

**TAPE STARTS - [00:00:02]**

DR. ERIN ANDREWS: Disability is neutral, right? And so it's not inherently a problem, but it very much can be a problem depending on the context and the circumstances. But in the diversity model, people kind of tend to not only just acknowledge disability but start to own it and start to embrace it. But really, you started to see a different perspective, which was people were talking for the first time about Disability Pride and rejecting that disability shame that had been for so long.

DR. DEBBIE SORENSEN: That was Dr. Erin Andrews on Psychologists Off The Clock.

[Background Music]

DR. DIANA HILL: We are three clinical psychologists committed to cutting-edge, integrated, and evidence-based strategies for living well.

DR. YAEL SCHONBRUN: On this podcast, we bring you ideas from psychology that can help you flourish in your work, parenting, relationships, and health.

DR. DIANA HILL: I am Dr. Diana Hill, practicing in Seaside, Santa Barbara, California.

DR. DEBBIE SORENSEN: I'm Dr. Debbie Sorensen, practicing in Mile High, Denver, Colorado.

DR. YAEL SCHONBRUN: And from coast to coast, I'm Dr. Yael Schonbrun, a Boston-based clinical psychologist and assistant professor at Brown University.

DR. DEBBIE SORENSEN: We hope this podcast offers you ideas for how to live a full and meaningful life.

DR. DIANA HILL: Thank you for listening to Psychologists Off The Clock.

DR. DEBBIE SORENSEN: Hi, this is Debbie. Today, I'm bringing you an interview with Dr. Erin Andrews who is a psychologist, and she is here with us for this interview because she is also a very strong voice for disability, for disability rights, awareness of disability, and disability culture. And she's widely published in this area, and you'll hear she has some really just thought-provoking and like pretty cool ideas about this. What did you think about the episode?

DR. DIANA HILL: I was just blown away by it, Debbie. First, it was really nice to hear about your work at the VA, what you're doing, and I really want to thank you for bringing Dr. Andrews on. I think that she's an example of how when compassion gets into the drive system, it is pretty phenomenal what can be done with it. And I was moved by what she's doing in the field as well as just personally looking at my own life and areas where I can definitely have some room for improvement in terms of being an advocate for people with disability, in my children and in my personal life. So I just thank you for opening my eyes to some things that I haven't been paying as much attention to, that I value.

DR. DEBBIE SORENSEN: Well, I'm glad you think so. I think so too. I've learned a lot from her work and from working with people with disabilities. And so I hope that other people find this episode interesting and useful as well.

## 91 Disability with Dr. Erin Andrews

[Background Music]

DR. DEBBIE SORENSEN: Dr. Erin Andrews is a clinical associate professor at Dell Medical School and supervisory psychologist, and the co-director of Psychology Training at the Central Texas Veterans Health Care System. She is a board-certified rehab psychologist with her doctorate from Wright State University and Bachelor of Science from Michigan State University. Dr. Andrews has had numerous publications and professional lectures on disability topics related to her areas of research interest in disability culture, identity and inclusion. She is the past cochair of the APA Committee on Disability Issues in Psychology and chair of the Division 22 Disability Identity Committee from its inception until 2018. Dr. Andrews has completed innovative work to address the needs of parents with disabilities. She is the cofounder of the Disabled Parenting Project, DPP, a resource for support and information for parents and prospective parents with a wide range of disabilities. Her advocacy work in this area includes representing the American Psychological Association during a 2013 congressional briefing regarding parents with disabilities, and participating in a White House forum on the civil rights of parents with disabilities in May 2016. Dr. Andrews has received numerous awards for her work, most recently an APA Citizen Psychologist Presidential Citation in 2018. Congratulations, Erin. That's amazing.

DR. ERIN ANDREWS: Thank you.

DR. DEBBIE SORENSEN: And Erin, you have a book coming up, I understand, called *Disability as Diversity: Developing Cultural Competence*, and that's coming out later this year. Is that about right?

DR. ERIN ANDREWS: Yes, that should be right. It's in production with Oxford University Press, and I am hopeful, fingers crossed, that we'll have it out maybe October or November of 2019.

DR. DEBBIE SORENSEN: Well, it would be a wonderful contribution to the field. And you showed me your table of contents, and I think we're going to cover some of the topics today, but I'm sure the book goes much more into depth. So for those listeners who are interested in this, I'd really recommend -- we'll link it to your book when it comes out. I recommend taking a look at the book so that you can take a deeper dive into these topics.

DR. ERIN ANDREWS: Sounds great.

DR. DEBBIE SORENSEN: Yeah. So Erin, we're both VA psychologists and we met a few years back through VA circles. It's really nice to cross paths again.

DR. ERIN ANDREWS: Yeah.

DR. DEBBIE SORENSEN: To start, I want to just note, so you're clearly a psychologist who's really been published in rehab psychology and has been a really strong voice for disability rights within psychology and outside of psychology. Can you tell the listeners a little bit about why this issue is so important to you both professionally and personally?

DR. ERIN ANDREWS: Yeah, of course. I mean, when I went into clinical psychology as a career, when I studied graduate school, it was always with the intent of understanding people with disabilities and

## 91 Disability with Dr. Erin Andrews

getting out the community, and work with other disabled people. I am disabled myself. I was born with a congenital disability that means I'm a triple amputee. I have no legs at all. I have a congenital disarticulation, which means amputation from above my hip. And then, I have a left above elbow amputation. So my kids refer to me as, "My mommy has no legs and one arm," and that's pretty accurate. That's pretty much the situation. And so I've always wanted to study more about disability. I knew from my formative years that the experience of living as a person with a disability is a profound experience. It's something that really affect every aspect of you. And so when I decided to go on to graduate school, I kept that in mind. I chose my graduate program based on that. I chose my career specialization in rehab psychology based on that. And so it's both professional and personal to me.

DR. DEBBIE SORENSEN: That's a wonderful example of how the professional and the personal are tied together, because you've taken your personal experience and really used it I think to be a strong voice and to help other people navigate in this area. So for me, I'm not personally disabled, but I have several jobs. My main job is as a psychologist in the VA, in the spinal cord injuries, and I work with folks with spinal cord injury, MS and ALS. And so a vast majority of my clients in my VA job are people who have either physical or cognitive disabilities. So to me, it's very professionally important, and then personal, people that I know in my personal life as well. And just in general I think for our listeners, I'm imagining that pretty much probably everyone who's listening either has a disability themselves or know someone with a disability personally or professionally. I was reading in some of your literature, Erin, that disabled people are one of the largest minority groups in the US, an estimated 56.7 million people in the US live with some type of disability, and that 45% of the people in the US have a chronic health condition that involves some physical disability.

DR. ERIN ANDREWS: Right. And that's really the start to question minority. I'm hardly a minority and at one point we're not going to be a minority. I mean, it's so prevalent that what you just mentioned about nearly half of the population deals with some chronic medical condition.

DR. DEBBIE SORENSEN: And so it's definitely not a minority numbers-wise. Well, one thing I think is really interesting, and I know you've been really speaking up about this especially, is in our field of psychology, we care, I'd say as a whole, as a field, about diversity issues, and we make a point of it. But really, it seems to me that disability is overlooked a lot. And I'm just thinking about some of the professional groups and organizations I'm in, and the training I've had. We talk so much about race and gender, and sexual orientation, and all these types of diversity. And yet, to me, I feel like we don't talk about disability as often or as much as we should. What are your thoughts about that, Erin?

DR. ERIN ANDREWS: Well, as you might imagine, I have a lot of thoughts about that, and I agree with you. I mean, you're right. We don't care about disability in the same way that we sometimes care about other areas of diversity. And to be clear, this isn't a competition and in no way would I ever suggest we think less about race and think less about sexual orientation, or other diversity variables, because they are so, so crucial. And importantly, many people with disabilities also identify other areas of diversity as part of their selves, so people of color who are disabled, a disabled woman. So I think we've got to take this conversation in psychology around diversity. We've got to take it into the realm of intersexuality and really start thinking about the multiple ways in which people are impacted by different identities. But we have seen that psychology, and I've been very -- I think very frank about this over a long time, even in my work within APA, I was previously the chair of the Committee on Disability issues. And so what we see is that disability is not the table of so much of this time. So for example, I've written a couple of articles where I've done research looking at psychology training. And what we see other

identities, it's starting to improve some of their marginalized status, students of color, students identified as LGBT, their num -- in psychology in terms of representation are climbing. Now, they're so low, they still need a lot of work. But the problem is, is that when we look at disability representation, I have this graph in one of my journal articles and it's like a slump. Like we peaked in the 1980s and then just slumped off since then, which is terrible, the complete wrong direction. It's not what we're seeing in terms of all of these other marginalized groups. And so I think that really speaks to what we see in the broader field, is we're not able to mentor and recruit, and retain students with disabilities in psychology, then they're not going to become disabled psychologists. And so we aren't seeing the representation that we probably need to see. And so there's a lot of barriers for people with disabilities to break into the field. There's a lot of biases and then functions, and that's particularly frustrating when we're an organization or a field that really prides itself on awareness to biases and all of those things. So it remains a huge problem and that's actually part of why some of my recent article, I know that we're going to be talking about like to say the word article, was in response to some of the negligence that we've seen from the profession.

DR. DEBBIE SORENSEN: Right. And they think that's -- to me, that's part of what's sad about it, is that as a field, I feel like we should do better. We could do better representation within the field, and yeah, bringing these issues to the forefront.

DR. ERIN ANDREWS: Well, I think we have to do better because we just talked about these numbers and people with disabilities are a huge group of people. And I think if we don't do better, we're going to miss the boat. And psychology is in a place right now where we have to make our relevance clear and there's much of level mental health providers. There's other professions and folks that are willing to fill these gaps if we don't fill them ourselves.

DR. DEBBIE SORENSEN: Right. Right. Alright. So you mentioned the -- say the word article that just came out, and it's a wonderful article. We'll link to it on our show notes for this episode. I really encourage people to take a look at it. So this article is a disability culture commentary on the erasure of disability, and it's become a social media call to embrace disability identity. And in the article, you tell a really interesting story about how the original seeds for this article came about at an APA convention. So it's a group of -- it's a big conference for psychologists. Can you tell that story? Because I thought it was very interesting.

DR. ERIN ANDREWS: Yeah. Yeah. So over the years working, volunteering in terms of leadership and governance roles in APA, I'm pretty aware of the history of disability and the organization. And one of the biggest issues that comes up is just having this APA convention, which is it's just is a gigantic conference. It's really a convention more so than a conference. There's multiple hotels and there's a whole matrix of places to be and things to do. And as you can imagine for people, a psychologist with disabilities and students with disabilities, it can put a lot of challenges. Well, one thing that we've always had is the disability resource room. And I'd say always, meaning, during my 10 years into the past 20 years or so, we've had this disability resource room, and that's a place where it's in a main convention hall area where the vendors are and things like that. And there's screen readers for blind attendees. That's where you can go instead of an ASL translator if you're deaf. That's where you can go. I mean, an ASL interpreter. That's where you can go in to rest if you got a chronic health condition and you've been trying to book it from session to session. You can rest. But it's also been a social -- a place where we can meet in terms of just a very scarce number of people with disabilities in the profession of psychology. It has been our home base per se. And then, I've been at the community for a few years

and I've been -- I haven't been to APA every year the way I used to. And then I hear this e-mail through the Division 22 with there saying, "So they renamed it the multi-abled resource room." And I was like, "What? What does that mean, multi-abled? What is that?" Well, I've never heard that word, multi-abled. Like multiple abilities? Who has multiple abilities? And then why are they in the resource room? It was very confusing to me. Immediately, I reached out to other colleagues, I think Linda Mona, a friend of mine over at the Long Beach VA. It's like, "What is going on? Do you know anything about this?" And I said, "No," and I called Carrie Pilarski. She's the former DRP chair as well at the University of Michigan, and she's baffled. And anyway, so we came together and we asked APA, like, "What's up with this? Why did you change the name of the resource room?" And so the feedback we got was something along the lines of people aren't using the resource room because they're saying that they don't want to be identified as disabled. And we thought, wow. I mean, that's not -- wow. Wow. So here we have authorization where disabled people are underrepresented, and they're supposed to be this resource to help them to be able to fully participate, and shame is keeping people from accepting those resources. So it really struck a chord in me that in 2019, almost 30 years after the APA had passed, shame is what's getting in the way of people using the resources that are available to them. But I was frustrated with APA because I felt like to remove the word disabled and to replace it with this really, what I would consider to be a ridiculous euphemism, and there's a history of euphemism when it comes to disability. I just thought, we're being complicit and it's wrong. And I felt very, very strongly that APA was taking the wrong stance here and the wrong move in taking that feedback, and trying to just say, "Oh, well, we won't call it the disability resource room, and then people will feel okay about it." But historically, that's been something that's been done, and that's why the title of the article talks about the erasure, because disability to us is not just a word. In disability community and disability culture, it's not just a word. It's an identity. It's a part of our identity. And so when you try to take that out or erase that, it's very threatening. And so I think it was a very threatening situation and so we thought it was important. My colleagues and I thought it was really important to act. And so a part of what we did was -- in writing the article, was therapeutic, to just get out the frustration and the upset. And it turned out at the same time, Dawn Ehde, who's the editor for Rehab Pscyh, was like, "Write me an editorial." And so we took our initial response and we formulated to say the words, commentary. And it was just really the subjection to taking that word, disability, and trying to make it go away, trying to what we view as sugarcoating to make people feel more comfortable.

DR. DEBBIE SORENSEN: Yeah. I think language is important in terms of identity. And one thing that you can write about it is that this partly an identity thing. It's also almost it's a part of your experience. And by trying to erase it or get rid of it, it minimizes that. And I think you mentioned that there are a lot of different silly ways that people talk about disability. You mentioned a few in your article, handy-capable, these things that you sometimes hear. I think it's people who are, to some degree, maybe well-intentioned. They're trying to be politically correct or something like that. And yet, really there's something I think in terms of stigma, what's your response towards like that when you hear them?

DR. ERIN ANDREWS: Yeah. It's just an eeky response. I mean, words like that are silly and they're patronizing. They're words that are typically made up by nondisabled people, which is your first clue. Words that describe people, they should be owned and developed by the people who actually own that identity. So it's usually made up by nondisabled people oftentimes like you say -- or I would say all of the time, well-intentioned people, people who are trying to say, "Oh well, you still have time to --" people with disabilities don't have a lot to offer. I mean, those are just sentiments that the problem with those euphemisms is just sugarcoating, and it's not very accurate, and it doesn't allow people to own an identity. I mean, if you don't think that there's anything wrong with an identity as a disabled

person, you don't have any reason to try to sugarcoat that word. You don't have any reason to try to substitute a different word. But what we see, and one that's much more common than any of the ones that we even have just talked about, is the idea of like special education. Everybody uses that term. It's a field of special education. In the disability culture community, I mean, we don't feel like that. We're don't care for that, right? Because we don't think of it as special education. We think about it as education. We think that student with disabilities deserve equal education, equal opportunities just like other students. But it's something about calling it special, like to feel better two people outside, people who aren't disabled. And so we really want to challenge that and encourage people to use the word disability, because if I'm a child and I go to special education and I'm being called all of my life I'm special and differently-abled, I mean frankly, I don't know what the hell I am. But I sure don't think that I'm somebody that have a disability and I'm not understanding that there's other people out there with disabilities that I can join with in solidarity and that are going to support me, and I know nothing about this whole disability culture and community that hopefully eventually I'm going to find. But that's really what the problem is, is that we kind of try to sugarcoat realities with these silly words, and it doesn't help particularly young people or, I think, as we'll talk about later on, your newly disabled people to kind of have any chance of forming an identity.

DR. DEBBIE SORENSEN: Right. Right. Well, you mentioned defining some of these ways of talking, patronizing, and I know another thing you've written about that can feel that way understandably is called inspiration porn. Tell us about that, because to me, that's something that I think I see that sometimes in the popular media. And given my work with spinal cord injury, I'm like, "Oh no." What is that?

DR. ERIN ANDREWS: So inspiration porn is very -- people hear that and they're like, "What are you talking about, porn? With people with disabilities?" But inspiration porn, I mean think about -- so we got to break that down a little bit. Inspiration is this whole idea of there's the term inspiring or inspiration that we hear in the disability community all the time. People say that to you when you're disabled, "You're such an inspiration. I'm so inspired by you." And that can be for any reason. It can be because you did something -- you achieved something, virtually anything, and there's some problems with that, right? Because what that reveals is that when anything virtually that someone with a disability does is inspiring, it reveals the bias, right? The expectations for people with disabilities are very, very low. And so when a disabled person does something like get a degree or sometimes go out to the grocery store on a Saturday, when that inspires nondisabled people, it tells us more about what they think of people with disabilities in general. And so the disability community has really rejected that term and it just gets very annoyed, has been generally by that term. But the porn aspect comes in because when we think about porn, that's where we -- there's a gratification that comes from objectification of somebody else, of someone else. And so when we talk about inspiration porn, what we're looking at is there's nondisabled gratification and then objectification of someone or some ones with disabilities. And so you do see this in the popular culture all the time, especially on social media. So an example that you might see as an inspiration porn meme on social media, there's one I can think of that depicts a little girl with bilateral upper extremity amputation, writing with a pencil between her thumb. And then it says, the meme, there's usually some phrase or some caption that says, "The only disability in life is a bad attitude." And so it's inspiration porn because it's not about her. It's about nothing to do with this little girl with a disability. It's for the gratification of people, nondisabled people. And so when someone looks at that, I guess they're supposed to feel like amazed and inspired that this little girl can write even though she doesn't have any hands, and then just to make them feel like they can do anything. And so there's just countless examples of these but they're really problematic partly because they're ridiculous.

## 91 Disability with Dr. Erin Andrews

I mean, I don't know the little girl on the picture, and I don't know if her parents were aware of the picture that they used in that way, but I can guess they probably didn't. But from what I do know, the likelihood is that she was born like me with a congenital -- one deficiency. And so she's probably even writing now with her whole life, and for her writing with her two thumbs is no harder than you or I writing with our fingers. And so it takes her normality and just makes it into something really extreme, and it's not for her and it's not about her. It's for nondisabled people to feel better and to feel good, and that's what we call inspiration porn.

DR. DEBBIE SORENSEN: Well, I think it trickles down in another interesting way. So I work with people with mostly veterans who acquire the disability later in life, so spinal cord injuries after for example an accident or something like that. And where I see that trickling down is that sometimes they almost take it as a, "Well, if I think positive enough, if I work hard enough, I'll gain back whatever I've lost because of my injury, whatever mobility. So I'll be able to walk again," or something like that.

DR. ERIN ANDREWS: Yeah.

DR. DEBBIE SORENSEN: And I think what's so hard about that is that physically it might be that that's not the case. And yet, that gives them the message that they should be able to, through a hard work and a positive attitude, and I don't try to be the person out there squashing hopes and dreams. That's not my role, but I also feel like that's unfortunate that people are in that position, and they have a whole another source of shame related to, "Oh, well I should have been able to overcome this or something."

DR. ERIN ANDREWS: Yeah, and that's a great point, and that is exactly how that hit people with disabilities. It's pretty much universally it -- that sets this narrative that it's on the person with the disability to "overcome" their disability, which is ridiculous. And there's a really good quote by the late and great disability activist, Stella Young, who was an Australian, and she has this amazing TED Talk. If anyone ever just wants to Google Stella Young, TED Talk, you will not regret it. But one of her I think the best quotes ever was, "No amount of smiling has ever turned a flight of stairs into a ramp."

DR. DEBBIE SORENSEN: That's right.

DR. ERIN ANDREWS: I mean, that's the thing, right? Because so many of the barriers that we see are environmental and attitudinal, and those are not things that a positive attitude is going to fix. But the cultural owners is on the individual. You just need to cope better with your disability or you just need to smile, like as if those things are going to change a reality, a systemic reality that is much larger than any one disabled person.

DR. DEBBIE SORENSEN: Yeah. Earlier, you were talking about stigma, and I think for those veterans I've worked with who, again, usually got their disability later in life, they may not have the same connection to disability culture or the disability rights community that you have, because they didn't have access to that or any connection to it prior when they were able-bodied. And so what I see in my practice a lot, Erin, is that for people, it can be the stigma that they've been carrying around related to disability that turns into self-stigma, shame. I work with a lot of men in the VA, and often I think for them, it can be tied to issues related to masculinity, connected to their body. What thoughts do you have about that, and any, I don't know, advice for working with folks like that?

DR. ERIN ANDREWS: Yeah. That's a great point. And professionally, I work with a lot of folks as well. And in fact, it's much more common for somebody to acquire disability. That's a more common route, and they don't have access or connection to the disability community in the way that people who were living with disability for longer have. And so you can't expect -- I mean, you wouldn't expect them to have any awareness or knowledge, or socialization to disability culture. And the thing is, is that it also -- what do we do as psychologist, right? We work with the individual and the family. And I know the great work that you do and I think that that is such important work, right? Like you're not going to be in there discouraging somebody, saying, "Well, look, you're never going to walk again." No, that's not our role, but you are going to be there to support them and help them navigate as they discover their new realities. But again, I think our society wants to put the onus on that person with the disability to cope and figure it out, and rearrange their values, do all of the hard work. And yeah, that work's got to be done, but the problem with this whole thing is that if our society continues on the way that we are, it's really not going to get any better. So if people who acquired disability, they're living in this world that reinforces all of those horrible stigmatizing ideas about disability. They didn't come up with that on their own, right? So everything about American culture says masculinity and men that have to do with strength, right? There's no room in our culture for a different narrative that maybe says that masculinity can take on many forms and that strength isn't the only important thing about being a man or the only good quality that a man can have. And so I think it frustrates me oftentimes because I feel like these people are just put into a trap. It's like they're socialized to learn how awful disability is, and then they acquire disability. And it's like, "Okay, come on. Get over it," right? So I think that is really, really challenging work, and I hope that as disability culture and the disability community get more vocal -- I mean, even interviews like these are an important piece of getting the word out there that disability is not this tragedy or this horrible thing that everyone has been socialized to believe. Now, that doesn't mean that there aren't some really difficult things about having a disability. There are, and that's, in a lot of ways, what makes disability a little bit different than other identities. But I do hope that overall, things would change, but I just don't think that we can put all that onus on the individual to make those shifts when society just keeps on keeping on with attitude.

DR. DEBBIE SORENSEN: Yeah. So clearly, the culture shift is important. I'm always struck by the research about how people overestimate how just difficult and awful it would be. So there's even research about medical providers working in a rehab setting and how they think, "Oh, that must be so awful. You must be so depressed." And yet, from the perspective of the person going through it, they're often more resilient. They're not as depressed as people might think. And so I think there's a lot of assumptions going into it. And I think that's maybe a big thing to take a look at, is for people to check their assumptions to do what we can to change the attitudes in general, and then helping people like you said, a smile is not going to help if you need a ramp. Just helping people access things and to look at it at that level is huge. And then also the community, you mentioned earlier that people sometimes just need to be around other people that have had a similar experience, and I think connecting people to the disability culture to other folks that have maybe had a shared experience can be a really great source of support.

DR. ERIN ANDREWS: Yeah. I totally agree with all of those things, and I really cannot underemphasize enough what you said about the medical providers. I mean, in medical settings, the responsibility is that much greater, and we see that not just in rehab scenarios, but think about a parent. I mean, think about a parent who has a child who's born with a disability and all that. Those physicians and specialists and all those folks that are experts in the natal health area, but they're the ones making predictions to mom and dad about whether or not this child's going to have a good quality of life. And my concern is that

oftentimes those folks are spouting off things that maybe they learned in a textbook maybe 20 years ago. I mean, how many people with that disability grown to adulthood did they actually know? I mean, what is the accuracy of the information that they're giving to the parent? I think that you can make a pretty solid argument that it's not always based in reality and it tends to be very dire. And then you set up an entire expectation for a life, starting with the parent that this child is going to suffer, and then it's going to be difficult. And we really -- we know from psychology about what's the power of expectations? It's pretty powerful. So I think that those are the areas where my help in my career is that I'm going to be able to help make some inroads. And that's why every opportunity I get to talk to a group of physicians, do a [indecipherable] [00:37:45] at a medical school, anything like that, I will jump, because I think if I can change those attitudes even a little bit, that that has great potential to influence people's lives positively.

DR. DEBBIE SORENSEN: Well, that's great. I'm happy you're out there doing this work. I think a related thing and something I've found really has changed my thoughts as a rehab psychologist are the models of disability. I'd love to spend a little bit of time on this. I first encountered this in a book called, *What Psychotherapists Should Know About Disability*, and I know that this is something you've written about and you're going to cover in your upcoming book. It just really shifted how I think about disability. Erin, are you willing to run us through these different models of disability?

DR. ERIN ANDREWS: Yeah, totally. I want to tell you a little bit of an anecdote too about you just mentioned Rhoda Olkin's book from 1999, *What Psychotherapists Should Know About Disability*. And I think that remains an amazing classic, and I remember when that book came out, I was in college. I was an undergraduate at Michigan State, and that book, along with another book, called, *No Pity*, by Joseph Shapiro, those books really changed my life and changed the path of my life. For me to read those books in here, number one, about the history of our people, the history of different people in this country. And number two, about how much attitudes and social factors play a role in the experience of disability. I mean, not just completely changed my path and that it really inspired me to decide to pursue a career as a psychologist. And so what Olkin did really well in that book -- well, she did so many things so well in that book. But that caption that she writes about the models, disability models, it's really, really good, and I think it really opened people's eyes up to understanding that there are different ways of looking at disability. So she talks about the moral model and that's the oldest model, but it's still prevalent today in certain ways. So the moral model is the idea that disability is somehow associated with morality or virtue. So sometimes we see that with -- I'm sure you've seen this in your practice, Debbie, where somebody acquired the disability and they feel like they're to blame for it, maybe if I've lived a cleaner life or those things. So that's that moral model mentality. The medical model is really more looking at disability as a medical problem. So the disability is still seen as a problem that resides within the individual, but with the medical model, is okay, you're not really to blame for that per se. Let's just tackle the medical piece. Let's just try to fix you from a physical or medical, or sometimes even rehabilitation perspective.

DR. DEBBIE SORENSEN: And I think that fix you piece is key that, yeah, this is the medical problem to be fixed and that it's on you to adjust to this, right?

DR. ERIN ANDREWS: Yeah. So the medical is fix, fix, fix. The rehab is adjust, adjust, adjust. And again, where is the onus? The onus is on the disabled person, and it's all about them and their problems. It really is ignoring the problem in the environment, the broader environment. And then, starting it out, the 1960s and then at the height of the 1980s, the social model came out and all of those super

important models, a turning point for I would say disability studies in general, to where people started to push back and say, "Well, this medical problem or this whatever disability is just going on." It really wouldn't even be that much of a disability if, for example, the environment was different. And a great example of that is deaf people. I mean, deaf people really don't have any disability when they're among people who are fluent in ESL because it's linguistically -- there's nothing really that they can't do. It's just that in the broader society when people are not fluent in ESL, then you start to run into barriers. So that's I guess a classic example of the social model. And one area in psychology that was super important, and I talk about this a lot in the book, is there is a psychologist named Beatrice Wright, and she's considered the -- like I would call her the founding mother of rehabilitation psychology. And she was really the first one to take these concepts that extends from Kurt Lewin's field theory and say, "Yeah." I mean, this makes sense, and it applies really specifically to disability that the environment is really, really important, in particular, the social environment, the attitudes of other people. She was one of the first ones to really talk specifically about stigma in disability in particular. And so that was a huge turning point. But then in the '90s, they think -- people started to make the link that there's other groups of people that are marginalized whether they'd be ethnic or racial minorities, or LGBT-identified folks, or whatnot, that we're having a parallel struggle. And so that's been -- Olkin calls it the minority model. In my book, I call it the diversity model and it's pretty much the same thing. And basically, the idea of the diversity model is that disability is neutral, right? And so it's not inherently a problem but it very much can be a problem depending on the context and the circumstances. But in the diversity model, people tend to not only just acknowledge disability but start to own it, and start to embrace it. And so we thought a lot of inspirations from the civil rights movements in the 1960s. And the disability rights movement in the 1980s was in its heyday and it had culminated in the passing of ADA in 1990. But really, you started to see a different perspective which was people were talking for the first time about disability pride and rejecting that disability shame that had been for so long, really pushed upon people with disabilities.

DR. DEBBIE SORENSEN: So it's less about there being something wrong with the person that needs to be fixed and more about how our culture is accepting or not accepting, and working toward accessibility, and acceptance, and whatnot?

DR. ERIN ANDREWS: Yeah. That has a lot to do with it, and also it talks explicitly about pride and a disabled identity and informing a disabled identity. In the social model, it's like, "I'm not disabled, the environment is disabling me," right? But in the diversity model, the difference is, "I am disabled and I'm identifying as someone who's disabled, and I'm taking pride in that, and I'm going to reject a lot of the norms that society is putting on me." And it's not as simple as what we would see with to let just the environment and have ramps and things like that. It's more like, wow, my body doesn't look anything like bodies look like on TV. My body doesn't look anything like what I've been told my whole life is an ideal female body. And so as part of a disability model perspective, people are rejecting that. They're saying, "Okay, but I don't have to change my body to fit those norms."

DR. DEBBIE SORENSEN: I could liken it too for instance with feminism, a shift from the belief that, "Oh, well, women need to be more assertive and leaning, and get high powered jobs," and putting the burden of sexism on women changing to fit in more to the male world versus taking a look at it socially as it's not the problem with women, and we have an identity, and we can be who we are. But it's --

DR. ERIN ANDREWS: Yeah.

## 91 Disability with Dr. Erin Andrews

DR. DEBBIE SORENSEN: Yeah.

DR. ERIN ANDREWS: Totally, totally. Yeah. So feminism of thinking, "Yeah, great. Women can be in high powered positions and they can also be stay-at-home moms," and all of that can be feminist, right?

DR. DEBBIE SORENSEN: Right.

DR. ERIN ANDREWS: And so that's where we're at I think too in terms of the diversity model. I mean, great. There's Paralympians who are out there achieving wonderful things. Awesome. That's great, but most too with disabilities aren't going to go do some competitive sports and that's also okay too. It doesn't have to be what we would call the Paralympian mentality plan of like the super fit, and you see that a lot in rehab, right? Like there's this one poster. I don't know if you guys have it in your area, but I've seen it in so many different places. I like this guy with a spinal cord injury in his manual wheelchair, he is literally mountain climbing. I don't know if you've seen that.

DR. DEBBIE SORENSEN: Oh, I've seen some of those, yeah. Mountain climbing, yeah.

DR. ERIN ANDREWS: Like you too, nothing can stop you. But the diversity model is like, "Hey, you know what? That's okay. I don't have to go be a Paralympian. I have muscles that are weakening and gradually weakening, and I'm never going to climb a mountain, and I'm okay with that body.

DR. DEBBIE SORENSEN: And that's okay.

DR. ERIN ANDREWS: In fact, I love that body." Yeah.

DR. DEBBIE SORENSEN: Yeah.

DR. ERIN ANDREWS: Yeah.

DR. DEBBIE SORENSEN: So I know a lot of your advocacy work has been for parents who have a disability and that that's part of your personal experience, and also that's a group that tends to be overlooked. What are some of the concerns that you think need to be addressed there in terms of the advocacy?

DR. ERIN ANDREWS: Well, there's a lot that remains to be done. When we started the Disabled Parenting Project, we had a couple of objectives in mind. One and the foremost was to provide an opportunity for parents with disabilities to get support and guidance from other parents with disabilities. The people that we feel are really the most qualified to give that support and advice. It's great. We got wonderful medical experts out there that have an important role to play. But again, how many genetic counselors or medical doctors who are going to tell you all about the genetic testing for spinal muscular atrophy actually ever talk to an adult with SMA? And that's the thing. So we really wanted to provide an opportunity for parents to connect with other parents and to share tips, and support, and things like that. And so our online -- at present, I've done that. We have a website. We have a Facebook group. We have forums. So there's lots of opportunities for that. The other thing is that we want to continue to work to develop resources for professionals, and there's a lot of professionals that are involved in disabled parenting. Obviously, there's the medical professionals and we'd like them to do some of the things I've been alluding to like maybe link potential parents of

disabled children up with organizations that -- have adults with those disabilities where there can be some mentorship or things like that. But the other thing is that there's a huge legal component to this and people might think, "What does legal have to do with parenting?" Well, when you have a disability, it has everything to do with parenting, because the legal system, the child welfare system is disproportionately involved with families where parents, one or more of the parents, have a disability. And so we have all of these cases where we've heard about or been involved in cases where the child has been removed from the parent's custody [indecipherable] [00:51:17]. The problem with it is it's based on the fact that the parent has a disability. And so we're not saying, "Every parent with a disability is capable," just like we wouldn't say, "Every parent without a disability is capable." What we're saying is disability itself doesn't make you a capable or not capable parent, but there needs to be a fair and culturally competent assessment of those abilities, but that doesn't really happen. In reality, what happens is assumptions make decisions. So the assumption that the parent with a disability is a lesser parent is going to result in the nondisabled parent world for custody, or the assumptions that these two blind people who happen to have been taking care of themselves their entire adult lives lives are not going to be able to take care of this newborn baby, so social service is going to take it away. And people don't know that that's happening. People just have no awareness that it's happening and how incredibly scary it is for people with disabilities that if we need help, it's like don't even ask for help because it's so scary. People are scared that their children will be taken from them and their parenting abilities and skills will be questioned. And now, they won't have any recourse. And I wish I could say to these parents like, "Oh, don't worry about it. It won't happen to you," but I mean, that would be irresponsible, because it is. It happens to people and there are a lot in many states today that say -- I think we covered 20 something states still have laws in the book that say that disability itself is a reason that you can consider removing the child or deeming the parent to be unfit, disability alone, without any actual assessment. So that's what we're really focusing on, is trying to make people aware of this issue, and speak up, and get involved in legislation that's going to provide parents with more resources so that they don't have to be so afraid that their kids are going to get taken away.

DR. DEBBIE SORENSEN: I had no idea. That's really sad and scary.

DR. ERIN ANDREWS: Yeah.

DR. DEBBIE SORENSEN: I appreciate you spreading the word and the work that you're doing to help with that. And what about talking with children about disability? On this podcast, we often ask our guest for pointers on working with kids and for parents. And in my experience, I think that sometimes parents, able-bodied parents, get embarrassed or they're not quite sure how to talk to their children about disability in a non-stigmatizing way. So for instance, if a child sees someone who is using a wheelchair and they ask a question or something like that, the parent sometimes acts so like, I don't know, weird about it, I think out of their own embarrassment. How do you recommend that parents approach these topics related to disability with their children?

DR. ERIN ANDREWS: It's funny that you mention that because this is an ongoing I think issue that comes up, and it's actually something I've been thinking about or maybe writing something up about just a little bit more in-depth than what in usual conversation is, is the usual response, because I think it's a really important issue. And I think what you're nailing right off the bat is that by the parent getting really uncomfortable and trying to shush the child, it's setting up a problematic dynamic, right? This happens to me all the time because my disability is super visible. I mean, my body's asymmetrical. I'm really noticeable. I use a power wheelchair. I might as well have a target right on my head for children. And

so they see me and they've never seen anyone like me, and they're curious, and that's really natural. And so what we always tell parents, for those of us in the disability community, we tell parents like, "Hey, don't try to shush your child. Don't try to shame your child for talking to or for asking questions about disability. Let them talk." And I don't think that means you have to put all the onus on the disabled person to like handle the situation but you can model. Model some good social skills, like, "Hey, why don't you say hello or introduce yourself?" And what that's going to do is it's going to normalize the kid that people with disabilities are people and you can go up and say hi. And if we shush them and tell them, "It's rude to point. It's rude to stare," it'd get in their minds that disability is shameful and it's not to be talked about, and that people with disabilities ought to be avoided. So that's my typical response but I also see that there's more to unpack here. And like I said, that's one of my -- on my to-do, my very long to-do subject list of things that I'd like to write up. But I mean, I guess what I would do is like I would encourage parents too to think about the diversity model, right? Like so if you're a white woman and with a white child and you're out in the community, and your child is pointing and making a big deal over somebody who's black, they've never seen a black person before, well, that tells you something about your community, and it tells you something about your life and who you're friends with, and who you bring in to your home. And I think that that's also a fair conversation to have about the facility. So I understand that disabilities are different and you could go through your whole life and never run across somebody like me. But if you do have other people in your life that looks different or other people in your life that maybe use assistive device or something like that, your kid is going to be a lot less freaked out by somebody who is that different. So part of what I want to do is to just encourage parents to think about a little bit more exclusively about your life, and it's going to open up some really hard questions, because most nondisabled adults are going to think, if I ask you if your house is accessible, you're going to start running through it and you're going to realize it's probably not, because houses aren't accessible, and that's a universal thing. And that's where people with disability stays every day. I mean, like if I go to buy a house, like houses aren't made for people like me. And so I can't take my kid over to play day at some other parent's house unless there's all of these other instances that are -- or situations that are going to mitigate like my able-bodied self can come with me or they happen to have a disabled child, so they happen to have an accessible house. But those really aren't the odds. And so just being thoughtful and inclusive, like when you're planning your kid's birthday party, like are you thinking about the fact that the place where you hold it might or might not be accessible? If there's disabled kids in the school or in the class, like are they getting invited to these events? Because we still continue to hear about this exclusion and it's well-intentioned exclusion, like a friend of mine -- I couldn't believe this even though it probably was to some degree, well-intentioned, but like my friend who's in a wheelchair, her little daughter was not invited to a birthday party, because the birthday party was at their house. And the other mom was like so anxious that their house wasn't wheelchair-accessible, so my friend and her husband who were both in wheelchairs like -- but instead of just talking to them and saying like, "Hey, so and so is having birthday party and we're planning to have it at the house. And here, I'm realizing like our house is totally inaccessible." It's just like you're not going to get through this and come out on the other side better for it and not experience some amount of discomfort. So people need to be prepared to do some of that self-examination, willing to experience some of that discomfort, and learn, listen and learn, and I think we can all be better for it.

DR. DEBBIE SORENSEN: Yeah. I think it takes you say the word, hashtag. Hashtag, say the word to a whole another level, which is more than just a word. It's how we're thinking about it and how we are or aren't being inclusive. I think there's a great example in Rhoda Olkin's book about people might say to her like, "Oh, are you coming to this restaurant? Because if so, we'll find an accessible restaurant," when in fact, that would be like saying, "Oh, black people aren't allowed at this golf course. Would you

still go to the golf course?" Like if you truly care about inclusivity, "No." You would say that so as not to, whereas we may not be thinking about that with disability.

DR. ERIN ANDREWS: Right, and we're not. We're just not, and I think that that's where the ally piece comes in, like there was this article on social media that recently made around a couple who went to get married these two men, and they had their wedding outside at like a national park or something. And then the whole article was about how like they were so shocked and horrified that the park wasn't accessible and their -- one of their wedding guys like couldn't come. And I mean, I understand the point was like, yeah, I mean, in 2019, no park should not be accessible. I mean, sure, everything should be accessible. I mean, ADA, and I'm like 30 years old, but that's not reality and allies know that. Nondisabled allies get it. They know that that's not reality and that we still are going to face inaccessibility every day, and the nondisabled ally isn't going to ask whether or not you're coming first, right? He's going to just make sure that his venue is accessible, and he's going to take the ownership of that. Because for so long forever, the ownership's been on the individual person with disabilities and that's exhausting, right? So what we want to do is as good allies, is take some of that ownership ourselves so that it doesn't have to be on them. Like I don't have to say, "Hey, is this an okay restaurant for you?" I'm going to just go ahead and call and let you know, "Hey, I checked it out and I made sure they're accessible. We're good to go. You in?"

DR. DEBBIE SORENSEN: Right. And if it's not accessible, whether or not you're in, maybe find a different venue, right?

DR. ERIN ANDREWS: Right. Right.

DR. DEBBIE SORENSEN: Well, I have really just been so appreciative of all the advocacy work that you've done and how much -- I don't know. I feel like you've made a big difference using your career to do this work, and I really appreciate it. I'm wondering if we can wrap up by offering resources or places people can turn to if they want to learn more or if they want to do some advocacy work. What recommendations do you have? And we'll be sure to link to any resources you mention on the show notes for today so people can easily find them.

DR. ERIN ANDREWS: Yeah. I think that the very reason why people become psychologist is always more complicated than just wanting to do the work, right? So I mean and that's why I think it's just beautiful and absolutely wonderful about working with other psychologists, is like nobody goes through and gets a doctorate in psychology for the fun of it, because it's not really that fun for each of us for a lot of times, what we go through. And you do it because you're -- of course, you have the urge and the desire to help people and make the world a better place, and you're doing your therapy or your assessment, or whatever it is that you deem professionally. But what I found in my career is that that's not the total package for me. So being an advocate is allowing me to use my training and my skills, and my professional identity in a way that really fills me up. And so I would encourage people to consider getting involved in something that they're passionate about, and everybody's passionate about something. I mean, it might be a diversity issue like for me, it's disability. But for other people, it could be something entirely different, but I think that getting involved with your community in some way, giving back, is just so worth it. Even though yeah, it's a lot of time, it's time away from your family, and it's on top of your day job and all of that. You can also involve your family too. That's the wonderful thing about advocacy, is I've gotten to, like on both my trips to DC, like I brought my family with me, and what an opportunity like for my child to know that I went and participated in a White House briefing or a

## **91 Disability with Dr. Erin Andrews**

congressional briefing. That's for them to be able to know that I did those things. I think that's really important. But one initiative that I think is really good that people aren't familiar with is the Citizen Psychologist initiative and that was done by former APA President, Jessica Henderson Daniel. And there's a whole resource on the APA website about how to become a citizen psychologist, and this is just recognizing the things that psychologists are doing in their communities every day that go above and beyond. And so there's a lot of ideas there. You can read about other psychologists, what they've done in their communities, how they've been advocates, and what they've gotten from it. So I think that that's been a really wonderful initiative. And so if you're looking, "Well, what can I do?" I think that's a really great place to start.

DR. DEBBIE SORENSEN: Fabulous. Thank you. Yeah, we'll be sure to share that on the show notes. And I encourage people to take a look at your work and other work we'll link too, some of the APA rehab psych resources, and some of your articles, Erin, and hope that people will take this as a call to learn more and to do their part.

DR. ERIN ANDREWS: Right.

DR. DEBBIE SORENSEN: Well, thank you so much for joining us, Erin. It was really nice talking to you. I really appreciate it.

DR. ERIN ANDREWS: Thanks for inviting me to be here. It's such a great opportunity to share some of this work, and I am so grateful about you inviting me to be here and talk to you today.

DR. DEBBIE SORENSEN: Well, and our listeners, if you could please do your part too to share the episode with people who might be interested, we'd really appreciate it.

DR. DIANA HILL: Thank you for listening to Psychologists Off The Clock.

DR. YAEL SCHONBRUN: You can find us on iTunes, Facebook and Twitter.

DR. DEBBIE SORENSEN: This podcast is for informational and entertainment purposes only and is not meant to be a substitute for mental health treatment. If you're having a mental health emergency, please dial 911. If you're looking for mental health treatment, please visit the resources on our webpage.

DR. DIANA HILL: Our website is [www.offtheclockpsych.com](http://www.offtheclockpsych.com). That's [www.offtheclock, P-S-Y-C-H .com](http://www.offtheclock, P-S-Y-C-H .com).

**TAPE ENDS - [67:14]**