Interview between Speaker 1 (Meg) and Speaker 2 (Sarah)

[Introductory music]

Welcome to the Two Sides of the Spectrum Podcast. A place where we explore research, amplify autistic voices, and change the way we think about autism in life, and in occupational therapy practice. I'm Meg Proctor from learnplaythrive.com.

Meg: Hello, welcome to the podcast. Today, I'll be speaking with Sarah Selvaggi Hernandez who is both autistic, and an occupational therapist. We talk about everything from how we can respect the autonomy of kids on the spectrum to raise, foster care, and important changes we want to see from inside of occupational therapy. I learn so much every single time I talk to Sarah, and I'm sure you will too. So let's dive in.

Alright, I'm here with Sarah Selvaggi Hernandez from the Autistic OT, and I am so excited to have her here, because this podcast was actually born during a conversation between me and Sarah! So, in January we held a summit called *Neurodiversity in the New Year*, which a number of amazing speakers spoke on autism and OT. On the last day, Sarah and I talked through some of the highlights from the week, in the final debrief of the summit. So, I'm gonna play you a recording of this chat we had. We were revisiting a moment where Sarah talked about hand-over-hand assistance, or using an adult's hand to guide a child's hand, to help them do an activity. This is a fairly long clip and we hit on so many hot topics— so after the clip, Sarah and I are going to dig back through everything together with you.

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Meg: Okay— so a moment that I was watching the comments and I felt like, the biggest string of applause I've ever seen in a Facebook comment thread was when you talked about why we don't use hand-over-hand. I have been on this soapbox for so long, but it is so powerful the way you present it, and it is so compelling! I feel like there are a lot of people who are like, *'Yes, I've thought and known this for a long time,'* and there are others who are probably like, *'I felt this but I hadn't named it'—*

Sarah: Mm-hmm...

Meg: — and there are others who didn't know to think it, and now they're reconsidering hand-over-hand. So, you know, we were talking about all the different reasons not to use hand-over-hand; it can become a routine, it can be hard for the child to learn the skill independently, it can be hard to fade-out that prompt... But the real reason is, people have a right to control their bodies, and we don't have a right to move their bodies for them just to try and make them meet a goal. I feel like it was very moving for a lot of people. Can you talk about that?

Sarah: Well, you know, and I think that we actually communicated— the first time that I ever came across you was your article on hand-over-hand, and that was my *'Aha!'* moment. I never felt comfortable because it's just like— if a child pulls away, well, what do I do? Do I clamp down and pull back? And you know, it was so uncomfortable. When I read your article— and it was right at the beginning of my journey with the *Autistic OT*— I said, *'What? Wait a minute— we have a right to our own bodies!'* And that is so— so we've planted that seed, like you said, and I'm gonna take it a little deeper. Because as OT's, we talk about a lot of different things.

But something that one of my peers and best friends talked about quite a bit is sex, and we have to talk about the fact that when you're in a compliant— excuse me— compliance-based therapy, and you learn that you don't matter. What you want doesn't matter. If you're uncomfortable, it doesn't matter. People on the spectrum are eight times more likely than the general population to be sexually assaulted. And already, it's too much! But then you look at this population— I'm getting red, because it matters.

Meg: I'm feeling it too, yeah.

Sarah: And I don't— again, we come back to this place where we say— like, I don't want to upset anybody, I'm not saying you were intentionally doing this, but I am saying that there comes a point where I have to say, *'I hear that it's uncomfortable for me to say this, but I need to. Because as uncomfortable as it is for you to consider that in some small way you may have contributed to this passive sense of compliance, it's more uncomfortable for the individual who believes they have no autonomy. So we have to talk about it.'*

Meg: We do. I hadn't made that connection. That's so important to talk about in the culture and in the world that we live in. Thank you for making that tie.

Sarah: Yeah.

Meg: I get focused on kids. And you know, kids become adults. And kids get sexually assaulted too. But even as adults, in the absence of any sort of reported sexual assault, just not being able to feel like you have agency over your body as a developing sexual person, is not what we want for girls and women, or boys and men.

Sarah: Right. And you think about this, and let's expand it even a little bit further, because I'll take it— you know, we went into the adult population, but let's pull it back into Pediatrics. What are we doing in our Sex Education Programs? We have general— well, I'm gonna use technical lingo— we have the *"Gen-Ed,"* you know, *"Sex Prep Program,"* and then we have things that we do for the more intensive pull-out classes. But what are we doing for those autistic kids who aren't on 504's? You need to talk to me about sex differently.

Meg: Yeah.

Sarah: We really— and think about it— we really take so much from other people. You have to, we have to think about those things. So I think that's, you know— I don't know. I'm gonna pull back. I could ramble, but it's just so important to me that we have these conversations. And again, acknowledge that your personal discomfort is fleeting. It will pass. Because you will continue to challenge yourself and expand. I mean, listen to learn. That's all we can ask. But we have to do this for this population who desperately needs our support.

Meg: Well, Sarah— man, we're going there. So I'm gonna go there with you. One thing that I saw when I was in the schools, that I nearly lost my job over, was an armed police officer picking up and moving a young black boy...

Sarah: Hmmm…

Meg: ...who wouldn't change classes.

Sarah: Right? And so— oh, my God— alright, we're gonna go there.

Meg: We're goin' there. Yeah, let's talk about race too.

Sarah: Okay, so let's talk about the fact— oh, my goodness— that number one, the black community and people of color and women, are completely excluded from the diagnosis — like the diagnostic criteria and process. That autism was normed against little, white, boys. And what that has meant is that we are not able to get those resources and support for people of color. And then, now we say, *'Oh yes, there's so many autism centers'*. But I'm gonna tell you something— I have foster kids, and when we had that state-sponsored insurance, our wait is two years. And so when I have somebody who's— and poverty completely affects people of color more frequently. I'm sorry, I'm probably not saying that all the right way.

But you just have people who can't even get a diagnosis and they never get those supports. And what has happened to them? Well, I'll tell you what's happened, because I hear it in the way that people talk about my autistic foster kiddos. My autistic foster kiddos, who are little kids of color, get talked about like, behavior problems. Where my little white kids, get talked about like, *'Oh, the sensory— oh, this is so hard'*. It's a different way, and it's so stark, and it's so disturbing.

Meg: Yeah. And they get assaulted by police officers in school, and they get arrested in school.

Sarah: Yeah. Right, right. And so you talk about, then, the school-to-prison pipeline. And then you look at disabled kids. And you look at other kids who are unidentified, and— why show up to school? Oh, my goodness. They're dropping out in 7th grade and, you know— oh, mental health! You know where they end up? In the wrong places with the wrong people who are willing to take advantage of little kids who think they're broken and they're worth nothing. And somebody—

Meg: Could we do a podcast together? I just feel like we could talk.

Sarah: Yes. Oh, my gosh.

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Meg: Alright, so fast-forward to the spring and the podcast is here! Sarah is a super busy woman with tons of amazing projects, so sadly she isn't able to be a regular co-host on the project. But I am extremely excited to have her here with me today! Hi, Sarah!

Sarah: Hi, Meg! I am so excited to be here!

Meg: Yes! First off, can you introduce yourself and tell us a little bit about the work you do?

Sarah: Sure! So, like you've mentioned, my name is Sarah Selvaggi Hernandez, and I am a woman who does many things. One thing— currently, right now, let's see— I am a PhD student with *Nova Southeastern University,* with my thesis being focused on *Occupational Engagement and Late Identified Autistic Women*. There's one. Two, I am a professor and currently am teaching Pediatrics, which is my jam. Mental health is my jelly. Those are my two things that I super love in teaching pediatrics right now. And I just recently joined the advisory board of a nonprofit called *Neuroclastic*. So, those are professionally. Personally, still a mom, still like my kids. And you know, everything is going actually really well here in quarantine. So.

Meg: That's awesome! You are an extremely busy woman! So, let's talk through that moment in the Summit. First, walk it back with me for folks who didn't catch the original talk. Can you just back it up and share your perspective on some of the reasons why we shouldn't use hand-over-hand assistance in our work with autistic kids?

Sarah: Sure. I think, you know, when we originally had that conversation— and it feels like a long time ago that it happened— but the main point, and what really resonated with me when I read your writing on hand-over-hand, was that I was struck at how important it is to reinforce autonomy. Just having, you know, *'This is your body,' 'This is your personal space'*. And also, it was really important for me to reinforce the notion of task initiation. So that, *'Not only is it my body, but I can begin and I can start and do a task on my own'*. And hand-over-hand really damages those neurological pathways, because it takes away all of that power.

Meg: Absolutely! Yeah, I'll link to the blog posts in the show notes. It's interesting, because I think a lot of therapists use hand-over-hand to sort of compensate for gaps in their clinical skills. But like you said, it really is working against them, because we know initiation is one of the jobs of the frontal cortex, and executive function is really hard for a lot of our autistic kids. So if we're taking over that task of initiating and doing it for them, not only are we violating their right to autonomy, we're really working against our clinical goals.

Sarah: Absolutely. And I really appreciate that you— like again, just highlighting the neurology of it. And I want to bring it to an autistic perspective. And so, specifically, when we know that one of the features of autistic neurology is that we process sensory differently— and so, therefore the way that we take in sensory information and process it sometimes can feel like a very— not just dangerous stimuli, but a life-threatening one. And we know, as Occupational Therapists, that when you feel threatened, your amygdala comes on and so your base brain, that fight, flight, fright— and it's really hard to learn how to process and say, *'Okay. Whoa— my body thinks it's in danger,'* and then to take a breath, and a pause, and say, *'Wait a minute— I'm not in danger. It's okay'*. And then your brain literally will come online, and you go from that base brain.

And it's a process, but eventually you do learn how to access those frontal— the, you know, the prefrontal cortex and all of those really important parts of our brain where we make decisions. It's a practice. And when therapists literally sever that pathway, it's so difficult to really establish later on in life. So especially EI therapy, pre-school therapy, like those early— you know, really, I know that there's that, like— it comes from a place of love and, *'I want to jump in and help,'* but we've got to remember scaffolding, and we've got to remember that this is a cha— it's supposed to be a challenge. And you've got to let them work through it.

Meg: Yeah. I think one of the places it comes from, too, is this idea that our job is to make kids meet their goals. And I had a really amazing mentor early on who was not an OT. She was a Special Educator and the parent of an autistic adult, and she said, *'Meg, your problem is you think you can make any kid meet any goal just 'cause you wrote the goal. But that's not your job. Your job is to make sure that you have presented the environment and the activity in a way that they can understand, and to teach them skillfully, so that if they're ready to learn it, they'll be able to.'* And I think shifting from this compliance mindset of, *'I have to somehow make them do this,'* or, *'I'm failing,'* to, *'I have to figure out how to present this opportunity for learning in the best and most respectful way I can'*. It's actually a pretty big shift for a lot of therapists.

Sarah: It is, and I'm curious where that shift occurred. And I think for me, that I pinpoint, really, in the 60's when we made that move to a medical model. And everything that we do now is dictated by insurance reimbursability. And so I understand why it's very difficult as Occupational Therapists right now, to advocate for those more occupa— it feels difficult. Let be back it up, it feels difficult to advocate for occupation-based. It feels difficult to go back to what we know to do, which is look at our models, like PEO. You know, whatever model. I like PEO, but I know that there's so many out there. Whatever model resonates with you, go back to it and look, and like, do an analysis of your own practice. Are you meeting the tenets of occupational therapy within your own practice? Use what you learned in grad school to pull that apart and examine your own practice.

Because, I think you're right. I think we just lost the point of what we were doing, and it's not to make somebody— you're right— it's not to make somebody meet a goal. And that shifts the power away from the client.

Meg: It does. And power was so important in that conversation we had in the Summit. We talked about all the different lifelong impacts of taking power away from kids who are so often disempowered, and how that can impact their lives in ways that I know we as therapists don't actually want. And we wouldn't value making them meet their goals over maintaining a sense of autonomy, when that's actually in the forefront of our brain. But, I do see there's sort of a gap in an understanding of autism learning styles, and actually having the right tools to do something other than hand-over-hand.

So, can you talk a little bit about routines and autism, and how that relates?

Sarah: Oh, my gosh. You know, one of my favorite things about you, Meg, is that we are so same brained sometimes. And I would love to talk about routines, and I would love to talk about specifically rituals. And I'm going to tie this into— you know, I'm just gonna segue into talking about the current setting that we're in as Occupational Therapists, with giving so much more TeleHealth, and things like that. Because I see that there is a struggle between therapists, and that there's a struggle with parents and having their children engage in TeleHealth sessions. And I want to talk about why that may be, using the terms *'routine,'* and *'ritual'*.

Because, here's the deal— when we were talking at the Summit, we talked about rituals, and I really highlighted the difference between a routine and a ritual. Where a routine is something about getting a task done and there's no emotional component. But a ritual has some kind of emotional meaning behind it. It's not restricted by time. It's restricted— it's not even restricted, it's marked by experience. The feeling of something.

And when I was talking before, about how autistics experience sensory differently, and we talked a lot about, you know, the different senses. One thing that I'm so grateful— I mean, it's been, obviously, in the literature for quite some time— but, I'm grateful that we're talking about interoception. And interoception is this really huge umbrella that captures a lot of things. And one of the things that it captures, and I don't think we do a good enough job talking about, is emotion. And emotion is a fact. Like, we experience, like when we feel sad, we feel this way.

And so, autistics often— or people on the autism spectrum, whichever is your preference when you're listening— but I prefer autistics. We are trained to ignore what's happening inside of our body, because we're supposed to produce. We're supposed to do a test. We're supposed to— and so therefore, we always look externally for our feedback because we've learned that we can't trust, and we can't— or that our inside experience isn't going to be respected. So, if you have a task that you want me to do, it doesn't matter how I feel inside. I need to push out that sensory experience and just focus externally. That is really damaging, because—

Meg: That is really damaging, and it seems like it ties back, too, to that stress state you were talking about, and how we really don't learn when we're stressed.

Sarah: Right. Right. We don't learn when we're stressed, and so now we have people going into the context of the home. And you're entering into a space that is just filled with rituals. It's filled with experience-based connection, learning, sanctuary. And we have therapists who are going in with goals and being so hyper-rigid, which to me, is hysterical. We're supposed to be the rigid ones! You have these therapists, and they're being rigid with the goals, and what's happening is that you're introducing a whole new— like you're pushing the school context into the home context. And the home context is such a place of regulation, safety, and sanctuary, that— my God. Like we're asking them for an hour a week. But to a child, they don't know when they're ever gonna get that feeling back, of sanctuary. And so maybe, like, let's just be curious and say, *'Well, maybe the reason that we have so many children who might be struggling, is because this is really scary.*

And this— the one place that they had to feel safe was their home, and now we're pushing school into the home.' And that's why I said earlier, like, we need to be doing home assessments. We need to be observing. Maybe just take a couple of— like set the iPad in the corner, and just play observe for an hour.

Meg: Yeah, so we're recording this during April of 2020, during Social Distancing, when a lot of therapists are doing TeleTherapy for the first time, and a lot of school-based therapists are coming into the home, a lot of clinic based therapists are coming to the house, and a lot of home-based therapists are doing something different. So, that's the current context. So tell me a little more about what you would like to see therapists doing during this opportunity.

Sarah: Right, so what I would like to see specifically is again, a home assessment. A really— like, an observation schedule. Maybe two or three sessions where you're just simply observing like what is happening with the home. An honest interview with the parents to find out what their home flow is like. And, this is what I'm gonna challenge you, because this is what I know to be true for my family. Let go of the idea that school has to happen at a certain time.

Because, when we pulled my son out of public school— I mean, it was— there were many reasons, and it's so funny because we actually pulled him after the best teacher in the world! So, it had nothing to do with the teacher, it had nothing to do— it just, you know, it was too difficult to meet his needs, and we had the opportunity to do that at home. And so when he came home, we set up this schedule, we were like, *'Oooh, we're gonna homeschool'*. And it was— you know, at 9 o'clock, at 10 o'clock, and that does not work for my son. And what I find that works for my son, and a lot of autistics, is learning later (in the day). Because what happens, is that you spend the morning, and a lot of times, the morning is getting the sensory information you need to just wake up. And if you think about that, school is like a giant punch in the face of sensory information, and so it wakes you up pretty quickly. Well, home is not like that.

So first of all, your kids probably aren't ready to do anything at 9 o'clock in the morning. Second, what about if you went to a more consultative model? Like, what if you went more towards just saying, *'Hey, these are the things that we need to do. This is how you can do them,'* and giving permission for either the parent to do it at night, or— I don't even know if this is possible because I'm not a union, like I don't know the union of this— why can't you have a session at night? You know, like really, just kind of breaking everything apart and saying, *'How can I meet the need?'* Because now we're talking about the needs of a family. We're not talking about the needs of just a student. How can we meet the needs of this family? And that's not gonna look like an 8 to 2 school day.

Meg: You said earlier about how us neurotypical therapists and people in general can be so rigid, and it's so easy to overlook that. We talk about, or have historically talked about, autistic kids as being very rigid. But I know there's a lot of people out there right now saying, *'Your kids need routines. Your kids need structure.'*

Sarah: Mm-hmm.

Meg: And what that means, is your home day needs to look like your school day. You need to have a schedule, and not such from— I'm taking from what you're saying that that's such a shallow interpretation of it, because it doesn't take the child's actual needs for self-regulation, and what their own best timeline might look like into consideration.

Sarah: Right. It's a very shallow of interpretation the child's home, and it's very presumptuous, like my gosh! Like, who thinks that they can come— you know the— like, that's... And it's not— I say that and I laugh, because it's so not intentional. That's why I say it with a laugh, because I know that every single therapist out there is going in, and they're like— they've got, you know, their little home set up, and they've got everything ready to go, and they're so excited because they really want to provide services!

And I just want— and so I'm gonna put this out there— I just want to be curious about this. I think that this goes back to when we talk about the medical model. We talked about goals and we talked about this idea, this systemic ableism, where you are broken and so therefore, *'I know better than you'*. And so, *'I'm gonna tell you what to do'*. And that's very true about autism and people on the autism spectrum. I still struggle, even among OT's, who argue with me all the time that I can't call myself autistic! And, yeah, all the time! And I'm like, *‘Stop it! Yes I can. Yes I can.'*

Meg: Yes, you can!

Sarah: I can. And I do. And so, that's the level that we're working at; of people thinking that they know better than me about myself, and so that is being pushed in. And it's nothing that anybody is doing intentionally. It is literally a part of our system, because we see disabled people as being broken.

Meg: I like the language you use about *‘being curious,'* because I do feel like that should be a big part of our job. I cannot have a first-person experience of what it's like to be autistic in this world that we live in. And so, I feel like my role is to maintain openness and curiosity to learn more about how to support autistic kids. Both by listening to autistic people and keeping up with research. And I wonder if that's really the foundation that we need— is respect and curiosity, as our sort of an entry point into learning about people who think differently.

Sarah: I totally agree! And the really interesting thing for me is that it is there already, and it's called *cultural competency*. And where it's breaking and where we really struggle, is to acknowledge and respect disabled people, and as a culture.

Meg: Yeah!

Sarah: Yeah, and I am like— I struggle, I personally struggle to find the words to convey that, because people will take— when I say like, *'Wow, you're not even considering our rights to culture,'* and it becomes (that) I'm calling— or it's perceived as being like, *I'm against you*, or, *You're against me*. And it's— that's not my intention personally. My intention personally is just to be like, *'Huh?'* Like, wow, that's— you know, like, let's talk about this, because this is how I'm perceiving what your words are, and this is how it excludes me as a marginalized community.

And what happens is that nobody wants to admit that they're doing that. And I don't think that anybody's doing it intentionally. But the systems are set up to remove my own personal agency and power as a disabled person.

[Intermission begins]

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[Intermission ends]

Meg: Sarah, this often happens when I talk to you. I'm having very big feelings. And I imagine some of our listeners are having very big feelings too, and some of them are probably guilt or fear that they're, you know, playing a role that they didn't know they were playing, didn't want to play, don't want to play; maybe starting to ask themselves questions like, *'I find myself doing (this) all the time— what do I do from here?'* or, *'What can I do differently?'* What advice do you have to those therapists who are like, *'Oh, I didn't know better. What do I do now?'*

Sarah: So, that is such a cool question, and the answer that came to me immediately, and I'm just gonna go with it, is that maybe you should be, like— embrace being autistic. And what I mean by that is that, I talk a lot about disability identity. And disability identity is about, you know, *'Who I am,'* and part of literature— like, actually, what the literature says is that, *'It's who I am based on the reflection of my actions and others.'* And so, I do something and I see the reaction from somebody else, and I make that decision: Do I like it, do I not, what do I want, do I want to change anything? And the really cool thing about being autistic is that at a very baseline level, we don't care. Like we're guided by those emotional principles, like we are a very ethical people, because when something doesn't resonate with our soul, it will tear us apart.

I mean it, and we can't ignore it, because we're so sensitive to sensory information. And so, I think that probably the first step is to say, *'Is this what I think, or is this what I've been told to think.'* That's where you start getting curious. Because what I want to reinforce is that, if there's something that's making you uncomfortable, or if it's guilt, or shame— all of those things are just words that we apply to dysregulation. It just is. Like there's something that's making you go, *'Huh!'* And if you can just examine those, that feeling, without a judgement, and say, *'Why am I feeling this?'* and really kind of pull in. But I'm saying this out loud and I recognize, also, how hard that is to do in our current climate of productivity, our current climate of isolation. Meaning, not— I'm not talking about quarantine— I'm talking about how the field itself, it's so difficult to connect with each other. We need to have— I don't know where it would be, but we just need to have spaces to have these kind of conversations.

And honestly, Meg, now that I'm saying this out loud, I think podcasts are the place to do it, because it cannot be academic. Coming from somebody who's in academia, you don't want academics controlling that conversation, because— and they say this— oh, my God, I love you all, but we are the most intellectually defensive people on the face of this planet. And that is ableist. That is. Because even that in itself, there's barriers for people to access the information that we have. Called data, you have to have a database subscription. Oh, my God, it goes on and on.

So this is where I really— amplifying autistic voices, having these kind of podcasts, getting... Being curious and letting go. Like if the very first thing that you say is, like— because I've actually heard this, too— like, *'Oh, it's just those Facebook groups.'* Well, yes. Autistic people are gathering in Facebook groups. Because that's where we have access, because we've been excluded and marginalized from spaces for a really long time, and so we're claiming our own. So if that first feeling is, *'Oh, I don't want to take information from a Facebook group,'* hmm, where is that bias coming from?

Meg: I connect really personally to some of the things that you're saying. When I was in graduate school, I actually said that I did not want to work with autistic kids. And that was because all I had seen was behavioral interventions, and I think what I said at the time was it wasn't a good fit for my personality?

Sarah: Mm-hmm.

Meg: But what I meant was, on a deep level, I feel really uncomfortable doing this. And I thought that meant I just wasn't good at it. But if I dug a little deeper, it was that it didn't feel right, and I was so excited later on to learn different approaches that felt right. But it wasn't until pretty recently, learning from people like you, that I could really start to name the place that I want my work with autistic people to come from, versus why I was feeling uncomfortable with some of the things that I knew I didn't want to do. And so I hear what you're saying, that when we feel that twinge, we don't need to say, *'Oh, that's not important.'*

I'm just still learning how to do these interventions. We need to be curious and wonder about why, and then take it further, like you're saying, and make an effort to to listen to autistic voices.

Sarah: Yeah, yeah.

Meg: The other thing I thought about, is how autistic people are asked all the time to understand neurotypical people. And this podcast, the name of this podcast, was actually born between the two of us, talking about approaching a topic from two sides of the spectrum. And that autistic people are asked, and given homework, and therapy, to do perspective taking— to understand neurotypical people, and to learn the social skills expected by neurotypical people in different contexts. And us non-autistics are almost never asked to do that, (or) are challenged to do that. How can we take the perspective of autistic people and learn the social skills to create spaces in which they can flourish too?

Sarah: Yeah. Oh, absolutely. So one of my favorite things that I like to compare it to— but it's true— I feel like I'm the child who's saying, *'The emperor has no clothes,'* and the crowd is telling me to get social skills. And so, I'm like, *'Okay... But the emperor still does not have clothes on. And I'm actually an OT, so I can help with that.'* I'm like, come on. I'll take the social skills, but let me help this person get some clothes on.

Meg: Can you, for folks who don't know *The Emperor has New Clothes*, can you explain that a little bit?

Sarah: Sure, absolutely. So the story is about an Emperor who, like, has all this power and authority, and, you know, he wants the best and most beautiful suit. And nothing is good enough until finally, the tailor who is making this, is like, *'Fine. I'm gonna give you exactly what you want,'* which is the ego boost. Of course, this is not— he doesn't say this out loud, but what he does is he, quote-unquote, creates this amazing, beautiful, regal, powerful, important outfit. And only the people who are true to this Emperor can see the outfit. And so the Emperor says, *'My gosh, like, this is perfect, because now I'm gonna know who is actually loyal to me and then I can, you know, get rid of the others.'* But what is also true is that he's wearing nothing. He is out there completely vulnerable, and not realizing it, I guess.

So this Emperor decides— because all the people around him, of course, they are so bound by their societal obligations to the Emperor, that they all fawn over him, and say, *'My goodness, you are so magnificent and wonderful.'* And so, the Emperor gets this false sense of superiority, and decides he's gonna take it even further and go out into the streets. And so this Emperor walks out into the street in his... Glory, I guess, or what he perceives to be his glory, but it's a very different reality. He's naked— his actual glory. And all the crowds around him are praising him, because that is what they have been groomed and trained to do. This is their Emperor, and he is wearing the most beautiful outfit, so they're just going to say that.

But then, in the crowd, there is a beautiful child, and the child— one of my favorite things about children, period, is that they're honest. And then you take that with autistics— like, autistics are super honest. So this beautiful child is like, *'Everybody. The Emperor is not wearing clothes.'* And they are, you know, they get changed, they get shushed, they get, you know, all of these things. But that is the truth. And really, the most loyal person in all of the crowd, and all the people around this Emperor— the real true loyalty was found in authenticity. And saying, *'You're not wearing any clothes,'* and that's the true gift. And that is where I feel, like with autistics, if that we're told over and over again to say things in, you know, this format with these words, and they have to be nice. And there's so many expectations placed on how we say something that people forget to care about what we're saying.

Meg: I haven't thought about that story in a long time. It's a great allegory for what you're talking about. And I've heard you speak before about how autistic people can be such great champions for social justice because of that ability to see things with honesty and clarity, and to not be so inhibited by what they're expected to say, versus what needs to be said. That's sort of a nice segue. One of the things that we talked about in the clip at the beginning of this episode— we hit on sexuality, and we hit on race, and both of those are worthy of their own episodes, and I'm sure we'll get to that. But I did want to talk about your experience fostering autistic kids of color.

Sarah: Yeah, absolutely. And I appreciate this because I'm trying to amplify this particular message, and especially to occupational therapists, because I'm seeing that there is an emerging need. We have, as a profession, always talked about our role in supporting, not just autistic foster children, but foster, you know, in the foster system. And we're really figuring out how we can best serve. But there's something happening right now, and I have so much concern because I can see it just peripherally in my state, which is Connecticut.

I am a foster mom. I'm not able to foster right now because I have, actually, just recently was diagnosed with three different autoimmune disorders. So I'm like immunocompromised all over, and my foster kids— my two foster girls, we're getting ready to transition to their next step, and so they actually just moved them a little bit earlier because of, you know, the quarantine. But I'm not able to take any foster children, which is super weird— that you've been a foster mom for like, I think it's 16 years now, I don't even know anymore. And I've never not had foster kids. So this is really— this feels weird for me. But what I'm seeing is that especially, like, the system— because of the quarantine, and because of the dysregulation that's occurring in homes— number one, you have biological families who are really struggling to maintain safe spaces during this time of dysregulation. Then you also have foster families who are really struggling, because if the quarantine is going on right, now not only are all the routines, all the rituals, everything that a foster family has built to support their child are gone, but that child is also likely completely disconnected from, you know, the one thing that often remains the same— which is school.

Because I don't— like, if you don't know a lot about the foster system, we call their school of origin their Nexus. And so a lot of times, no matter where the foster child will move to, you try to keep them at their same school, because that's that's their anchor. That's the one thing that remains true. So foster children are— everybody is just dysregulated. That is everybody's baseline. I'd say dysregulated, but our baseline now is just a big ball of anxiety. And so you have people being— we call it disrupted from their foster homes, meaning that they're being— the foster parents are, for whatever reason, are saying, *'I cannot manage. Like, this is— it's too much.'*

So we have kids who are disrupting from their foster homes, and there's no place for them to go! And there's an overwhelmingly— again, in my 16 years of being a foster parent, I have had precisely one white child. Everybody else has been people of color, and almost all of them have been autistics of color. And so there's a disproportionate representation of autistics of color in the system, and now it's just exploding. And I see— I'm just so concerned, because the other truth is that my autistics of color are treated like behavioral problems from the get-go. I have never seen ABA— like, you know me and my personal feelings on ABA— I have had court-mandated ABA in my home. Biological parents have court-mandated ABA, and they have to do it or they lose their kids.

Meg: Wow.

Sarah: And you— and again, you know me and my personal opinions— I can't even hold it off. And so—

Meg: For those who don't know you and your personal opinions, do you want to summarize them?

Sarah: So, I feel that ABA is not appropriate for autistic people. And to the point that it provides a foundation for outright abuse of autistic people. And so, I say that with love— like, I can't even say it with love— I love the people, I love ABA therapists, I don't like ABA. And I will also say that I am a fan of many behavioral strategies. ABA is not all behavioral strategies. But my specific problem of ABA is not— it's that it's— it can become abusive, and I can't find a way to have a conversation about that with ABA.

So until I can have a space where there's honest conversation, and there's honest dialogue back and forth, I cannot and will not ever recommend ABA for autistic people. So that's my feeling there. But you take ABA, which is very— it's about suppressing, again, that inside— like what's happening inside of your system, because you have that stimulus and you're looking for a response. And however you get there, there's just so much focus on getting from A to C, that B doesn't matter. There's so much depression. And so when you take that kind of a mindset and you apply it to trauma— oh, my God. That is not appropriate.

But the first thing— like, literally, my friends who were with me the last time, they had just been removed. I was their eighth placement in six days. That's not even a placement a day!

Meg: Oh, my gosh.

Sarah: And so because of all that turnover, they hadn't even been— there's like an intake process where they meet with the doctor. The doctor, the pediatrician, came into the room. Hadn't even— I don't even know if she had laid eyes on the girl— and the first question was, *'Are they on ABA?'* Because if they weren't, she was ready to write the script for 40 hours. And I'm like, *'Whoa. Whoa.'* And so I introduced myself, and I say, *'Hey, I'm an occupational therapist,'* and, you know, not even listened to. It was, *'Here's a script, 40 hours, ABA.'*

And ABA— so, trauma and ABA is not appropriate. Because behavior is communication. And when autistic people especially are processing a trauma, it's going to come out as behaviors. And I don't mean to say that in a way of saying, like, you know, you should— like safety is important, you should protect yourself if they're you're aggressed on. That's not what I'm saying. What I'm saying is that, you have to, at some basic level, respect that behavioral communication. And to me, and what I see in practice in the field, is that ABA does not respect that behavior as communication. The focus is in extinguishing that behaviors in order to do engagement.

And as somebody who's worked like that two decades, in mental health, and pediatrics— that is a disaster for trauma. I've seen it at pediatric level, I have worked on inpatient psychiatric for adolescent males, and I can tell you the damage it causes. I see it. When the suppression— and it's painful to see. And I'm so nervous, personally, because the foster system is about to be— is already overloaded with autistics of color, and it's about to be even more overloaded. And I don't want— I want to make sure that we're giving them appropriate supports.

Meg: Yeah, when you said the first question was, *'Are they in ABA,'* it sounds like the first question should have been, *'What are we doing to address their trauma, and to help them feel safe and secure with this new transition?'* Yeah.

One other layer to being autistic and a person of color— I sort of touched on this in the clip from the summit— is the presence of police in your life, and trauma by police; and kids, even young kids in schools, usually young, black kids— often young, black autistic kids, being treated as criminals for their behaviors in a way that non-autistic kids often aren't. And certainly white kids often aren't. And there's that legacy of police violence especially in the black community, and also in Latino-Latina communities, and other folks of color that's going to pass down that trauma as well.

So there's— when I'm listening to you, I'm feeling how important it is for us. Like, we've been talking about this whole episode, when we're entering the lives of an autistic person, to enter it from a place of, *'How can I create respect, safety, and understanding?'* which is easier said than done, right? Understanding takes so much listening and so much curiosity, *'How can I add that to your life, rather than helping you meet some other goals?'*

Sarah: And I just want to say, because you're picking up on that, but I have heard in my community is that so many people are saying that they're really afraid to have therapists in their home because of DCF and CPS, whatever it's called in your state. But it's because autistic parents feel like they're having demands put on them, and if you know anything about an autistic person, especially by the time they reach adulthood— like, we're going to do our darndest to meet that expectation. And we might be doing it in a way that's not— it doesn't respect the flow of our household, and it creates a power struggle. And so now, parents don't even want to get on their therapy sessions because they're afraid that they're gonna have DCF called on them because of the power struggle, you know?

Meg: So there's a lot to digest in this episode.

Sarah: Yeah, it is. What I really appreciate is like, this is the point where we have these conversations, and we have them in a space where it's not judgmental; it's not a fight, it's just a like, *'Huh, I never thought of that.'*

Meg: So a lot of the people listening to this podcast are OT's. What's one takeaway you hope they'll get from this, or one thing you'd like to see OT's doing as we begin to shift our clinical practice?

Sarah: Please consider autism as a way of being. I feel like if there's that respect to our neurology— it's our neurology, and it's a lot easier if you work with it instead of trying to break it to make it neurotypical. And I think that we can't even get to that level of advocacy as occupational therapists because we gotta go one step down, foundationally. Please, just consider it, autism as a way of being. And then, that's going to open up— well, then, is being autistic a culture? Is that cultural? And then you can say, *'Well, then, how do I establish cultural competence?'* But we've really got to down to that foundational level first.

Meg: I love that. Thank you, Sarah. Tell us a little bit about your upcoming projects and where we can find you online.

Sarah: Sure. So, you can find me in many spaces, but my favorite space is Facebook: *The Autistic OT*. Some people think that I'm going to give more OT advice there, and that's not— and actually, now that I'm thinking of it, it goes along with what I want, or the intention behind the Facebook page, is I simply want you to see me. I am an autistic OT. Like, I'm not here to give you OT, I'm here to show you what an autistic OT looks like. And sometimes it's very serious, and sometimes it's really funny, and sometimes it's a little angry. Like, all of those things are there. So that's my big project. I keep threatening to break into like Instagram, but I just like Facebook.

But what I'm really excited about is that, recently, I've joined the advisory board of Neuroclastic. And Neuroclastic is a nonprofit organization, and it's about autistic-led advocacy that is created by, and run by autistics. Every single person on our board is autistic. We have all ages, we have pastors, we have Muslims, we have— like, all of the things. It's true diversity. It's such a beautiful board. And we are constantly coming together in a space and saying, *'What do autistics need, and how can we provide it to them?'*

And so what I have been developing, and it's, you know— oh, my goodness, May is my target— but I'm gonna be doing sensory profiling. I'm gonna be doing it for individuals. I'm going to be doing it for families. And that's something that I'm really good at, because we talk a little bit about like autistics and synesthesia. That's my thing. I see sensory. So I'm really excited about that. I'm going to be doing it under than the umbrella of Neuroclastic, because I believe so much in the power of autistics leading the way for autistics, and bringing in allies, versus allies bringing us in, you know? And that kind of thing. And then the other really big thing that I have coming out, and think it's in the next two weeks, is my book! My little children's book!

Meg: Yay!

Sarah: It's called, *'Melt Like Ice-Cream,'* and it is a progressive— well, it's a book that was designed for co-regulation between a reader and the person that they're reading to. So, typically, that's parent and child, but it could be anybody. And it goes through— the book itself takes you through a series of progressive muscle relaxation activities, and it's a way of being able to really calm, and bring each other down. It's a book that I wrote with my OT bestie. Her name's Tessa Newell, and we actually presented— we did a whole research project and presented at a national conference in San Diego years ago. But the ending wasn't right. Actually, a little, four-year-old autistic girl named Rosie gave me the right ending, and I said, 'That's perfect! We're doing it!' So, yeah, we're— in about two weeks, I'm releasing my first children's book. It's called *'Melt Like Ice-Cream,'* and it's with an autistic publisher. Like, it's so autistic, it's wonderful! So, I'm really excited about that!

Meg: That is so exciting! I will link to all of your projects and pages in the show notes. Sarah, I learn so much every single time I talk to you! Thank you so much!

Sarah: Thank you! I love talking to you, Meg. You are the epitome of like, *'Hmm.. Let's be curious!'* That's so… I love that.

Meg: I'm trying! I'm learning!

Sarah: You're doing a great job, and I appreciate the platform, and I appreciate your dedication to amplifying autistic perspectives, and being such a wonderful ally to our community, so thank you!

Meg: Sarah, I can't wait to have you on the podcast again soon.

Sarah: Millions of times. I've got a fancy microphone now, so lets.

Meg: Alright, see you soon!

Sarah: Thanks!

[Ending music]

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