

Embracing How Different Our Brains Are with Elena Sabinson (Transcript)

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CC: Elena, thank you for joining us on Work Better Today.

Elena Sabinson: Thank you so much for having me. I'm really excited to be here.

CC: Well, I'm excited to talk to you because you're studying something that I think is really important. I find it personally really interesting to think about how design and the physical environment can do a better job of supporting people who are neurodiverse, which I know is a really broad term, and we're going to talk about that a little bit. But before we start on that, I want to share with everybody in our audience a little bit more about you, and you are diagnosed as having both autism and ADHD. You also introduced me to a term I'd never heard before, so I was hoping you'd share that, and I'd love it if you just talk a little bit about your personal journey, about how you became so passionate about this topic.

ES: Yeah, thank you. I'm in what we call in the neurodivergent community and ADHD, meaning that I'm autistic and I have ADHD, and we kind of talk about these as being neurotype beyond just thinking of these as a diagnosis, but kind of a way of being in a way that my brain is in the world. So I started thinking about the physical environment when I was doing my master's in interior architecture and design. Really, I've always been very sensitive to my environment, had very particular needs for tactile sensations. Very picky eater, didn't like a lot of smells, very sensitive to those. And so I've always been kind of thinking about how is this environment affecting me? But then when I started working to design environments, I started thinking a lot more about beyond my own personal sensations, but kind of how the design of environment is affecting people broadly, and we're spending so much of our time indoors. The classic quote, we spend 90% of our time in indoor environments. So as an interior architect, I saw a lot of opportunity to make those spaces more supportive of people's needs. That led me to pursue a PhD in human behavior and design where I could kind of connect my interest in mental health, something that I had struggled with throughout my entire life with my passion for the design of the physical environment. And actually during that program, I am studying some interesting topics we'll get into, but thinking about sensory environments and how we're being affected by stimuli in their environment. And I actually started to have a lot of alignment and I was constantly feeling like the experiences of autistic people that I was researching were really resonating with my own experience. So I didn't get diagnosed with autism and ADHD until I was in my mid-thirties pursuing my PhD, trying to actually study these topics for other people. And then coming to realize that a lot of the experiences that I had had throughout my life and some diagnoses that I had previously received didn't really resonate with me the same way that autism and ADHD did. And that's actually happening to more and more people because the diagnostic criteria for autism is broadening.

CC: Elena, I feel like when I hear you talk, you're describing half of my family or half of my offspring sometimes, and I just want to go back and hear a little bit more. What was that like for you to have this diagnosis later in life? Was it surprising? Was it upsetting? How did you feel about that?

ES: A lot of mixed emotions. I think my first experience was a sense of relief. I think a lot of people see labels as something that's going to limit you or increase stigma, and for me, it was the exact opposite. I've been so hard on myself for so many different things that seemed difficult for me, that didn't seem so difficult to many of my peers. And having a framework to say, Hey, this is what you're experiencing. These sensory experiences you're having are very normal if you look at them through this lens and not through trying to make your experience make sense through everyone. I also felt maybe, I think this is a common experience for people who are late diagnosed. I'm not sure, I can only speak for myself, but a little bit angry actually, that I hadn't received a diagnosis because of the way that I presented and because I was socialized as a female growing up as a woman, and because I actually had a very classical presentation of autism, I have a very pronounced hands stim that I had to spend my entire life

trying to cover my happy hands. And so, I was kind of like, oh, if I hadn't necessarily been born in this body with this identity, I might have been receiving this diagnosis a long time ago. And being given access to community and resources and a reduction in social shame, the complicated thing is that there's so much stigma around an autism diagnosis. And particularly 10 years ago, 20 years ago, there was even more. So I can't really say that if I had received my diagnosis earlier that that would've necessarily been better. I can only live in the life that I have, and there are a lot of people who were diagnosed earlier and really don't feel that they received the supports that they wanted or needed. So a nuance experience, both relief, joy, access to community support, and a lot of tools to help me that I never had before. And also some frustration that the scope of diagnosis for autism was so narrow for so many years and excluded not only women, but people of color and gender, non-conforming indigenous people. There are a lot of people who were excluded from that.

CC: Yeah, wow. There's so much to unpack there. But I think one tool that we could help everybody with is if we start out just by defining neurodiversity because it's a term that's getting used a lot and I just kind of want to ground us all in. What do you mean when you use the term neurodiversity? How should we think about that?

ES: Yeah, thank you. That's good to take. Give me a step back too, because I often through the lens of autism and ADHD, because those are the ones that personally affect me, but neurodiversity is so much broader than that, and there are so many other ways that you can be neurodivergent. So first neurodiversity just means that there is a natural variation in brains, and that leads to differences in cognition, in emotion, in the way that we experience sensory stimuli, the way that we engage in social interactions. And it's not just about autism and ADHD, it can be OCD, schizophrenia, dyspraxia dyslexia, any sort of mental health issue. You could categorize yourself as neurodivergent. And this is one of my favorite things about the neurodiversity movement is that we're really arguing let's embrace how different our brains all are. You don't necessarily need to have received a diagnosis to identify as neurodivergent. It's basically taking a stance that this is how my brain operates and I'm going to embrace how my brain is existing and ask that people take the time to understand me and how my brain works, rather than assume I should do things the other way that they think is correct.

CC: I love that way of thinking. It just feels so much healthier to say rather than expecting everybody to behave in kind of more of a normative way that is just celebrating the differences. And I want to build on that a little bit and think about from a spatial perspective, if I were starting out thinking about an environment and wanting to create something that accommodates people who are neurodivergent, is there a risk that we exclude any other people in the process of doing that?

ES: This is a really important question and a complicated one. I think especially because I really am a proponent of trying to aim for universal design, but I'm also very clear that that doesn't mean there's one solution that's going to provide a universal solution for everybody. And so thinking about this one thing that I can think about just in terms of neurodivergent needs and how those might kind of come into conflict with one another. So for example, I tend to move a lot, I make a lot of noise and I need to do that to work and focus, and that's how my neurodivergence is showing up for me at work. For somebody else, they might be neurodivergent and need complete silence and not have a lot of visual movement around. I think it's very overly simplistic to be like, let's put all the neurodivergent folks in one corner and assume that their actions are going to work out well because that often might not be the case. But also, a strong proponent of that when we start focusing on or designing for people who have disabilities or who are sensitive and have higher support needs that often has overlay spill out effects of benefits for other people. We can think about this intersectionally even thinking about the deaf community and the neurodivergent community, so including captioning. Oh, interesting. On video, a really, really important accommodation for people who are deaf, but a lot of neurodivergent people struggle with auditory processing. So it's not that we can't hear the sounds, it's that our brain might not understand them best when hearing them auditorily. And so having visual captions can help with that. So as much as there might be times where people's needs come in conflict, a lot of the times these needs are actually benefiting more people than the intended group. I think the best way to approach it is just make people comfortable to talk about their unique needs and so that we can kind of say, okay, what are your sensory needs? It's not that you're a divergent. What are your particular needs and how can we make that fit well with somebody else's sensory needs? Who's going to be in your immediate surroundings and such like that?

CC: How do you have this range of spaces that allow people to seek out what they need and to feel like they have permission to be able to utilize the spaces that are going to work for their brain in the best way?

ES: Yeah, I think having a flexibility of spaces and zones of different spaces is one of the key strategies, providing an environment that can support diverse people. And so thinking about having sensory rooms where people can go if they need to move their body and have a low sensory experience and a high sensory experience. And these shouldn't be ideally rooms where it's just like this is the sensory room for the neurodivergent people, a room where people know it's okay to do these types of activities and people can go there when they need to do that. Also, having a range of spaces, talking about maybe having private offices for certain types of work and then maybe some open offices for other types of work rather than taking a one solution fits all, we're just going to have an open office space and everyone's going to have to make it work in there. Why not have both options? And if I'm in a certain type of activity where I want to have somebody next to me in neurodiversity movement, one of the terms that people are getting really excited about is body doubling.

CC: Oh, interesting. What's that?

ES: Body doubling is a strategy where the presence of another individual can increase your ability to focus and get stuff done. And so there's a couple different theories of how that's working, but whether just having that amount of stimulus next to you, having the social pressure of somebody else working next to you or just seeing somebody else can often prompt us to want to get stuff done. And so I think an open office space can be really great to provide opportunity for body doubling. If maybe there's an area where there's desks and people can come sit because they want to work with other people, but when we only have an open office space and don't allow for there to be private rooms or private offices, then that can be really difficult. So just even by having those two different zones of private versus public and programming them in a strategic way so that don't have sound bothering people from the public areas into the private areas can make a big difference and provide opportunity for people to work in the style that suits their sensory needs and the activity they're working on.

CC: That feels like that could solve for a huge range of problems. I mean, we actually started talking about this years ago with just whether people were introverts or extroverts, and it seems like it's still the same ideas kind of resonating. I want to dig a little bit into some really interesting research that you've done on environments that could make a difference, and in particular one about creating breathing wall panels. That idea just fascinates me. So can you tell me what that was about?

ES: Yeah, so during my doctoral studies, I was looking at interoception and interoception is another type of sensory experience where you can sense your own internal body signals and states, the one that we usually talk about most frequently can be heart rate just because it's non-invasive to measure. And I think many people have had an experience they can relate to where they understand how their heart is being affected by their emotions, and I'm getting stressed, my heart rate's going up. Something along those lines. What I was discovering, and partly how I discovered I was neurodivergent, is that a lot of neurodivergent people are having different experiences of interoception, and so they might be either very hyper or hyposensitive to those signals, meaning I either sense my heart rate every time it moves and I'm very aware of it, or I might not actually be getting that information. And we're starting to see that this can have a big effect on emotion regulation. So, for example, if you are stressed but you don't realize you are stressed because you don't get that information from those body signals, you might start to have some difficulty in identifying those emotions, what we might call alexithymia. And if we don't know or having an emotion, it's really hard to choose to take a self-soothing behavior to make that emotion come down. So if I'm really, really stressed, but I don't know, I'm really, really stressed until I'm so very stressed that it's really difficult to bring my body down, that can be problematic. The goal was to use biofeedback in the environment, and biofeedback is just representing those internal body states, so representing your heart rate in some visual, tangible, or auditory way so that people could get that information about what's happening on the inside. So our idea with these self-breathing walls, sorry, it was a little roundabout way to get here, was that if we have these wall panels in the environment that inflate with air and kind of encourage you to take a deep breath, which we know can really down, then when people aren't necessarily aware of the body sensations that are causing different emotional experiences, they can still choose to self-soothe. For example, the walls, they can be connected to a heart rate monitor. They sense, oh, the heart rate's going up. I'm going to start inflating at a slower pattern. And people due to environmental entrainment will often start to match their respiratory patterns to things in their environment. And so can you get people to realize, Hey, I need to take a breath and calm down...

CC: So, the wall kind of cues me to start breathing. The wall doesn't breathe fast with me if I'm freaking out, it doesn't go, but it's more like, ah, take a deep breath. Is that right?

ES: Yeah. Providing cues in the environment to take a self-soothing behavior. And so we've been testing these where we actually have people breathe while touching the panels, and people do find them effective as a guide. People reported a reduction in their stress after interacting with them, but they also infected people's awareness of breathing and how deep people felt they could breathe because by having that physical sensation of something that was also inflating while your lungs were in inflating helped people to kind of breathe more deeply, which can help to activate your parasympathetic nervous system and cause you to calm down.

CC: Got it. That is so fascinating. I want to go back to something you said a minute ago because we often think about spaces when you're talking about walls that can give you kind of that biofeedback, which I know it's, I don't think any of our panels in our Steelcase systems can do that just yet. So maybe that's not widely available, but we've talked a lot about spaces that could be more calming. But the thing you said I wanted to go back to is a term called stimming. When you talked about hands, my oldest son always used to use his hands when he was talking, and in some ways he still does, and so do I in some ways. Can you tell us what is stimming?

ES: Yeah, so stimming stands for self-stimulatory behavior. So it's something that you're doing to regulate your energy. You could be doing it to maybe distract from a negative thought, you're having to get let go of extra energy or just to have fun and enjoy. It's a regulating technique that a lot of neurodivergent people do in increased frequency or intensity compared to non-neurodivergent peers. So everybody stems, we can think about this, if you're nervous and you're kind of rocking your foot back and forth, shaking it or chewing on a pen or clicking it, those are all types of stimming. When we talk about stimming in neurodivergent populations, we're often talking about increased frequency or intensity of the stimming behavior. And it can be a really helpful strategy for people when I'm having an intense emotion, if I do this with my hands, it helps me to process those emotions. Having lived many years of my life trying to prevent myself from doing that behavior due to being perceived as weird or the social stigma that was accompanied it, that prevented me from being able to regulate my emotions in the way that was most natural to me. So we kind of think of these breathing wall panels that we made as really large scale fidget toys, which I think is something else a lot of people have heard of is a fidget toy, but those can kind of have their own social stigma. They're often designed for children and youth and not always as acceptable for somebody in a professional setting to pull out a little slug fidget and play with it. So it's one thing that we're trying to think about is how do we embrace stimming, normalize stimming, and are there ways to design environments that can also be a type of stimming? Stimming can be body behavior, but you can also have visual stimming, which is looking at a stimulus that's really beautiful. If you go into a lot of those sensory rooms, you'll see there's lots of lamps with bubbles or lava lamps type thing that we find fascinating and mesmerizing, and there's something really soothing about watching it, and there are things that are now that you're describing it that can also just be aesthetically pleasing, just beautiful to look at. And I think that's a really interesting thing for designers to be able to think about how adding those elements can actually solve for a number of issues. They're not just another pretty object, but they have purpose. It's so important to think about too because I think when people think about designing for neurodivergent folks and designing a sensory friendly environment, the assumption is that we need a low stimulus environment and that it should be completely neutral and barren of any exciting patterns or textures or colors, and that's not the case. It's about really providing the right type of stimuli for the right activities and for the right people. And actually a lot of our interior environments don't have enough stimuli for us, and that actually can be just as problematic as too much stimuli or kind of experiencing sensory overload. And also that this isn't happening. People aren't just a low stimuli person or a high stimuli person. I hear a lot of people talk about, oh, well they're a sensory avoider or they're a sensory seeker, but there's a lot of nuances to how that's happening. Some people might be sensory avoiders for touch that they find unpleasant, but sensory seekers for visual stimuli that they find captivating. We shouldn't just assume if somebody's a sensory avoider that that's happening across the different senses equally. And additionally, it's not a static trait. We have different states of sensory needs. So it's not just that I'm a person who only wants low sensory objects or low sensory experiences all the time. It might have to do with what other stressors do I have in my life? How much stimuli have I been exposed to in my recent experiences? And that can change how much sensory stimuli I might need in that moment. So I think we need to think about these with a lot more nuance and less categorically, people are experiencing a gradient of sensory needs and experiences both across sensory experiences and within different times of day. And

CC: I think there's such a great desire for understanding on the part of the design community and organizations wanting to know where do I start? If I want to begin to introduce the kinds of things that you're talking about into the workplace and support this very diverse set of needs. Do you have thoughts, advice for people about where do you get started?

ES: This is such a great question. I think the first thing to do is to really make sure the company culture is saying, what needs do you have? What are your sensory preferences? So that if somebody's coming into a new work environment, they have the opportunity to have that discussion rather than necessarily having to out themselves as neurodivergent if they aren't comfortable to do so yet and ask for an accommodation. So accommodation should always be given and they're very important, but I think creating the opportunity so that that conversation feels natural and everybody's getting the chance to give input is important in terms of design, really smart programming can make a huge difference. We really do want to be thinking about if we have some large equipment that makes a lot of noise, let's make sure that that is not spatially close to where offices and areas where people need to focus are. And that can be happening in the pre-building phase. Also, thinking about the materials that are being used and kind of thinking about how acoustics can be addressed. There's so many interesting panels that can be reducing reverb, reducing glare, providing natural day lighting. These are things that benefit everybody. Having control over the lighting in a situation is extremely impactful and pretty easy to achieve. So if the building hasn't been built yet, it'd be great to put on a five panel lighting control so people can choose to dim it. But if that's not already there, we can still provide a task lamp or a floor lamp that can be dimmable. There are ways to think about what phase of the design are we in and what are the type of cost effective solutions we can make to provide people to have more control over their experience. I know there's a lot of offices that have glass doors now and that's really great. It lets in light, but maybe we need to provide some curtains for people so that if they want to close that curtain and have privacy to move and they have that possibility, a lot of nature-based strategies are hugely impactful for everybody. When we think about biophilic design, I know there's a lot more designers who are focusing on that and how humans have an evolutionary desire to affiliate and be surrounded by natural objects and elements. And this is also really true for neurodivergent folks and I think has a lot to do with sensory needs. So thinking about not in the daylight, but adding plants, natural patterns can be also a really great idea. One thing that can be really tricky is in circulation zones, like on stairwells, I really don't recommend busy carpet patterns. Those can cause a lot of experiences of making people dizzy and people who struggle with proprioception, which is their ability to sense where their body is in space, can kind of have those difficulties compounded if the circulation zones have too many stimuli or pattern on the ground.

CC: That makes so much sense. I've experienced spaces like that where I even just feel like where does the step begin and end because the pattern has kind of confused me, but everything that you're describing in terms of this vision for how workplaces could be, it gives me a little spark of a little joy because it envisions a future that I think could be great for so many different people when they're coming to work. And so I want to ask you about moments of joy a little bit in your life. So it's, before I let you go, I'd love to just hear about something that maybe you would want to acknowledge in your journey or just a moment of delight that really made an impression on you and your work and your life.

ES: There's been a lot of joy recently. I just started a new job and I'm an educator and a researcher, so I kind of get to have two different ways of bringing me joy through my work. One in creating research that's exciting and that I think could help people, but also teaching other future designers to care, to have a deep sense of responsibility for designing environments that are supportive and that addressed the needs of many diverse people neurodiversity and beyond, and really taking an intersectional approach to how we design spaces. One thing that I'm really proud of recently, one, my students did an amazing job in my class, so that was a huge moment of joy, and I was super excited to see that many of them were identifying what their learning needs were. I had one student who was like, I love the slideshows because I'm a visual learner. And the other student was like, the slideshows were so boring. That was not helpful to me, but I really love those one-on-one conversations. And so seeing students advocate for their own needs and their own styles of cognition and learning is really satisfying. And also I think one experience that brought me a lot of joy was being open about my autism at my job. I just started this new year at the University of Colorado-Boulder in the environmental design program, and they asked me to introduce myself, and everyone knew I was neurodivergent, but I said, for the first time at a new job, I'm autistic and I have ADHD, and this is what I research and this is what I'm passionate about, and it's brought me so much joy and peace to be able to have that conversation openly and to be able to bring it into future conversations where like, Hey, would you mind writing that down in an email for me? Because I probably didn't remember if you said it to me. Just knowing that I'm autistic and ADHD and open about it brings me joy and it brings me strength to do my job and allows me to have the conversations that might've been really difficult in the past or where I might've just been too ashamed to say anything. So that makes me really happy.

CC: It just makes me happy too. Thank you so much for sharing that. I think that's so important. And I also really, when you were talking, was thinking about your students and other students who are more self-aware coming into the workplace and not only being able to identify their needs, but if that culture, you said this earlier, the culture gives them permission to talk about it and to not stigmatize it. I think that's such an important thing for us to think about as well. Thank you for sharing that.

ES: We all deserve to have our needs met, and that's really the tone. And that doesn't mean that everybody always gets what they want, but that we're all going to try and show up for each other and accommodate each other when we can.

CC: Yeah, that's perfect. Thank you so much for joining us today, Elena. I really appreciated it, and I'm sure that people in our audience really have just learned a lot. So thank you for sharing with us today.

ES: Thanks, Chris. It's been such a pleasure talking with you, and I appreciate you having the space to have this really important conversation. So thanks so much.