on the street just saying that. , and so these kinds of things are invisible because we think it's appropriate that people think that it's appropriate to say that you're an inspiration or I would kill myself or think about I think it was this film Million-Dollar Baby. Uh Hillary Swank plays this boxer, right? And the endof the movie is uh oh, what's his name? Uh Clint Eastwood. Yeah, Clint Eastwood pulling the plug on her because she's I think quadriplegic after an injury or something. And the that's the happy ending is that he's put her out of her quote unquote misery. Which think about that that you're better off dead. Yeah. Uh that came up in my in my research and my book too. I had one of the one of the men that I interviewed as he was leaving rehab after I you know his sort of six week stay.The only resource they sent him home with was a suicide prevention pamphlet. So there was no like you're a disabled person now. There's other disabled people. There's life on the other side of this. There's so many ways to be disabled. there's so many things for you to know and people to connect with. Rather than that, it was, well, you might prefer to be dead. We don't, but we don't really want you to do that. Here's this, you know, suicide prevention pamphlet, which ishorrifying, right? But we think it's appropriate. , so there's so many ways that this comes up. I remember too, we often think about, and then I'll be quiet. my I remember uh when COVID sort of started and the Social Security administration was really overwhelmed with long-term co uh longcoid uh claims and needing you know respit from work because they had long COVID and there was just sort of this catastrophe sort of brewing with the budget for the SSA and what people needed in the wake of having hadCOVID And I remember there was an announcement that SSA was sort of getting more resources and was going to try to meet these needs. And I was having a conversation with a family member telling him about oh this news piece that you know the SSA is going to expand their their funding for this to meet this need. And his response was well I guess that's good but I don't want people to find out about that and then go and try to get that money. this sort of sense that there's like these marauding people out there tryingto fake it. And that's part of disability, too. That's part of ableism, too, is that assption that you can't be trusted, that it's untrustworthy in some way, that it's when you look at the Social Security Administration's sort of fraud rates, it's less than 1%. when you look at their actual data and when you talk to people as I did for my book about how to qualify as disabled under the SSA, it involves paperwork that is so uh mountains like file boxes, multiple fileboxes of getting every get getting your hands on every piece of docentation you can that has to do with your medical condition and your financials. And you don't have to do that once. You have to do it yearly. You have to get reertified constantly. And it is a lot of work. We talk about that, sociologists talk about that as administrative burden. , and there's a a disability law uh lawyer who talks about it as disability admin. Liz Emmens talks about this. , and it's part of our response to what we think ofas the disability con. , another lawyer, uh, Deron Dorfman, who's a disability lawyer, writes about the disability con, this belief that, , it can't be real. , and a lot of that has to do with, well, if other people's disability is real, then I might have to face my own fallibility. I might have to face my own limitations. It's I think there's something psychological going on there that we can't sort of accept disability as a normal routine absolutely expectable part of life. Itjust is. There are so many han experiences that we the collectively especially in this culture uh you know with this belief in personal responsibility that we believe if we do the right things we we won't end up in that position. , and I think it's something that allows so many of our biases, both the ones we're talking about today and and many others, to exist and continue to exist. I really like that point. Yeah. And you shared so many , you know, so much information about the thechallenges and the obstacles that people in the disability communities face. And as you were, I was thinking about, you know, how the challenges we put in place for people with all kinds of disabilities, you know, including those that are very visible, but how many people live with disabilities that are not visible? And you you use that phrase that I appreciate a disability con as if you know, folks are out there trying to to get one over. And I was thinking so many examples of clients I've worked with and people I know in mypersonal life who face exactly what you describe. you know for instance maybe are pursuing some benefits because of neurodeiversity and autism diagnosis let's say that makes communication or social interactions difficult and then are required to sit through hours long interviews as part of the application process. Yeah. That itself could be its own barrier. So that people who need Yeah. they can't actually do the thing that helps them get what they need. Access what they need. Exactly.Yeah. you had used the phrase before. I really appreciate it. There are so many ways to be disabled. And I know uh hopefully I quoted you correctly there. I certainly that's true in terms of type of disability, but I assed you were uh also tapping into ways that people may choose to live their lives with their disability and that there's such a a range of of valid uh and but we you know again I think as part of ableism we don't always see it that way and that we tend to see thatthat you know there are right things to do and and you know not right things to do. when we were you know kind of talking earlier about that idea of being an inspiration I guess as an extension of that I've talked to folks who have talked about like almost this uh I guess what some people have called toxic positivity like these narratives about you know we're never given more than we can bear and you will rise above this that there is you know if especially for acquired disability you've acquired thisdisability and you know you will go out and or the expectation that you will go out and and whatever it means to rise above. But again, I think that's pretty narrowly defined in our culture. I think there's that too is also like it is ableism and it's also this I think psychological impulse this to oh well if that happened to me I would want to be able to just do xyz and then everything would be restored right there would be restitution through my excellent you know whatever I do my diet my exerciseplan my whatever that we sometimes when we don't have language for ableism and we don't have a way to talk about it and we don't have a way to put language to our shame or our hesitance to get the care we need or anything like that. When we don't have that, we sort of respond in this sort of lizard brain like, "Oh, if this was me, then I would want to have this off-ramp, right? And so I'm just going to tell this person that they'll just they're going to rise above. They're going to dothis thing and it's going to be fine. But that's about our own discomfort. I really appreciate that. I agreed. Yeah. and that's that's really hard. And I'll give a a personal example even just I live with a couple of uh non-apparent disabilities. And whenever I'm sort of down for the count uh and I have to like be in bed for two days, I say to my partner things like, "Oh, I'm so sorry. I I'm just the worst. I I I'm putting all of this on you because I'mhere, you know, with child care or whatnot, and I'm not contributing how I would normally contribute, which is how I get my sense of selfworth, like we all do. , and you know, my partner just looks at me and says, "Do you read anything that you write?" You know, do do you read it? you know, and so I think some of the things we're talking about are really kind of intellectual in a way that can be just like with any other therapeutic process, right? It's easy to kind of intellectually understand thatthis dynamic is happening, but it's much harder to make that emotional shift and to actually internalize a counternarrative that you either had never had access to or just don't have practice, you know. uh operationalizing in yourself, right? Because we just don't have that kind of culture. Let me try and understand and and give you a specific or we'll generalize off of a of a minor example into something that's more serious. So, I I broke my ankle years ago. Uh just by way of of u reference, uh ifwe were walking down the street, I'll guarantee you right now neither of you would be faster than me. Okay? I kind of like walk like New York fast. It's just what I do. so consequently, my wife's always telling me to slow down. Kids are always telling me to slow down. Grandkids are getting dragged along. The whole bowl of wax. I broke my ankle. And uh when I broke my ankle, I I couldn't walk. Okay, it took me a while to get back to to where I needed to be. And so I I actually kind of got if ifyou will a little depressed about it. I even told my wife that I felt like I was being called from the herd. Now the reality is I you know did physical therapy. I worked at it. I worked at it. I'm back to walking faster than everybody else, etc. Okay. So I'm very happy about that. But there's people that that don't get better. they in fact end up living with that disability that that issue. So if I if you know someone who is able-bodied had a minor little scrape that caused me to not walk as fast as Inormally do, not walk first and then not walk fast like I normally do, felt like I was being called from the herd. What does somebody who has that on a more permanent basis or periodic basis throughout their life, what do they do? What do they where do they mentally it's it's it's a strain on them. So what do you do to get help? Do you are there are there groups? Do you go to ministers and and and rabbis and priests? What friends? What what what do you do in order to feel better to feel like you're part ofsociety again or to be happy with where you are? I have I have some thoughts on that question, but I want to ask you a follow-up question. Yes. I'm very curious about your use of the phrase cold from the herd. Yeah, that was that's that's actually what I uttered to my wife. By the way, I I'm so curious about this. I think that tells us something. What does that mean to you to say called from the herd? Well, first of all, I'm probably the only one on this call that was born inKansas. Okay. So I know a little bit just a little bit Texas not too far Texas. That's true. Okay. Fair enough. Fair enough. You know I know a little bit about about animals and whatnot. And you know, when you you imagine this group of animals, whether they're han or they're cows or they're bison or buffalo, whatever, that are zipping along, the ones that die are always the ones that straggle, that are different that that aren't attached to the to the group. It's kind of like a if you're afisherman, there's a a baitball. Why do fish create a baitball? So that they could appear giant. Okay. and and try and keep other fish away. And the ones sometimes the bigger fish will dive into the into the bait ball and get get other fish, but they certainly pick off the ones that are on the outside. So, literally, I felt called from the herd because I was no longer in the herd. I wasn't leading the herd and walking. I wasn't in the center of the herd. I was back here. My wife, to her great joy,was dragging me along. I this is so interesting to me because what you're describing of course in animal populations they don't have the kind of uh cognitive capacities that we hans do to sort of make different choices for different things. uh they're sort of moving along in their instincts, right? And and you're right sort of that's the stragglers sort of just die off. they don't have health insurance systems or like systems of of care necessarily that would take that into account. And Ithink what you're describing is less about I think that you experienced it as an individual as the outsider as the one left behind but there are social uh arrangements that created that feeling and what I mean by that is sort of and forgive me because I do sort of move in and study and am part of disab disability communities and particularly in disability justice worlds, there's a phrase that says we move at the pace of the slowest person so that we rearrange ourselves such that no one is left behind and noone has to feel called from the herd. In fact, we become we reshape the herd to surround that person. And so one of the things that I would say to sort of answer your sort of endpoint question which is what do people do when they just are disabled for the rest of their life? They just this is it. the people that I know just from my own social circles bond together with other disabled people across impairments so that there's solidarity across it could be a you know I know one person who uses a caneanother person who uses a motorized chair another person that uses a a manual chair another person that is deaf another person that's blind another they and they all sort of find a way to create community with each other and it is in the daily affirmations that you are cared for and loved in this space and we rearrange ourselves to meet all of the needs that no one needs to feel cold from the herd, right? Just to use your phrasing. But that is something that is much harder to do on this sortof largecale total rearrangement of our entire society that you know I live in New York City there's it's like go go go productive productive productive you know there's this real sense of you know we leave people behind all the time I got to catch the train I got to do this you know so I think the answer is and I think this goes back to some of that research that I was sort of calling out from the psychology professor uh professor Bogart at Oregon State is precisely why what she has found is thatwhen people create these connections with other disabled people that they share knowledge that they share political affinity that they share a sense of I am not bad it's just that the world isn't designed for us that that disability identity development actually has been shown to mitigate and lessen anxiety and depression in disabled people. It's actually a predictor for lower rates of anxiety and depression, which is amazing. Right. And as you're speaking about that, Laura, I I'm thinking about some of yourwhether past work or maybe past interviews I've seen with you where you've addressed uh deaf culture and deafness as a disability. And I I think maybe I was carrying into this interview almost like an uh either or versus mentality. The way I'm hearing you speak about it now, I'm wondering is that that that both may coexist for many people to be part of a as you said disability community, disability culture and but still acknowledging the disability as it exists. Absolutely. Absolutely. There's aswe've already sort of established, there's so many ways to be disabled, you know, and some people move in those disability communities and some people don't. In fact, research shows that most people that count as disabled by the census, the WHO, you know, whatever, the CDC, whatever uh sort of entity is making those definitions that most people who qualify or meet those conditions to be labeled as disabled don't actually identify as such and would never. You know, there's thissense of one of the people in my book refused, I was not I am not disabled. Even though, you know, long-term chronic very serious medical problems and mobility restrictions and all these things that were never going to go away. And in our conversations, he said, "Okay, with you, I'm sort of thinking about using the term chronically ill, but I'm still not sure about that." Right? That there's this struggle because, and what he said to me was, "Once I say it, then I become it.And that's ableism too is that disability is bad and we don't want to be associated with it. So if we talk about it then that makes us bad and that again is that internalized ableism that tells us it's a bad thing. So we don't want to associate with it. So, we try to do things to pass as able-bodied or do things that sort of help us feel like, well, I'm I'm contributing anyway or I'm I'm still productive even at the price of our own mental and physical health. We may keep pushing and pushingand pushing because everything about this concept of disability is bad. And so even though this is harmful, I'm exhausted, I'm depleted, I'm physically experiencing these symptoms from burnout or overwork or whatever because we've pushed beyond our limits because that's what often in work spaces gives us value. we experience those consequences as that's the price of doing business and that's how I can avoid ever becoming that that bad thing that associates withdisability and there are consequences to that mental health-wise. This is really resonating on a personal level. I am a person who lives with a chronic illness that classified as a disability and I have stared at forms before where I'm asked to check a box and to this point I have checked the no box and I am fortunate to live with minimal to no functional impairments at this up to this point in my life. but I am aware that uh you know the illness could change or progress at some pointand so I have uh had that internal dialogue with myself that you know if my functional status changed at some point in time uh would I ever be able to allow myself to check the the yes box if that was more appropriate or kind of like the person that you just referenced how would that impact me psychologically if I made that shift at some point in the future. Yeah, I mean that's such a great example. And I think there's that psychological sort of discomfort with it, but then there's also the question of what counts like am I disabled enough? Yeah. And that too can be ableism. I mean it can be a a form of internalized able I mean I talk about all this stuff and a few years ago I was profiled for the organization stat news. So they report on technology and medicine that's their kind of journalistic uh area. And the person who was profiling me says to me so are you disabled in the profile? And my answer was I don't know. even though I talk about these things because I still question my own. Am I disabled enough?Does that count? It's non-apparent. Uh I have flare-ups. h I don't know. And it is a question that I think is both it's it's it can be ableism, but I also feel like well maybe it's just that I don't want to like step on anybody's toes or claim something that I shouldn't or I mean it's all so murky and conflicting. And I think again it's probably a result of just not really having a language for this and just that broader culture of ableism that says these are kind ofshameful things. We shouldn't talk about these things. And so therefore we're kind of stuck individually trying to make sense of it. And I think that's probably why the disability identity piece and the disability community piece is coming out as so important in research. I wanted to ask, I know you've done a lot of work with families, , caregiving for a disabled family member and couples, , and if you could speak a little bit more to that experience, maybe the experiences of the the non uh,disabled partner, but also how ableism can play out in those intimate family relationships. Absolutely. Some of my earlier work was on mothers and mothering children with various disabilities in particular deafness but not limited to that but that was sort of the majority of my work. And what I found was that that sort of cultural system of ableism ended up internalized by mothers as if there's something wrong with my child. Number one, it's wrong and bad. And the that logic leads to I have to fix it. And that logic leads to okay and the best way to fix it would be through these medical interventions and then there's this whole therapeutic culture and expectation that involves a lot of care labor, right? So making appointments, coordinating care, sitting at the doctor's so much becomes you get sort of wrapped up in this whole world and it takes time and because we don't have you know we don't have universal health care you don't have universal child care a lot of this labor falls on mothers and so that I wrote mostly about mothers because when I was doing my ethnographic work in clinics that's who was there 95% of the time it was the mom I think I met one dad. , which is, you know, great for that person, but this was just a a pattern, right, that this care is gendered. One of the things that was driving this need was it wasn't that they didn't love their child, not at all. But they were motivated by this sort of cultural narrative, the script of you have a child, there is something wrong withthem, you must therefore fix them and you must engage in these things to do that fixing, right? And that often people would work with their children. sometimes to the you know degree that they might miss out on just being with right rather than working with right in terms of like therapeutic interventions. So th that kind of can play out in our relationships because how do we feel if we're being constantly worked with, you know, how how does that make one feel? How does that sort of I I haven't uh Iwould love to see those studies on looking back and having disabled adults talk about what that felt like to be moving through that kind of world. And a lot of deaf people have written about that uh memoirs and such about being sort of pathized in that way. But of course, it's not coming from a bad place, right? It's just there's this so I sort of blame this larger system or culture that's having people react to disability like that. And I've done some research with siblings whoactually reported the higher care so siblings of folks with dis developmental disabilities specifically was this data set and showed that the higher care responsibilities the more they saw their sibling as a a positive in their life which you might have guessed otherwise right. , so that was interesting to think about this kind of the capacities for relationships to flourish even in the context of one person needing what we might consider too much care, right? Oh, you need too much. It's it's notreciprocal, right? There's there's something unequal. At the same time, my research with spouses, it gets very tricky because when one person, well, we think about the spousal relationship nber one, which is uh something that we sort of hold up as giving us everything. That's the thing that makes us lovable. when you find the one, right? And the sort of ableism that courses through that is well when one person can't do certain things anymore there is a whole host of complex feelings on both sides of that dynamic that again I don't think are necessarily bad but are certainly manifestations of this larger culture that tells us that disabled people aren't worthy worthwhile and on that broader level abandons them. So there's not, for example, universal long-term home care. Who does that care in the spousal relationship? The non-disabled spouse. But we also know that over time about 30% of those spouses through those care demands from the burden of being abandoned not the burden of someone needing care but the burden of being abandoned to do it alone actually disables the non-disabled spouse over time. And I even saw that in myself. I I had PTSD after caring for my partner who passed away for I cared for her for about 5 years. So and there were profound mental health effects for me.

So, it's a shared load when the ableism is sort of in our culture and seeps into our most intimate relationships and teaches us that we might not be worthy and also teaches us,well, you're the spouse, you're supposed to do it all and you're abandoned by the state to do it all. There's devastating consequences physically, mentally, emotionally for everybody involved. You know, I I I appreciate your point and then and from a long-term perspective, I can I absolutely know u from family experience the impact the negative impact on the person that is providing care. Okay. Uh you know, my mother with my father who was sick for 10 years diagnosed you know you're going to diein six months lasted 10 years. That was that process was just it was brutal. That said, in the short term, you know, in in in in my spousal relationship, if one of us is doing well or doing well for some period of time, the other one picks up the slack. That's what we're supposed to do. That's what we do. Whether we're supposed to do it or not, that's what's just what we do. Okay? it whether that's an a societal expectation or not. I would do that for my wife. My wife would do that with forme and there'd be no question. I have people in my life that are neurode divergent, have autism, right? When you talk about providing, you know, getting understanding the diagnosis, getting diagnosis, understanding the diagnosis, and then then fixing it, the people, the parents, uh, that ended up getting that diagnosis for their child certainly had a very difficult time and had to to adjust to it. But then they did in fact flip into fix it mode. and if you and in with autism in some cases or in many cases having that ABA therapy actually help seems to to help significantly. So you want to do that, right? So it's not necessarily ableism in that in that regard is not really a negative per se, is it? It's just like part of the way we exist. I see what you're saying. I think again this goes back to all the different ways there are to be be disabled and that includes to what extent you utilize interventions whether that be medical technologies, mobility aids, whatever thing it is that helps you. and I yeah there's absolutely room to engage those things as you see fit and feel are needed. And people do that all the time. I have a friend who uh has CP and talks about his uh physical therapist and his prosthetics and how they're like the greatest things that you know make his life work. And I think about excuse me my own physical therapy. I mean PT is like my home away from home and I have long-term relationships with my physical therapist but there are ways that we can engage with such things without sort of betraying any sense of our worthiness as uh an individual with a particular condition.

Absolutely. one does not sort of preclose you know prelude the other. , so there's so many different ways that we can engage with these systems. It's part of just I think being aware of that we are making choices within a broader culture that is saying something to us and how can we make sure we're engaging in the most thoughtful way that is the most caring for both the people who are disabled and the people who are tasked with caring for them. So there's a lot of ways to do that. , and you know, I don't think anybody should listen to me on policy. I'm not like a policy person, but , we could there are ways that we could make things better and different for everybody that would require that sort of acknowledgement of disability and the need for care. And I don't think there's anything ableist about acknowledging disability and a need for a certain kind of care.I don't I don't think those things are opposed at all. Yeah, Dan brings up uh neurodeiversity and right so in my corner of the the health care world and mental health and it's certainly not limited to neurodiversity but is that is where the conversation takes place a lot about affirming care versus a more historical fix it care. , but I I appreciate you speaking to, you know, this is not an all or nothing proposition and the importance of autonomy and agency of the person of the family to say like what areas would you like to work on? , are there areas that you could use more solutions, support, accommodation, , and other areas that you may embrace, tolerate, accept, , and you know what are, as you said, there are many ways to be disabled. And it's so important for met like mental health professionals or providers to know this stuff, right? so that they can provide that kind of care and that kind of guidance and be attentive to these larger issues around ableism so that we can encourage that kind of thoughtfulness about it and disability doesn't have to be a bad word. So Laura, uh Erica, our time is going to come to a close and I don't want to to overstep uh the the time that you know I ask each of you for. Uh so uh Erica perhaps you could uh take a minute and s up what what you need to uh what you'd like to say and then afterwards Laura I'll ask you do the same. I'll do probably a 30 second version of that and then close. Erica, well I think I'm going to use my time here.

I know the these there's nothing simple about what we're talking about here. , and so I certainly don't want to ask Laura to oversimplify it, but I often find it helpful to end on an actionable step if the listener wants to take one. So if someone is listening to this today and thinks like, I have something to learn here, , what can people do to increase their awareness, to educate themselves? Laura? Yeah, I mean, I think sort of my takeaway message is that ableism is everywhere. We often don't realize it.It goes unnoticed. It's rather invisible. That it isn't just about dis disability discrimination. It's also about deeming some of our bodies and needs as worthy or not. and maybe the question is what is to explore what is your relationship to disability? think about your own uh perhaps conditions or impairments like earlier we reflected on our own you know we both talked about our own sort of things and maybe think about how that word disability makes you feel and why maybe investigate you know I'm going tobe sort of old I'm going to be like an old person right now and there's tons of Facebook groups and subreddits on particular conditions but also on disability community if you even just look at those and you start to see that people are out there talking about their condition, talking about disability in a positive way, in a supportive way, and that can help create that community. So it might just be a matter of oh having a little bit of an opening in yourself to think about what is my relationship to disability? How do I feel about it? And how might I explore that for myself in a way that sort of reduces that shame. Thank you. And Laura, do you want to tell us a little bit more about your book or summarize for us in uh in some other way? Well, I'm super excited. I can't wait for February 10th, , 2026, which sounds really far away. , but I'll just say this that the book is extraordinarily narrative. It tells stories above all. , and peppered in with those stories is sort of a little bit of context just in the exact moments when you need to know that, hey, this is happening to this person. And if you see yourself in this situation, it's likely because this is coming from something bigger and it's not just you. You're not alone. And so that's the big thing for me with my book is helping people feel less alone whether they're the caregiver or the disabled person. Well, and let me just say from my perspective, I've seen substantial need both from a caregiver or a spouse or a family member as well as from the person that needs help short-term, long-term as the case may be. And I've seen where medical professionals have offered up uh groups, offered up education, offered up uh therapy or recommendations for therapy. And those that have taken advantage of it, I think, have ended up a little bit better off, if you will. And so I would encourage everybody to be thinking about that. I would like to say that if I could, I want to appreciate both of you being here with us. Uh our title sponsor is Equilibria Psychological and Consultation Services. They have seven offices in Philadelphia. Uh their mission is to help individuals achieve their personal potential and long-term growth. Visit equilibriapcs.com. equilibriapcs.com. Look for them on Facebook, Instagram, and LinkedIn. Also, look for me on Instagram. I'm a little bit of a newbie, but nevertheless, Daniel JGomez 24 and LinkedIn. Now, for the disclaimer. I am not a medical professional professional nor am I providing medical advice.The opinion of our speakers are solely theirs alone. This podcast is copyrighted and cannot re be reproduced without the express written consent of EPCS Management LLC.