**[START OF TRANSCRIPT]**

**Interviewer:** Great, we are recording. And I will be asking you about your perspective regarding your son's transition to adulthood in relation to his sensory sensitivities. And I'll be doing something called a semi-structured interview, and this means I have my planned questions in my script but will also be adapting them to fit our conversation, so they actually make sense for you and for your family.

**Interviewee:** Very good.

**Interviewer:** Alright. Any questions?

**Interviewee:** Nope.

**Interviewer:** OK. And if there any questions that you don't want to answer for whatever reason, that's perfectly fine, ‘I don't know’ is a perfectly fine answer as well. And if things come to mind from earlier, you're welcome to bring it up,it doesn't have to be perfectly linear. Alright, sound good?

**Interviewee:** Sounds good.

**Interviewer:** Cool. Could you please start off by telling me about your son's sensory sensitivities?

**Interviewee:** Sure, do you want current perspective or when he was a child?

**Interviewer:** I'll be asking about both, so you're welcome to start with whatever makes most sense for you.

**Interviewee:** OK, I'll actually start with when he was a child then, because that was the indicator for us that something more was different. So, Parker's 21 next week.

**Interviewer:** Yeah, happy early birthday.

**Interviewee:** Let me just have a moment here **[Rachel laughs].** 21 next week. When he was two and three years old, he was quirky, he was different. Pre-school teachers would say, oh, he just did these weird or different things. And he had some unique things like the moment he would get home from preschool, he would take all of his clothes off and just be in his underwear.And my husband at the time was a stay-at-home dad and so as far as he was concerned it was great.They were just hanging out, played board games and they’d run around the house or go to swim lessons or something like that. So, it didn't strike us as an odd thing, for example, that Parker didn't want clothes on or he would go to bed at night with a bag of smelling things.He would put stuff together in a zip lock bag that might have a smell to them and I would find them underneath his pillow. And that would cause us to be kind of like, *“what the…that’s a little weird.”*I don't know why you’re sleeping with charcoal briquettes under his pillow, for example.Like these weren’t normal…it wasn't like he was putting roses in a bag or something. They were odd, things that had odd smells to them. But we just sort of kept writing that off. We would talk to his pediatrician here and there about it and it never rose to the level of interesting. Keep in mind that 21 years ago or 20 years ago, the cultural norm knowledge of autism was still very, very bare. You had specialists who understood it, you had therapists who might understand it, but your average doctor, your average dentist, your average teacher, your average person that your child might engage with had…autism to them was the hand flapping, spinning child having a violent outburst and the concept that there was a spectrum was not known.So, he was four years old, and we were down in Portland, Oregon. And I don't know if you ever been to Multnomah Falls down in Portland where they have…

**Interviewer:** I have not.

**Interviewee:** …beautiful waterfall that cascades down right on a highway, so very easy to access, which means it's usually very crowded. But one of the unique things about it is that there is a set of train tracks that run in between the parking area and the waterfall, and so there's this big bridge that runs over the area.And I will always remember this day and I mean, I could describe it to you in living color in detail.We were down playing at the little creek that comes out from the end of the waterfall and a train came by over that bridge, and it was loud and it was definitely close by.Parker *screamed*, he came running out of the creek, he climbed into my lap, he buried his head under my arm and it was this almost *visceral reaction* from him that…my husband was standing next to me and I looked at him and I said, *“this is not normal, this is…”*I mean, he was shaking, he was rocking, it was intense for him. And then I looked up and I said, “*something else is going on, something else is different about Parker.”* So that started us on the journey of figuring out what is that. He actually was not diagnosed with autism until he was 13.

**Interviewer:** Yeah, I noticed on your form.

**Interviewee:** Yeah. So, from 4 to 13 he still was just different. We began experiencing significant academic deficiencies. I had him…I changed pediatricians at one point, and at age 8, the pediatrician office that we were going to also had a psychologist in the office, it was part of the practice. And so we…the pediatrician said, *“we should probably have him visit the psychologist.”* I was like, *“OK, fine,”* and so we do that. The psychologist gives him all the standard battery of tests – Wexler and…that's the only one I can ever remember, Wexler and ‘insert the other three.’Blue and green level forms that I've filled out ad nauseum over the years.And this pediatric psychologist when he came back after the assessment was complete and the results were done, he came back and he said, *“well, your son is definitely not normal, he will probably not amount to much of anything at all and I think we should put him on ADHD medicine immediately.”* And I'm sitting there and going, that's a lot to process! But it actually became a very *galvanizing* thing for us because I was like, *“well, I'll show you Doctor! My kid’s gonna amount to a lot. So, just go away.”* But in that time frame…so at that point we did put him on ADHD meds, he was on Adderall for a period of time and then switched him to Focalin. Yes, his academics got better, yes, his sensitivity to things decreased, but he also became like a child he wasn't.It was sort of as though – and I don't understand how these meds really work, ‘cause my understanding is that they’re sort of meth like, they're kind of ‘upper’like, but what they do or what they did to him was just *depresses* him all the way down.So, he could keep his clothes on just fine because things didn't bother him anymore, he could go to school fine because the sounds of school didn't bother him anymore.

He went away to summer camp, we started having him do things to learn how to be away from us. He did not make it through the night, I had to go pick him up in the middle of the night at the summer camp, but he was able to make it through a day at the summer camp and handle the dirts and the smells and the things like that. But he also was like having a dead child, he had no appreciation of things around him, no…it was as though it deadened all of his sensory stimulation. At age 12, I think it was, he and his dad went on a 6-day backpacking trip and they just forgot the medicine, packing trip, and so he went off it cold turkey and 6 days…my husband described it as *“6 days where he never stopped talking once.”* **[Rachel laughs]** But 6 days where our son was back and his liveliness was back, his joy was back, his energy was back. And interestingly, the sensory sensitivities didn't come back in full force at that time either. The two that stayed were taste and sound.

**Interviewer:** OK, everything else like the smell and the touch was gone?

**Interviewee:** Smell was more normalized, touch was more normalized, sound was still a challenge, but like clothing sensitivities were…I would say that was moderated, it wasn't quite normalized, but it was better. I still always had to buy him special socks that didn't have seams, I would look for jeans that had lots of lycra or elastane in them so they were soft and movable, not fit jeans. So, I took an approach of lots and lots of coping mechanisms. I've done work with other families, I've been a parent support provider, parent advisory provider at different times and it's been really interesting to find other parents who say, sort of take an approach of ‘suck it up, buttercup, these are the socks you're going to wear!’ And that almost would make my heart hurt, like, *“but it hurts their feet, you don't understand. It's not like you wearing a pair of socks with a seam.”* It's an amplified thing. We worked with a doctor at one point who described the amplification of sensory sensitivity is as if what is a dog barking to you is a 737 screaming over his head. What is a seam in a sock to you is *cactus thorns* on his foot? And so, to just describe this amplification of sensitivities. So, I always used a…we spent boatloads of money on just coping mechanisms, special socks, special genes, special shirts, special foods. He had a lot of taste-texture issues, and so food, his diet consisted of white pasta, chicken and milk. Even today he won't touch fruit with a 10-foot pole. Slimy, mushy…

**Interviewer: [00:09:53]** Is it a texture thing?

**Interviewee:** Yep, slimy, shmushy. I can maybe get him to eat an apple, and he actually will eat vegetables no problem now, but not in his eight-year-old plus era. And I'll describe a little bit of what a big shift he had when he turned 19. So, he had a lot of these texture and sound challenges, I would make him protein balls and he drank boost protein shakes because his diet was so poor that it was like he was losing weight month over month rather than gaining strength between 9 and 13, 9 and 15. At 13 we finally got approved for an autism screening test at Seattle Children's Medical Center, which is…there's a few that do them around here but they are considered to be very good.

**Interviewer:** I went to U-Dub

**Interviewee:** Interestingly, we were on the U-Dub list for two years and I got the phone, when you go on – back in the day, when you go on the U-Dub list, they don't ask you anything about insurance, you just get on the list, you wait 2 years, they call you, they say it's your turn, you're so excited, they take your insurance info and they say, *“oh, we can't bill your insurance, this won't be covered.”* And you're like, *“what? What do you mean?”* Like, yeah *“well it's gonna run $3200. So, are you all set? We can get you in next week.”* I don't have $3200! **[00:11:17 inaudible]** my kid and I bought him all kinds of special socks but buying special socks is different than $3200. So, we then had to go in the Seattle Children's list and wait another 2 years. So that's why the primary reason why the diagnosis was really 4 years after the honest [recognition] that he wasn't just quirky, there was something. From 9 to 13 we were just on lists. So the doctor we met, we met a neuropsychologist through that process, she was amazing. Parker’s gone back to see her every year or two for what we call a booster shot, just to reconnect with her and kind of point him in a new direction. When he was 18, I had him fully retested, fully reevaluated by her, the last time I did had to pay cash for it. But I wanted him to have an adult assessment that was his that he owned, and I wanted him to be tested as an adult, not a child, because I wanted whatever the results to be, I wanted it to not be ‘mom tells you this is what you struggle with’ and I wanted it to be a relationship he and the doctor had.

**Interviewer:** Yeah, for sure. That's wonderful.

**Interviewee:** Interestingly, during that process – so now he's 18 and 1/2 years old – during that process, she actually came back and said, *“I diagnosed him at 13, I have all of his original info, I have the video recording interviews, I have everything. I can’t diagnose him with autism now. But there's no cure for autism.”* And I said, *“so what does that mean?”* She said, *“you guys have done so much for coping mechanisms that he has covered, he's learned to present more normally.”* And so, she started asking him sensory kinds of questions and he said, *“well, I don't like it when I hear big noises, but I just know they'll go away soon, or I put my headphones in.”* He wears headphones a lot. As he got older, the fancy socks that I bought turned into a lot of fancy headphones **[Rachel laughs]** to block noise, to let him focus into himself, a lot of sound cancelling headphones. So, then he turned 19 and he was very *boostered* by that assessment, **[impersonating son]** *“I'm not autistic, I'm not autistic anymore!”* He's very arrogant and…not arrogant, he was just very proud of that. So, he signed up and joined a real job with a work crew in Idaho and went and lived by himself in Idaho for 4 months.

**Interviewer:** Wow!

**Interviewee:** With a crew, living in a tent and staying in hotels and other sorts of things. And he did so…like he made leaps and bounds in his ability to *cope* with sensory things, he had to. When you're out with a backpack for…they would go on these things called 9-day splits. You're out for 9 days, you just have a backpack, a tent, and Carissa on the crew is cooking dinner tonight, and Carissa is vegan, your dinner is going to be mushrooms and vegetables and fruits, and beans and things that he just would not touch, but you're starving. So, by virtue of necessity, he now, like most of his texture, things are gone. He’ll eat pretty much anything!

**Interviewer: [00:14:41]** But not fruit?

**Interviewee:** Still no fruit, still no fruit. Actually, he will eat pears now, I thought about that, he’ll eat pears, so there's probably like 2 more fruits that he’ll eat.

**Interviewer:** OK. And he’s still deterred by the texture of most other fruits?

**Interviewee:** Yeah, I put some mandarin oranges on a dinner plate one day and he looked at me and he goes, *“that's funny!”* And he scraped them off to his brother’s plate. I said, *“well, you eat like a whole lot of stuff now, I thought maybe you might eat these.”* He goes, *“those are slime.”*

**Interviewer:** It's always worth a shot to try though.

**Interviewee:** So that kind of gives you a bit of both a little bit of his life story, but also his progression from sensory sensitivity. I would call it not *extreme,* but a notch or two below extreme to really not much now.

**Interviewer:** Yeah, that's awesome. Thank you, that was so helpful. Do sounds still bother him?

**Interviewee:** I can't think…I would say there was one of the questions on the last survey that I just did of background noise. So, he does still wear headphones *a lot* and he still, like if his noise cancelling headphones aren't charged or one gets lost or broke or something like that, that's an all-points bulletin, we need to find the headphones. So, I would say that the loud noise, the vacuum cleaners, the dogs, the trains, those things that really consumed a lot of years for him being a challenge, those don't bother him, but he still needs to block out noise in order to focus on some schoolwork.

**Interviewer:** No, for sure, that makes sense. And has he ever or is he still sensitive to any visual type of stimuli?

**Interviewee:** No.

**Interviewer:** OK, cool. So, it sounds like overall, most of his sensitivities have like moderated or abated overtime? Is that a fair statement? **[audio cuts]** Sorry, was that a yes?

**Interviewee:** Yeah, that's a fair statement.

**Interviewer:** OK, cool, thank you. And you’ve alluded to this with your story, or your explanation rather, but do you think these changes that you've noticed in his decrease in sensitivities, do you think that's related to any independence that he's gained overtime?

**Interviewee:** Yes, I do, yeah. I would say both independence that he's gained overtime and necessity by independence. The independence yes, but some of what he chose to do in *becoming independent* created *additional necessities* thatI think sort of turbocharged, if that makes sense.

**Interviewer: [00:17:27]** OK. Can you think of other examples other than going to Idaho, I think you said, for work?

**Interviewee:** Yeah, so he did…after Idaho, he spent 5 months in Montana last year. And in 4 weeks he leaves to spend a year in Iowa.

**Interviewer:** Wow! And these experiences all forced him to kind of work on his sensitivities, you'd say?

**Interviewee:** Yeah, one of the things I am very pleased with is this…I had this concept, this hypothesis that if I made – ‘made him’ – you can't make anybody be anything, but take it with a grain of salt – if I made him own his own challenges, be responsible for his own challenges, he could then decide what he was comfortable with being and what he wasn't comfortable being, like that would give him the foothold to decide, like he is OK telling people, *“I don't eat fruit,”* and like, *“I don't eat fruit.”* But he's not OK telling people that he doesn't like the texture of some food, and he's not OK telling people that…like he still does wear more expensive type clothing, more sensory reduced kind of clothing. And he'll get some flack for that, people will say, *“oh, you have…”* I forget what the brand of jeans is that he's got, but they cost more than just going into Walmart and buying a pair of jeans. And he doesn't like experiencing that kind of flack and he struggles with whether to tell people that he's not like them, so he struggles in that space. So, sometimes he'll tell people, *“yeah, I don't wear Wrangler jeans because they're scratchy and I'm really sensitive to scratchiness because of these challenges.”* So, he kind of plays it by ear how much he shares and talks about.

**Interviewer:** Yeah, absolutely thank you. And then, both past and present, did or do his sensory activities cause or increase anxiety for him?

**Interviewee:** Oh yes, past, yeah.

**Interviewer:** Past, but not anymore?

**Interviewee:** No.

**Interviewer:** What did that anxiety look like when it did cause it?

**Interviewee:** He would make choices that were not appropriate. So, ‘I want to feel that girl’s dress in kindergarten that's velvet, so I'm gonna go…and I'm getting anxious because I can't feel it, but I *need* to go feel that velvet.’ And so, they would get into circle time and he would just sit next to that girl and then he would lay down in her lap. And then I would get a phone call that he was making bad choices about body distance from other kids. But for him it was like it was a *craving*. And he knew – overtime, we began teaching him that that's not an OK craving and we have to deal with this. And I had a lot of fears and a lot of worries that – actually, I didn't mention this earlier, but he had a lot of strong cravings for *soft textures*, so he would carry a blanket. He actually, when he went to Idaho, he took his baby blanket with him and *“kept it hidden from everybody.”* And it had gotten so tattered after 19 years that it was like down to just like a little square, but he tucked it inside his pillow, like he had to have this soft cotton thing next to him. And so, the anxiety would come when he didn't have those coping things available to him.

**Interviewer: [00:21:25]** Got you. And does he still seek out or enjoy these soft textures?

**Interviewee:** Yeah. And to some degree I feed that, which drives [my] husband crazy, his father, my husband, his father, *crazy*. We took two different approaches with Parker as his parents. Jeff never read single book, never went to a single therapy session, did not participate in *academically* trying to understand what research was telling us. But he had a great time fishing with Parker, taking him on backpacking trips, doing all kinds of things like that. I took the academic route and kept learning and learning and reading. We would go visit a psychotherapist or a psychoneurologist and they’d be like, *“oh, this is a book I want you to read.”* I'm like, *“I got that one, read that one last year.” “Oh OK, well this one will help, this one’s got some chapter on…”* “*Ah, read one 2 years ago, I'm good, I got that one.”* Like I have every book that's on your bookshelves, I don't have the *degree* you have, but like…

**Interviewer:** Close enough, right?

**Interviewee:** Yeah, I'm close enough **[both laugh]**.

**Interviewer:** You didn't pay for it.

**Interviewee:** Yeah, yeah, I just didn't want to pay for the schooling that you guys all pay for. So, that, sometimes because I would read in a book research that *withholding* something that the child needs to feel comfortable is not helpful, then I would leverage that and I would get him a soft…like even just last year, we went to visit him, I went to visit him during his program that he was in, and I brought him a soft blanket. And my husband was like, *“I can't believe you're doing this!”* I’m like, *“he likes them, he's fine.”* *“You're babying him.”* And when I gave it to Parker, he was like, *“it’s so soft mom, I'm going to just tuck it in my pillow,”* he was so happy with that.So, there's an aspect of sometimes I can make choices that maybe I should tell him to man up a little more kind of thing, but I’m his mom.

**Interviewer:** It doesn’t hurt anyone to have a soft blanket.

**Interviewee:** It does if you’re a manly man.

**Interviewer:** Perhaps **[both laugh]**. You mentioned that you and your **[00:23:35 inaudible]** husband would teach him when behaviors were appropriate or not appropriate, or like how to handle not having a coping mechanism. What did that look like? Was it like therapy? Was it medication or was it just…what did that look like, that teaching him you describe to abate that anxiety?

**Interviewee:** Some therapies. We live in a smaller community, and there just isn't the resources available where we live. So, I wanted him to be in…like Seattle has a lot and what Seattle has not really spread to Tacoma and then we live in Olympia – I’m telling names, 'cause I'm assuming you know, you can picture where we are, right? So, we're an hour and a half on a good day from Seattle, we’re 3 hours on a bad day from Seattle. So, there were times when I would put him in Seattle based programs or therapies, like the neuropsychologist that he sees lives up in Mount Terrace, Mountlake Terrace. Well, that sucks. We would go up there and stay overnight at my sister’s just so that he can see Parker kind of thing, like so far away. But here in our local area, I did have him go to a therapy practice who swore up down, right, left that they understood autism and it was clear that they did not. And so, we really just didn't have a lot of that. So really, I think that's probably why I picked up a lot of books and stuff. I kind of became his acting therapist.

**Interviewer: [00:25:07]** Yeah, absolutely. And then thinking about his sensory sensitivities, you’ve alluded to this quite a bit, but how does he or how do you help him manage and cope with these sensitivities?

**Interviewee:** I'm not sure what the right model would be to call it, but basically acknowledge that it's real and that it exists, acknowledge that it's not helpful to what he…so I've done a lot to help him identify what his future self looks like, so he's on a track to become a wildland firefighter and a forestry technician and he is not letting go of that track. And so, I will say things to him like, *“so you're sensitive to this thing and you want to be a wildland firefighter where you're going to be issued the clothing you wear, so how will this sensitivity help you become this future self?”* And then you can imagine the conversation, *“well, it really won't,”* and in fact, actually this next program that he's joined, they do issue the clothing that he's wearing.That will be really interesting to see how that goes.So, as an adult, it's things like that, because the – oh this is probably an important statement – when in school, having an autism label and having the label of needing special things is helpful because it gets you access to special services, it gets you access to special treatment, it gets you access to special rules.So, 9th grade PE, all the kids have to wear a PE T-shirt, it's horrible, it's like itchy cotton, tags all over it, seams all over it.And all he did was go into the PE teacher and say, *“so, I have an autism diagnosis and I can't wear this T shirt, I'm going to need to wear this this one instead,”* and then all the teacher can say is ‘check, got it,’ OK.Well, in the real world, having an autism diagnosis is a *label*…go back to not…more doctors understand it, more regular practitioners and professionals understand it, but your average Joe Schmo still doesn't understand, they still think that autism is the hand flapping, spinning temper tantrum kid.So, I have done a lot to help him make this transition that the coping mechanisms of the past, asking for the special permission will hurt him as an adult, and he's got to instead focus on, ‘if I push against this, if I ask for special, dispensation, does that help me become my future self or not?’And that's worked, that’s worked well.

**Interviewer: [00:27:53]** That's really interesting, thank you. When he was a child, I think on the form you said that he received occupational therapy for his sensory sensitivities. Can you talk a little bit about that?

**Interviewee:** Sure, yeah. We went to Mary Bridge Children's clinic up in Tacoma, and Diana was her name. Lots of working with weird textures and getting to play with weird textures. I didn't know…we didn't have a good, clear sense of who he was and what some of the challenges were when we were in this season, so she had him digging in cornmeal boxes, playing in rice bowls, putting slime all over his hands. My guess is that the strategy at the time was immerse him in weird textures so that they’re more normalized and less weird.

**Interviewer:** Do you think that helped him?

**Interviewee:** He loved going there, he didn't resist it. So, yeah, it did.

**Interviewer:** That's awesome.

**Interviewee:** And I would watch him play in this rice table and he was having such a great time and it was like, wow, that's so weird, like it's scratchy and itchy and he shouldn't want to do this. And so subsequently we would come home and we had a rice table and a cornmeal table and I replicated everything I saw going on in the OT clinic. My house was a mess, there was cornmeal always on the floor, there was rice always on the floor, things like that, but we just tried to replicate what we saw Diana doing with him.

**Interviewer:** And thinking back to your previous point, I raise a follow-up question, what are examples of how he has been able to modify his coping mechanisms so that way they're more age appropriate or more like developmentally appropriate for this person as an emerging adult?

**Interviewee:** Good question. He's overcome a lot of them, so I guess that's it, and that's been just work on his part. So, steak is an example from a food texture, wouldn't touch it with a 10-foot pole. Comes back for his five months in Montana and he's like, *“sure, I’ll eat steak.”* *“What do you mean you’ll eat steak?”* *“I love steak.”* *“You hate steak. You’ve hated steak for 20 years. What do you mean you like steak?”* He's like, *“oh it's great! Good iron, a good protein,”* and he starts reciting to me all the benefits of eating red meat. I’m like, *“oh, OK. Forgive me while I just sound shocked for a moment, but sure, OK.”* So, I think peer pressure in this way has become a positive. Sounds very strange.

**Interviewer:** It sounds like he's being exposed to things. Is that accurate?

**Interviewee:** Yes.

**Interviewer:** Got you.

**Interviewee:** In the general scheme of autism spectrum, he's fairly high functioning. So, although he has not been able to successfully make it through a semester of college without a lot of support still. And he has not held a real *paying* job consistently yet, he's been joining these programs that are funded by Americorps, they’re called Conservation Crew Corps, and that has just worked *beautifully* for him. As his mom, I'm always still going to worry that he still has too many sensitivities, too many challenges to be able to fully live independently and fully live without our support, but he's on the right track.

**Interviewer: [00:31:40]** That's wonderful, it’s all anyone can ask for. Thinking more broadly, thinking globally, what goals or hopes do you have for your son in regards to his sensitivities?

**Interviewee:** That he can continue to understand the social norms of them, so to continually increase his knowledge of ‘these sensitivities are OK, those ones are not, these ones are socially acceptable, those ones are not.’ To be able to get his needs met, his sensitivity needs met. I would say now he's probably 75% socially [normal], socially acceptable, and that needs to get up to 98, 99%.

**Interviewer:** That makes sense, thank you. We're gonna shift gears now on to the next chunk of questions, that was the biggest one, so we're over our hurdle. As your son has grown up and aged a bit, how has his and your community reacted to his sensory needs?

**Interviewee:** That's a good one.

**Interviewer:** Thank you.

**Interviewee:** Mom will get annoyed, mom will get protectionary. And when you say community, do you mean school and…?

**Interviewer:** It could mean whatever it means to you. School’s an example of community, it could be your family, it could be the stores you go into, it’s kind of defined by your life.

**Interviewee:** Yeah, yeah, that's a that's a broad question thinking globally like that, and I have to put things in sort of story form or example form. So, in 3rd grade we had him in a regular public school, he was in a small private school preschool, kindergarten for a second, and then we realized that just wasn't going to be the right environment, the academic deficiencies were becoming really evident. So, we put him in public school, and I told the public-school teacher, I said, *“look, all he needs to do is about every 2 hours or about every hour and a half, he needs to go out in the hallway, and he's got exercises he needs to do that will reset him, it's like a reset button. And if you can just have him do that about every hour and a half, he’ll be fine.”* And she looked at me and said, *“we're here to learn.”* *“Great! So, if you want him to learn, he's got to reset his button about every hour and a half, and he knows what to do, he knows what the exercises are.”* He had a weighted vest that he would wear and he would just do these different things while she was *adamantly* against it. And now we're in public-school. When we were in the private school, it was such a relationship, such a partnership that I wasn't even prepared for, ‘I'm sorry, you can tell me no? Wait, how can you tell me no? I don't know what to do with this now. And at the time, I didn't understand IEP language, I didn't understand all of the things you have to go through to be able to get protections for your child in public school. I since mastered that after several years, but this was our first year in public school and really our first year of understanding that things were different, and it was our first year we had to let go of our entire community where we were living, going to church and going to school with and had to start all brand new. So, it was very disconcerting. So, that's an example of a community thing.

My older sister has no tolerance or understanding of this at all, and so she would take him cross country skiing from time to time, 'cause they both like to do that and she would come back and say, *“oh my God, like he was eating the snow and he just wouldn't…[he’d] just keep going and he had to take his coat off and put his coat on and take his coat off and put his coat on.”* I’m like*, “yeah, yeah. Oh wait, you're telling me that because you think that's weird?”* And I'm like, *“yeah, that's pretty normal.”* And so, their relationship dissolved because he was weird to her and it dissolved further, actually, when she had her son, and her son was about three years old and I said, *“oh my gosh, this is what Parker used to do when he was three.”* And she said, *“I sure hope not.”* And I went **[00:36:09 shhh]** I'm not even going to say anything. So, family relationships differed. I have another sister who embraced Parker and *all* of his challenges, and so we're very close with her and her kids and Parker now goes skiing with her husband every year and just different things like that.So, it's been interesting to see in a community who is willing to accept what I would call a basic premise that we're all alike and we're all not alike at the same time.And obviously, in our society today, there's a lot around diversity and racism and all kinds of things going on.But this is almost a more abstracted construct of being able to say that you're different and I'm different and that's OK, and it has nothing to do with your skin tone, your class, your race, your ethnicity, your [whatever]*.* It's nothing to do with any of that.It's just truly you as a pile of carbon units is different than me as a pile of carbon units and that's OK.And so we have family members where that wasn't the case.

My husband's step-mom, so my husband's dad and his wife, really they would…they’d engage with Parker and then they would say to me, *“I don't understand why you think he's so abnormal, he's totally normal. You're making him become abnormal with your focus on this.” ‘*OK, thanks for your advice, didn't actually ask for it.’ So we’ve had those kinds of community experiences. And then we’ve had the other kind of…the Olympia school district at the time we moved to Olympia was fairly well known for having a *completely* different perspective on what it means to educate kids that are different, fundamentally different. In fact, as a parent when you get…when you have a child like this and you get diagnosed and you're in this kind of system, systematic system, let's call it, you get schooled in how to fight with your school district. Like you can literally go to classes on how to stand up for your child's rights and what the IEP law mandate **[00:38:24 inaudible]**.And I told our neuropsychologist, I said, *“I don't need to go to the class.”* She goes, *“no no no, you do.”* I said no, *“actually I don't, Olympia just wants to teach him.”* And they just want…and so when we got to the Olympia School District, for example, and I said to a teacher, *“look, he just needs to go out in the hallway and do this thing like every hour and a half.”* She's like, *“oh, that’s cool. Does he know what the exercises are?”* I'm like, *“yeah, he does.”* She goes, *“OK. Can he set his own timer?”* She said, *“can he just slip out of the classroom quietly, like not make a big deal of it?”* I’m like, *“yep,”* she's like *“OK, that’s fine.”* And boom, it was in place. So, it was that part of our community became fundamentally accepting of if there's a coping skill that you have figured out and…so they took the approach of ‘if what you're telling me is that you're going to make my job easier as a teacher, sign me up!’ **[both laugh].** So I was like, sorta makes sense to me, so.

**Interviewer:** Got you. That was wonderful, thank you. My younger son just woke up. Hang on just one second.

**Interviewee:** Take your time.

**Interviewer:** All good?

**Interviewee:** Yeah.

**Interviewer: [00:39:59]** Awesome. Would you say that the community was more or less accepting when your son was younger?

**Interviewee:** The community we were part of when he was younger was less accepting. We moved to an accepting community when he was 12.

**Interviewer:** Got you. So, you talked about a lot of different types of community like were more or less accepting. What about your church? I think you mentioned that in the beginning, were there other spaces or places that were more or less accepting?

**Interviewee:** Yes, yeah. So, we changed churches, and the new church we went to was…Parker would want to lay down in my lap even though he was 8 years old and he wouldn't…he didn't want to go off to the kids’ service kind of thing and they were like, *“oh, that's fine, that's cool, whatever works for you guys.”* So, it's almost as though the community of Olympia broadly is…we are known for being a very tolerant and accepting community, we’re known for being very left leaning. We have homeless camps, for example, up and down every street in Olympia these days. And we're just like, *“oh well, cool, they found a free place to live.”* And so, it's just like we don't even try to fight it against things that in Tacoma they are razing the communities every week and they're pushing the people and moving them and pushing them and moving them. And in Olympia we’re just like, *“oh well, we need to fix the root problem.”* So, in general our entire community here is more accepting, the schools were, the church was. We distanced ourselves from family and when we would be in environments or have relationships with people that were less accepting, I would just end those relationships, rather than try to teach them or try to think.

And even my employer, for example, I started at a company when Parker was 9 and my boss at the time, he was an unaccepting person when I said I have a son with autism and so I do need to take him to occasional doctor's appointments. *“Ohh, is he a hand flapper?”* OK, that's about like the worst thing you can say.And I said, *“well, no, he does not flap his hands. There's levels of autism, and that would be considered a level 3 and my son is not that,”* and blah blah blah.I changed jobs within the same company too and started working for a different Vice President, and that gentleman was like, *“wow, you do amazing things for your son, like you are so focused on him.”* He watched Parker grow up from 12 to 20 and just becoming, like he sort of…I mean, he knows my son and he's seen him and he's talked to him and he's helped him learn how to mountain climb and done little things like that with him and he's just watched him grow up a little bit and just has taken his approach.He would *never* say a statement like my first boss did.

So, I think…and this is interesting, none of your surveys asked about means or opportunity kind of stuff, but I think about we are an upper middle class income family and I think about all the resources that I can make available to my child, be it like at one point I stopped working full time, I only worked three days a week in the office because I needed more time with Parker.It was clear that things were going South, not better, since he was 14 and my boss just said, *“then you should only come to the office two or three days a week and you should only work six hours a day.”* Well, if I'm an African American woman living in subsidized housing and my job is at Walmart, that's not going to be how my boss responds.So, that has always weighed on me, and it's been very difficult for me to get comfortable with. I have insurance that lets him go to therapies, other families don't.I have a boss that lets me work whatever I want when I want, other families don't.I can provide therapies and things to him, I can buy books ad nauseum. I can turn my computer, my camera around and you can look at the bookshelf right here that's *full* of every book.And I don't like that dissonance that's created between haves and have nots when it comes to a child with special needs.

**Interviewer: [00:44:31]** Yeah, it's a very real thing, thank you for bringing it up. Thinking again more broadly and towards the future, what hopes or worries do you have thinking about how your son's community will react to his sensory needs in the future?

**Interviewee:** I worry that he won't be able to have an intimate relationship with a partner.

**Interviewer:** How so?

**Interviewee:** He's never been able to successfully have a girlfriend in high school. So, as much as he has had adult relationships that have been *incredibly* supportive and welcoming and accepting, he has not really had peer relationships that have been the same. His peer relationships when he got into the public high school, he fell into friendship with folks I wish he hadn't, and that was problematic. And so, I would introduce him, I would give him all these opportunities to be in different groups with different kinds of kids and he just couldn't click with them, they didn't understand him, he was weird, he was different. And if you know anything about peer friend groups in the teenage years, the folks who make the least positive choices will accept anyone and everyone into their grouping, and that's where he ended up. He had one girlfriend for like a week and a half, 2 weeks, and then he did stupid teenage boy things, said stupid teenage boy things and boom! She was gone. So, his ability to…this is less about sensory sensitivity and more about social boundaries and social norms, but he's still pretty weak there.

**Interviewer:** Do you have any hopes or worries about the community in regards to his sensory sensitivities?

**Interviewee:** No.

**Interviewer:** No? Awesome.

**Interviewee:** No, it's between the moderating and the coping skills for him, I don't think that those will hold him back.

**Interviewer:** Yeah, that makes sense, thank you. We're going to move to our next chunk of questions now. So, in this quote unquote transition to adulthood, where do you see your son?

**Interviewee:** Doing way better than anyone in the early years ever said he would be.

**Interviewer:** That's wonderful.

**Interviewee:** So, he is in college right now. He gets support services to make it through the academics of that, but he's written papers about the doctor who told me he wouldn't amount to much, and how that just did not define him, it did not become his future. So, I see him has as having accepted what he struggles with, managing it, using some of it to his advantage. For example, when he enrolled in his community college, he said, *“no Dr. Rugo said I'm not autistic anymore. I'm not going to go into access services and ask for help.”* I was like, *“alright dude, that's a mistake on your part as far as I’m concerned, because if you go in that office right there and you tell him that you have a diagnosis of autism, you can have someone take notes for you in class, you can have more time on tests, you can…”* He goes, *“ahhh OK, I'll go in that door.”* And so he's in this transitioning cycle of like, of the challenge of, when is a community supportive and when is a community not supportive? That I think will challenge him for a while.

**Interviewer:** Yeah. Could you talk a little bit about…

**Interviewee:** I have a work meeting that starts in 10 minutes.

**Interviewer:** OK, alright. So, this has been really great. We're not totally done, I don't think will finish in 10 minutes. Would you like to schedule another time to finish it? Would that be OK?

**Interviewee:** Yes, yeah. I apologize, I should have mentioned that to you earlier except looking at the screen and it popped up as a reminder.

**Interviewer:** No, this is a great time, this is a good segue, so that's not a problem. Let's look at my calendar, you look at yours and we’ll find a new time. Not a problem. You are not the first person, you will not be the last person, no problem at all. And thank you for telling me when you remembered.

**Interviewee:** Yeah. thankfully, Outlook remembered for me. We’ll be out of town all next week. Does that complicate things? It's not that I *can't* do an interview from there, but I would worry about scheduling something since I don't know what our weeks really gonna look like.

**Interviewer:** Then you tell me when you're good, don't worry about it.

**Interviewee:** How about…let’s see, because you're an early morning person too.

**Interviewer:** I can do whatever I will do late, I was in Seattle for 4 years so I am very comfortable with this time difference, so I don't care. Whenever is good for you, I'll make it work. **[00:49:34 inaudible]** I don't already have a meeting at that point in time.

**Interviewee:** So, the week of the 8th is not too late or bad?

**Interviewer:** No.

**Interviewee:** I'm just looking into my work calendar here real quick.

**Interviewer:** Yeah, of course, take your time.

**Interviewee:** So, what I'm hoping for is Tuesday the 9th.

**Interviewer:** I can do that. I have a couple of meetings, but will you let me know what's good for you and then we'll see if that works?

**Interviewee:** OK, how about my early morning? So, 6:00 AM, 7:00 AM, which would be 9:00, 10:00 in your time.

**Interviewer:** Yes, I can do 9:00 or 10:00. Which would you prefer?

**Interviewee:** Let’s do 9:00.

**Interviewer:** OK, so I have us down for Tuesday, February 9th at 6:00 AM you, 9:00 AM for me. Is that correct?

**Interviewee:** Yep, that's correct. And I do have a meeting that starts at 8:00 AM that morning my time, so I've got 2 hours.

**Interviewer:** We should be…we don't need 2 hours, so that's perfect. And thank you for that full window. No, this is great.

**Interviewee:** Speaking of interviews, how did your grad school interviews go?

**Interviewer:** Oh, thank you. It went really well. I had one on Monday, it was great, and I have one this afternoon.

**Interviewee:** Oh, good!

**Interviewer:** So yeah, so on a positive track. So, thank you for remembering, I really appreciate that.

**Interviewee:** Very good.

**Interviewer:** So, I'll let you go prep for your next meeting, but I will see you in about a week and a half and I hope you enjoy your time away from home or wherever you're going.

**Interviewee:** Yeah, we're gonna go to Idaho and go skiing.

**Interviewer:** Ohh, it'll be lovely. Yeah, I'm glad we're not scheduling. You should enjoy.

**Interviewee: [00:51:13]** Speaking of sensory things actually, he loves cold and snow and ice, he does not like heat and sweat, like sweat is prickly for him.

**Interviewer:** Interesting. OK, is this more than the average person you would say in terms of likes and dislikes.

**Interviewee:** Yeah, like we just don't go to hot places.

**Interviewer:** OK. Well, you're in a good spot for it, it's not too hot over there.

**Interviewee: [00:51:35 inaudible]** I was like, why are we going to a place that's an absolute frozen snowball right now? Oh right, because Parker would not want to go to Hawaii, he would not want to go to Arizona, he would not want to go to Florida, someplace warm, notwithstanding COVID right now, we just wouldn't go someplace warm and hot.

**Interviewer:** Yeah, I mean it's 9 degrees here right now, so I understand.

**Interviewee:** It's 10 and Idaho, so I got you by a degree.

**Interviewer:** Yeah **[laughs]**. Alright, thank you.

**Interviewee:** Alright. This was wonderful, thank you so much. I'll see you soon.

**Interviewer:** Alright, take care.

**Interviewee:** Bye.

**[END OF TRANSCRIPT]**