**[Start of transcript]**

**Interviewer:** Okay, we’re recording, perfect. I will be asking you questions about your perspectives about your child's transition to adulthood in relation to his sensory sensitivities and interests. And I’ll be doing a semi-structured interview where I have a set of planned questions, but I’ll be adapting the questions to follow our conversation and make it fit for us. Do you have any questions?

**Interviewee:** No.

**Interviewer:** Alright, you’re a pro. **[both laughing]** Could you please start off by telling me about your son’s sensory sensitivities and interests?

**Interviewee:** So, he is a highly sensitive child. He has always been very sensitive to light, bright lights, that is a huge aversion for him, like, huge aversion. I have to mention that on that sensory survey they said, *“Bright lights and brightly colored rooms,”* or something like that. And he’s like, *“I don’t mind brightly colored rooms, but I really mind bright lights.”* And so I actually clarified it, but I just, he was super, and that’s absolutely true, he likes colors, he’s fine with colors, although he did mention he does not like yellow on white, something about yellow on white. So, anyway, that’s probably been his, no, that’s so unreasonable, he has taste sensitivity, he also has auditory sensitivity, and what was interesting about that survey was his awareness or lack thereof about his auditory sensitivity. I do not think he is aware how sensitive he is. I had him answer the questions for himself on that survey, but my observation as a parent is that loud noises really shut him down.

**Interviewer:** And he doesn’t feel like that?

**Interviewee:** I think he doesn’t realize why he’s shutting down, I think he just knows he’s shutting down, so he doesn’t have the insight into the fact that it’s because things are loud and overwhelming.

**Interviewer:** Okay, got you. So, what about taste? What is he specifically sensitive to, or what are his preferences for taste?

**Interviewee:** I actually sat down with him the other night to come up with a list of foods he will eat, there were eight of them.

**Interviewer:** Eight foods. What are his eight foods?

**Interviewee:** It’s macaroni and cheese, pasta, he will eat rice, he doesn’t like it because it’s boring, grilled cheese sandwiches, did I say cheese pizza?

**Interviewer:** No, now you did...

**Interviewee:** Cheese pizza, quesadillas, you noticing a theme here? Cheese and white things, whatever that might be. I’m trying to think what else he eats, he’ll eat a peanut butter sandwich, **[00:03:00]** no jelly. Anyway, yeah, he’s got an incredibly limited, a really seriously limited diet, and when he was younger, I actually was trying to be a good mom and so I kept trying, like when you move from breastfeeding to food, I would give him the sweet potato baby food, which is pretty mild, and he refused to eat it, he would fling it across the room, and he actually started losing weight because he wouldn’t eat any of the baby food I gave him. Finally we had to just mix rice cereal with breast milk and slowly introduce the rice cereal, but he would never eat any of the baby food, he only wanted rice cereal. Super, super sensitive to taste. His pediatrician actually told me I had to stop trying to feed him the other things, because he was losing weight and babies shouldn’t be losing weight. He said I was going to give him an eating disorder, so, okay, I’m stopping. I expected that to get better over time, so I expected that when he hit adolescence and got hungry, he would start eating more foods, but that has not been the case at all, and actually he is now severely underweight, so yeah, it’s a real problem. I sent a picture to, so, we’re working with a geneticist with him, because he’s got some kind of connective tissue disorder, I don’t know what it is, we’re in the middle of figuring it out, and he was like, yeah, that’s scary, so he’s scary skinny right now. Literally you can see every bone, every rib, like his elbows are bigger than his arms, it’s just a real problem.

**Interviewer:** And he won’t eat enough of the things that he does like?

**Interviewee:** He will, oh, ice cream, I forgot ice cream, he loves cookies and cream ice cream. But yeah, he’ll eat a lot, and this is why we think he may have, like something is up with the connective tissue thing, because he’s eating a lot of calories, but he is not absorbing them for some reason. And we have to supplement with folic acid, a prescription form of it, so his body can take it in, otherwise he gets very deficient in folic acid. And the other thing I forgot to mention is that when he was little, his doctor looked at the foods he couldn’t eat and said that he was pretty sure Oliver had an extreme sensitivity to citric acid, which is in a lot of things. And so we just don’t feed him things that have citric acid in them.

**Interviewer:** So, citric acid as in stuff you would find in more processed foods? I guess citric acid is in everything.

**Interviewee:** It’s in a lot of fruits, **[00:06:00]** so he will not eat most fruits, any fruit, really, he just won’t eat fruit. It’s used as a preservative in a number of processed foods, but vegetables tend to have less, but they still have some. Like, I don’t know that sweet potatoes actually have any citric acid in them. I honestly think part of his deal is just that he doesn’t like it when anything is different. So, it’s like he gets used to the food the way it’s supposed to be and if there is any change to it, he does not want to try that.

**Interviewer:** Got you, mm-hmm. And then shifting to the auditory, you said like loud noises, can you talk about that a little bit?

**Interviewee:** Yeah, that was an interesting part of the sensory survey. He loves listening to music, he really loves music, a lot, if he chooses it. Actually he and I have very similar taste in music so that works out great. He does not like talking, so if I’m listening to a news thing on the radio, he gets upset. Now, I think a lot of that is because he actually also has an anxiety disorder and he gets upset by the news, because, frankly, it’s upsetting.

**Interviewer:** Oh, absolutely.

**Interviewee:** They don’t report on everybody is feeling good and singing kumbaya, they report on things that are upsetting. So, he will make me turn the radio off, and he’s very distrustful of all talk radio, all of it, he will not let anyone, like on his bus, if the bus driver is listening to talk radio, he makes her turn it off, like it’s crazy, he’s crazy about that. And he can hear it through the walls. So if you’re listening in the other room, he’s like, *“Mom! Turn off the voices.”* So, talking is different than music for him. He does not listen to the music loud, though, like, his brother will listen to the music loud, but not him. We literally just do not take him to any events that have any kind of possibility of the music being loud, or something like that.

**Interviewer:** Mm-hmm, for the other son or for Oliver?

**Interviewee:** For Oliver. It’s true for both of them, so we leave them at home.

**Interviewer:** There you go.

**Interviewee:** And the other one I wanted to mention was vestibular, because he does get motion sickness and he gets dizzy very easily. There’s just a whole motion sickness thing there, you know, a fear of heights, all the stuff that goes with vestibular stuff, he’s got that. One of the things we tried to get intervention for him, therapy for him for that, and he is so anxious **[00:09:00]** he couldn’t even take advantage of therapies to help get his symptoms, doing whatever they needed to do.

**Interviewer:** And then going back to the bright lights, what type of bright light? Is it natural bright light, sunshine?

**Interviewee:** Yeah, terrible, it’s terrible. We literally just have to put dark glasses and a hat on him before we go out any time.

**Interviewer:** It’s not like bright lights inside a house that wouldn’t bother him? Or like screens?

**Interviewee:** He keeps things pretty dim in his room. Screens, he’s fine with screens.

**Interviewer:** Okay, and then, sorry, jumping around again. For talking, is it just talk radio or like talking in general, does that bother him?

**Interviewee:** I don’t think that’s a sensory issue, I think it’s a topic issue. So, if we’re talking about something he is fine with us talking about, he is fine with it. But, if we are talking about something he doesn’t want us talking about, he is not fine with it. So, I don’t think that’s a sensory issue. Now, that said, his hearing is so sensitive he can hear us talking about something in the other room and say quit talking about whatever.

**Interviewer:** Yeah, they kind of go together a little bit.

**Interviewee:** Yeah, yeah.

**Interviewer:** And so how does he manage his sensitivities? Or, how do you help him manage them?

**Interviewee:** He wears noise-cancelling headphones a lot. That has been a really nice, I mean, we got him some nice Bose noise-cancelling headphones and that has made a huge difference for him. He’s way less stressed out. So, it’s interesting, when I was filling that form out, that he didn’t think he was all that sensitive, and I was like I don’t think you realize how much we’re accommodating. We literally do not play music in our house. Before kids we would always have music going, and that is not our world anymore. So, there’s no music in our house because we’re worried it might trigger something and we don’t want that.

**Interviewer:** Do you think if you weren’t so accommodating he would realize?

**Interviewee:** We work on it with his therapist, all the time. You’re probably familiar with all this, but we do things like when I’m driving with him, I will make him tolerate having the radio on for a minute, and then 2 minutes, and then 3 minutes, and then 5 minutes. And so we’ve been gradually creeping that up to like an hour and it’s very, very hard for him. So, we are trying, but it’s hard, you know, it’s hard.

**Interviewer:** Yeah, absolutely, absolutely. And then for his taste, how does he manage that?

**Interviewee:** We try **[00:12:00]** to introduce new things, like we’ll say just take one bite of the peas. We can do that with his brother, and his brother’s palate has expanded nicely with that intervention, but Oliver refuses, he just panics about new anything. It’s all part of his anxiety. The anxiety and the sensory stuff interact, so when his anxiety gets big, his sensory gets worse, it’s very, very linked.

**Interviewer:** Absolutely. That’s actually my next question for you. Well, I’m going to jump around, but that was such a nice segue, I’m just going to ask about it. So, how do his sensitivities cause or increase anxiety?

**Interviewee:** Well the sensory, fear of being exposed to something he can’t handle definitely triggers anxiety. There are things like we carry ear phone plugs always with us, he has a little thing that carries with him so that he knows he can handle that, and like I said, he always has sunglasses and a hat with him, those are big. Touch, I realize I didn’t touch on touch, that was actually interesting, boy he craves, we didn’t talk about craving, he craves deep touch, like craves it, and so he’s constantly bothering other people to get that for himself. So, friends at school, he’s constantly banging into them or tickling them so they will bang at him to make him stop. I have to say, again, he was not an accurate reporter on the sensory thing, because he thinks he doesn’t need that, but he does stuff, like he’ll just come in and want a hug, you know, he’s a very huggy person, so that deep touch really helps regulate him. He’s definitely somebody who needs that deep pressure, and he seeks it out, and he tells you he needs it. So that’s to answer this question, then that’s that, I just forgot to mention that he mentions that deep touch.

**Interviewer:** Absolutely. When he does get anxious because he feels like he won’t be able to handle something or he’s exposed to things he feels like he cannot handle, what does that anxiety look like for him?

**Interviewee:** Total refusal, and if you force him to do it, he will run.

**Interviewer:** Literally run?

**Interviewee:** Uh-huh.

**Interviewer:** And then how does he try to manage these anxieties.

**Interviewee:** Well, as I mentioned, we’re working with a therapist to try and teach him. I actually found this article a few months ago about how **[00:15:00]** sensory anxiety is different than regular anxiety and so the way you have to think about it and manage it is entirely different. He has both generalized anxiety disorder and social anxiety disorder, as well as sensory anxiety. And so managing the generalized anxiety, fear of us disappearing when we go, or Ted won’t like him if goes to some even with him that he hasn’t been to before, that kind of anxiety, he knows the techniques, we’re using CBT to help him learn to manage all that stuff, or a test, you know, all the usual anxiety-provoking things, he’s pretty good at talking himself through that using CBT, he’s actually really quite good at it. But the sensory anxiety is different, it is fundamentally different. And so a lot of that really just has to be us talking through it, so I’ve learned, before we go somewhere, we talk about it, like, here’s what’s likely to happen, how are you going to handle this, what do you want? Because he also doesn’t like looking different. So, wearing those noise-canceling headphones, sometimes that’s fine, like if he’s on the bus, or something, he’s fine with that. I don’t know, he even wears them in a movie theater. I think he just knows how much they help. But he does worry about what other people are thinking about him, too, so we’ll just brainstorm, like I say, *“Okay, you can wear the foam earplugs, they’re not as obvious,”* but it’s hard to hear stuff with those.

**Interviewer:** Okay, got you, that makes total sense. And then how have his sensitivities changed over time?

**Interviewee:** Generally much better. The heightened sensitivity is definitely less heightened, and the craving is definitely less intense than it used to be, so they both have gone towards the norm.

**Interviewer:** Yeah, so he seeks out that deep touch a lot less?

**Interviewee:** Yeah, I mean, he’s still, you know, when I wake him up in the morning he wants a backrub and I guess we have our little rituals that we do, but it feels less like if I don’t give this to him, it’s going to ruin it’s day, it’s not like that anymore, whereas it used to be like that. We used to play this game with him on the couch, we had a futon couch where we would put him on the couch and then we’d fold the back down over him, and we called it making an Oliver sandwich, he loved that, and we would make Oliver burritos, we also had this thing we called the family sandwich where he would stand in the middle and his dad and I would hug each other with him,**[00:18:00]** we’d all hug each other, he loved that. He definitely doesn’t require that kind of pressure anymore, but that was a big deal. When he was starting to feel really dysregulated, like he would want that pressure to help him. Actually, I had a jumping trampoline and I would tell him to go jump on the trampoline, because I think the proprioceptive input was really helpful for him, and it definitely helped regulate him, if was starting to lose it. Now I have the trampoline sitting here in my office for me. **[both laughing]** So, between sessions with clients I can jump on the trampoline.

**Interviewer:** That’s nice, I’m sure. Awesome. Do you think these changes are related to any independence that he has gained over time?

**Interviewee:** I’m going to say no. The independence he’s gained has been through sheer force of will on his part. I think he just has had to learn to barrel through his anxiety about things, and remember, he has all sorts of anxiety, so it’s been a long process.

**Interviewer:** Yeah, absolutely. And his anxiety specifically related to his sensory sensitivities, has that changed over time, or has that also been pretty constant?

**Interviewee:** It’s less, it’s definitely less.

**Interviewer:** And what do you think has made it less for him? Knowing how to manage it more?

**Interviewee:** I think the sensory issues are less, and so it’s less, well, maybe because it isn’t as dysregulating anymore.

**Interviewer:** Yeah, absolutely, that makes sense. And then has he received any particular therapies to help him with these sensitivities?

**Interviewee:** We tried. We had an OT and she worked with him, we kept trying, we kept trying, oh my god, we kept trying. I will tell you the only thing that helped was medication, I’ll just be honest about that.

**Interviewer:** Absolutely.

**Interviewee:** And it was the anti-anxiety, so he takes Buspar, Risperdal, and Wellbutrin, and those are all targeting anxiety, and he needs all of them. If we pull any one of those out, his sensory stuff goes crazy, his anxiety goes crazy, everything just gets bad.

**Interviewer:** Yeah, absolutely. What therapies have you tried with him and why don’t you think they worked for him?

**Interviewee:** He couldn’t make himself do them. So, we tried Wilbarger Brushing Protocol, we were working with an OT, but I’m not kidding you, after two months she was just like, *“This isn’t a good use of your money.”***[00:21:00]** He would just spend the whole session running away from her, and if we tried any of it at home, he would just run away from us, it was just not, he just couldn’t even get over it enough to participate in the therapy sessions at all. He was just so reactive.

**Interviewer:** It’s nice that she was that honest with you, though.

**Interviewee:** Oh, well, she’s still a friend to this day.

**Interviewer:** Good.

**Interviewee:** She worked with my older son, actually, from when I think he was 8, until he graduated from high school. She’s really wonderful, and she actually had her own daughter who had sensory issues. So she really got it from both a parent and a professional point of view.

**Interviewer:** That’s excellent, I’m glad you had someone like that on your team.

**Interviewee:** Oh my gosh, me too.

**Interviewer:** What are your hopes or goals for him in regards to sensory sensitivities interests moving forward?

**Interviewee:** Well, I have to tell you, just in the last three months he has been getting more thoughtful about that. For years what he wanted to do when he grew up was to be a video game designer. So we were making sure he was getting experience so that he could do that, and about three months ago, during the pandemic, he came to me one day to breakfast, and he said, *“Mom, you know what? I think it’s a bad idea for me to be a video game designer.”* He said, *“It’s very high pressure and you have to work fast,”* which is definitely not his forte, and he said, *“I just don’t think it’s a good match for who I am.”* And I said, *“Oh, well, what are you thinking?”* And he said, and this is interesting with the sound stuff, because remember I said he wasn’t so aware of it, he said, *“I think working in a library would be good for me.”* And I was like, *“I actually think that’s right, I think it would be really good for you,”* because he loves reading. I think that’s actually a very thoughtful, good choice for him.

**Interviewer:** That’s awesome. So, do you hope that he continues thoughtfulness about his sensitivities?

**Interviewee:** Oh yeah, the school he’s in is really good about teaching kids to advocate for themselves, and they’re very respectful of sensory stuff, and so, you know, sometimes they won’t let him do what he thinks he needs to do, because they don’t think it’s appropriate, and sometimes I agree with them, sometimes I don’t. But, I’ve always, from day one, said about him, that child is an incredibly effective self-advocate.

**Interviewer:** That’s awesome. That’s a really good skill.

**Interviewee:** Now, sometimes his advocacy is running away, but behavior is communication and so he’s telling us he can’t handle it, but he definitely **[00:24:00]** does not try to deal with a situation that he truly cannot handle. It’s actually been one of our challenges, with that anxiety, is that sensory or not, just trying to face something that’s overwhelming for him takes a lot for him to just get it, to be able to face that, and it’s hard, so he has to work really, really hard at it.

**Interviewer:** Absolutely. Now, shifting gears a little bit to our next chunk of questions, as he has grown up and aged a bit, how has your and his community reacted to his sensory sensitivities?

**Interviewee:** Community really don’t get it at all. So, like in my other interview with my other son, I was saying the community is very accepting of him. I can’t tell you how many people told us that our younger son was a bad kid when he was little, and he was not bad, he was just overwhelmed and that was really hard, and I don’t know that that’s really changed, and it’s caused him to retreat. He’s a very extroverted kid, he loves people, loves being with people, but he’s had to retreat and not interact with people as much, because they’re very judgmental, and a lot of it is his sensory stuff, honestly. So, if we’re in a restaurant and somebody is having a big, loud table over in the corner, that’s very hard for him to handle, and we had to learn that we just have to leave, that’s just how it has to be. So, it is very limiting for him, and I would say the community doesn’t get it, they don’t get it.

**Interviewer:** I’m sorry.

**Interviewee:** It is what it is. I think this is one of the challenges of sensory processing disorder, is that if you don’t understand what’s going on, it’s very hard to understand what that other person is going through.

**Interviewer:** Absolutely, it’s so internal, it can be hard to understand.

**Interviewee:** Exactly, exactly. So, I don’t blame the community, but honestly, it’s just so hard to explain all the time, it just gets tiresome.

**Interviewer:** I’m sure, I’m sure. So you kind of answered it, but was the community more or less accepting when he was younger?

**Interviewee:** Less accepting because his reactions were bigger. And to be honest with you, I think we did not understand what was going on until it was too late, so we would keep trying to convince him to stick with it and to try to deal with it, and he would just get to a point where he would completely lose his marbles. Now, when he says, *“Hey, it’s too loud in here, can I go take a walk around the restaurant,”* or whatever, then we’re like, **[00:27:00]** *“Yeah, absolutely, go, whatever you need.”* So, we give him the opportunity to self-regulate, whereas before we were like, *“No, you need to sit in your chair,”* so I think that has been, I honestly think it’s just because we get it more and we allow him to do what he needs to do more, and so he looks more self-regulated now, so probably people are less judging because he’s not losing his marbles.

**Interviewer:** Yeah, absolutely. And were there specific aspects of the community that were more or less accommodating and accepting? Like you talked about school, briefly.

**Interviewee:** You know, I hate to say this, but it’s absolutely true with him, we just stopped going to community events with him, and so I don’t know that we’ve given the community an opportunity. I will say this, it’s funny, as we’re sitting here talking about this, I’m thinking about, there’s a local restaurant here called The Silver Diner, and a lot of waiters there work at the University of Maryland, and they are super nice to him there, they’re super nice, and the waiters get what’s going on. Very often they will get what’s going on and they will say something like, *“Oh, you know, my neighbor’s kid,”* blah, blah, blah, or they’ll say, *“Oh, you know, I have a kid like that in my class.”* So the wait staff is definitely more aware now than they were when he was little. I definitely see a greater awareness growing.

**Interviewer:** That’s nice, at least.

**Interviewee:** Yeah, there are some restaurants we cannot take him to. This is a great sensory story. So, there’s this fabulous restaurant near here called Franklin’s, it’s a brew pub, and they have just sort of general brew pub kind of food, and we have been going to that restaurant literally since we moved here 25 years ago, so we’ve been going there for a long time. And at one point they decided to take macaroni and cheese off the menu, and because they did that, there was literally no food that he could eat there, and so we had to stop going, because there was nothing for him to eat there. So, we showed up, and we’re friends with the owner, and we like the owner, and the owner saw us and he came over and he said, *“Hey, you haven’t been here in a while.”* And I said, *“Yeah, well, you stopped serving macaroni and cheese and there’s nothing Oliver can eat here. We talked him into coming to eat french-fries.”* And the owner looked like I had kind of punched him in the gut, because we had been very regular customers, and he knew that we weren’t there. **[00:30:00]** So he said, *“Yeah, the chef found it boring and he wanted to kind of spice things up.”* And I said, *“Well, you know, he’s a kid, and kids don’t like exciting food. That’s that deal.”* And I said, *“Alan, my husband, and I will definitely keep coming.”* So then he went away and about 20 minutes later he came back to our table, he clearly had been worrying about it and thinking about it, and he said, *“I have to tell you, I have had several families have this experience, and it’s all boys.”* And I was like, that is super interesting. So, anyway, that’s a little sensory story for you.

**Interviewer:** Yeah, did they put it back on the menu?

**Interviewee:** Nope.

**Interviewer:** Oh, that’s what I thought the gut shot was going to be.

**Interviewee:** No, no, we’re one family out of hundreds.

**Interviewer:** Absolutely, I was hoping for that ending of the story.

**Interviewee:** I was hoping for it too, but you know, c'est la vie.

**Interviewer:** Yeah, it is what it is. Thank you for sharing that story, it’s a really nice example.

**Interviewee:** Yeah, yeah.

**Interviewer:** And again, kind of thinking ahead to the future, what are your hopes where he is in terms of how the community will react to him in regards to his sensory sensitivities in the future?

**Interviewee:** Well, that example I think is a good one. I would hope that restaurants could, for example, provide a range of things so that people like him can go out with people like me who like to eat a wide variety of things, and we can all enjoy the food together. You know, the other thing I’ll just say about restaurants is some chefs can be super judgey, so they’ll try to make it look, we have to say constantly, we order the mac and cheese and we’re like don’t put anything on it, no little green things on top, no little fun additions to the cheese, just give us mac and cheese. And the chefs, sometimes they just can’t, I mean they’re creative people and they want make something yummy, but for my son, that is not yummy, he can’t eat his dinner. So, what I would hope is that people would understand that if you want to be creative, get creative with the creative foods, but provide something for the people who don’t, can’t eat that. So, that’s just an example, I wish that was an option. And another one I’ll tell you that I really wish for is loud restaurant, so very often in restaurants, and you will notice there is a theme here, restaurants can be very disabling. There’s this idea that if a restaurant is loud it is fun, and therefore they do things in restaurants where like all the walls reflect the sound, all the tables reflect sound, the floors reflect sound, and it’s very loud. And so that means we **[00:33:00]** literally cannot go to some restaurants because they’re so loud. And I really do think it’s an ADA issue, I really do. My dad also has tinnitus, and he can’t go into those same restaurants, because it sets his ears ringing, and so it’s really terrible for him. So, what I would love is if restaurants, for example, had a quiet area. All it would take is literally putting a tablecloth on the tables, it wouldn’t take that much to put something in there that would absorb some of the sound, or acoustic tiles in the ceiling. But I think there’s this thing in our society about how loud equals fun, and unfortunately for somebody like my son, it does not equal fun, it just means he can’t go. But my hope is that eventually people will figure that out. I don’t see things moving in that direction, but I wish for it. There are some restaurants I’ve noticed started opening, having sections that are separate, so I can hope for that to change over time. Food and sound are definitely something, I’ll talk about lights, let’s talk about fluorescent lighting.

**Interviewer:** Yes.

**Interviewee:** Or LED lighting, I didn’t even talk about that earlier, but actually, they trigger migraines for me, fluorescents do, and so very often I have to switch, and also I’m sensitive to the hue of light, I believe Oliver is too. So, cooler lights are not as easy for him to be around, and warmer spectrum, so more towards yellow, is definitely, he doesn’t get edgy as fast in rooms that have the yellow, the warmer spectrum. Again, this is something most people just aren’t aware of. I’ve had to learn to be aware of it partly because of me and partly because of him. So, wearing tinted glasses that change the hue of what’s coming into your eyeballs, is a good accommodation for that. And so his sunglasses, if we have yellow lenses, that will make it easier for him, so these are all things that we can do to make situations, but fluorescents that flicker, it’s terrible and it’s not about brightness, it’s literally about the flicker.

**Interviewer:** I don’t think you and your son are alone in that, I think it bothers a lot of people.

**Interviewee:** Yeah, it does, it does. And I’m seeing everybody move to LED lights now, and LEDs, you can change the frequency and some of them are still flickery, but some of them are not flickery, and it’s very helpful.

**Interviewer:** Good. I had a quick question, you mentioned that your son doesn’t like it when the chefs make mac and cheese all fancy. If you’re able to remove those fancy components, **[00:36:00]** like the parsley, or whatever, will he still eat it or is it no, not for me anymore?

**Interviewee:** I spent most of my parenting life with this child picking little pieces of parsley off of things. So, yeah, he’ll eat it, he’s fine if you take it off.

**Interviewer:** Got you, at least that.

**Interviewee:** And what will happen is I hate being a high maintenance customer, I really hate it, so they’ll bring it and it will have green stuff, and I’ll be like, ugh, or ice in his water, that’s another one, don’t bring ice in his water after we said no ice, and I can’t tell you how many cups of water I have just pulled all the ice from his glass into my glass and then given him the water without ice in it. And the waiter will come over and I’ll be like picking the little green things off, and he’s like, *“Oh, the chef didn’t do that,”* and just feel bad about it. And so I should be better about saying, *“Hey we said no green stuff, and you put green stuff on here, could you do it again?”* But that’s partly because I worked in a restaurant for a while and I know that chefs get mad at people when they send stuff back and they do things to the food, and so I don’t want to do that.

**Interviewer:** That’s reasonable. Does he not like ice? Is it a temperature or a texture against his teeth? Sometimes people don’t like the feeling of ice on their teeth.

**Interviewee:** Yeah, that’s a really good question, I think it’s definitely temperature and just recently he started putting together that the ice makes the water cool, and he does like cold water when it’s hot outside, so he’s starting to realize that might be a good thing. He’s 8, and he’s just finally figuring that out.

**Interviewer:** It’s okay, we all get there.

**Interviewee:** So, those issues all come to play for him, for sure. Those are sensory challenges. I worry about office buildings, if they have fluorescent fixtures in them, I worry that will be, if there are no windows and that’s the only light source, that may be really hard for him. It just depends on where he ends up working and how accommodating they are able to be. Because if you’ve got a whole library outfitted with fluorescent lights that come on when you go into that region, they’re not going to rewire the whole thing with a different kind of lightbulb just for him, I get that’s not going to be a reasonable thing.

**Interviewer:** Yeah, unfortunately, probably not. Now, shifting gears again, in that transition to adulthood, where do you see your son?

**Interviewee:** Do you want me to answer that just with regards to sensitivities?

**Interviewer:** In general, and then we’re going to put them together in the next chunk, but if you’d like to sprinkle some answers in, go for it.

**Interviewee:** I’m actually pretty worried about him. I mentioned slow processing speed, **[00:39:00]** he definitely has slow processing speed and I think it’s very hard to stay patient, I mean, it’s hard for me as a parent, and I know he has slow processing speed, and it’s hard for me to stay patient while he gets it together. I can’t imagine an employer will put up with that. So, I don’t know, I don’t know. I’m pretty worried about him, to be honest. I definitely don’t think he can handle a 40-hour work week, I do not think that’s possible for him, it’s just too much. As far as time goes, he literally gets 3 times extended time on tests, which is very unusual, and I have to tell you, the college board granted him 3 times extended time, I have never seen them grant that much extended time on anyone and I work with families to get those accommodations and I couldn’t believe they gave it to him, but they did. I think we had a very good case because we had gradually inched it up over the years, and he literally could not complete any of those standardized tests. I actually think that is the thing that is going to be the hardest for him in being employable, because nobody is going to want to pay him, I mean, if they could pay him at a third of the rate to get the same amount of work done, maybe they could do that, but it’s a real problem.

**Interviewer:** For sure. In terms of independence, where is he? I know he lives at home with you, does he want to live by himself eventually? Can he take care of himself on a daily basis? Things like that.

**Interviewee:** He lives at home with us right now, he wants to live independently, I would love that, and he can do his own laundry. He does not do hygiene independently, we have to constantly ride him about it, and I mean constantly. He had dentist appointment yesterday morning and I said, *“You know, you need to brush your teeth before you go to the dentist.”* And he said, *“Mom, I brushed my teeth three days ago.”* And I’m just like, that’s disgusting. And by the way, that’s also a sensory thing, the tooth brushing is also a sensory thing that causes problems for him. So, hygiene is just a big deal. I haven’t even talked about this, the feel of water on his skin literally burns, to him it feels like it burns, and so he does not like taking showers. He likes being in a cool water, like going swimming, he’s okay, and I think it’s because the coolness sort of offsets the sting of the water. So, anyway, that’s super challenging and we basically just had to say, we tried for years to figure out what way of bathing would keep him clean enough to be presentable **[00:42:00]** but that’s very limiting, right? You got a kid who can’t stay clean, that’s gross, and nobody wants to be around them, nobody wants to hire them, that’s a real problem, so it’s a big deal. And frankly, he’s a teenage boy, so there’s a whole thing with that, as well. So, that’s one thing. As far as cooking goes, he is pretty independent about cooking easy microwave type things, toasting things up, he’s good. He’s afraid of fire and so he makes his brother deal with the stove, which is not going to be a win when he lives independently, but he’s capable of doing it, he just doesn’t, he would prefer other people to do it for him, because, wouldn’t we all prefer to have our own personal person to do everything for us? But that’s not the way the world works. He’s very responsible, very responsible. As far as things like paying the bills on time or taking care of things like that, I think he will be good at that. So, he’s a pretty complex picture.

**Interviewer:** Yeah, absolutely, does he have any experience managing some money, does he understand the concept of money, how to manage it?

**Interviewee:** That’s a great question. One of the ways we dealt with our kids and money is that when they were little, there comes a phase in all children where they go from wanting really cheap plastic junk that costs nothing to wanting things that actually cost real money. So, when they’re little you can just say, oh yeah, I’ll get you the little thing that costs a dollar, whatever, where you don’t care, and then they’re like, and I want the fifty-dollar video game. And you’re like, yeah, the fifty-dollar video game is real money. So, what happened is when they made that switch, we started giving them an allowance, and basically anything that was fun for them, I was like, that’s your job to save up for that. So, of course, we give them presents for their birthday or Christmas, so we would give them an allowance and they would have to save for it. He was a little slower on the uptake than his brother was, so he would do stuff like go into the store and impulsively buy something with his allowance, and then he would be like, oh no, now I can’t get the video because I bought this other thing that I didn’t really need. It took him probably a year. Now, he saves every penny, and he did save up and buy himself an Apple computer.

**Interviewer:** Wow, that’s not trivial.

**Interviewee:** That was a three-year savings plan that he had to go through, so he saved up, and yeah, he spent little bits now and again, but he did save up. He’s very good with his money now. **[00:45:00]** And that’s true for both our kids, I’m really glad that one worked out, because you never know if it will. **[both laughing]**

**Interviewer:** That’s a really good life skill, that’s very important. And then what about, has he had a job before?

**Interviewee:** He’s at a school for kids with autism and his school does what they call job sampling, so they have you help with office tasks, they have a little student café, so you be a cashier, you can serve the food, you can run the food to classrooms, and one of them is you collate orders, and then you go to a restaurant and pick the orders up and give it out to everybody who placed the order. So, he has helped out with that. So they’re these little job sampling things, one of the things about this coronavirus that really sucks is this year was his big year to get real job experience.

**Interviewer:** Oh, that’s a bummer.

**Interviewee:** It sucks, it really sucks, because partly that kind of job experience is predictive of success, it just is what it is.

**Interviewer:** It’s very unfortunate...

**Interviewee:** He’s alive, he’s alive... **[both laughing]**

**Interviewer:** ...he’s alive, he’s healthy, but you can still be disappointed. They can exist at the same time. Yeah, and then what about a social life, does he have friends? Is he able to manage?

**Interviewee:** He is extremely extroverted, he loves being with other people. It has been interesting with the coronavirus stuff, so, we’ve been in quarantine basically since mid-March and he really misses his friends a lot, he misses them a lot. So, we kept working with his therapist to get over the anxiety about reaching out to contact them, and he has two really, really good friends that he enjoys hanging out with, and I would say it took him until about probably middle to end of May to reach out to these friends, he talks to them on Discord, and his friend Kyle, he’ll FaceTime with Kyle a lot. His other friend, he definitely prefers interacting through text, and the friend prefers that too, they’re both good. He’s very active in online communities and since he was 13 and was allowed to go on them, he was definitely always making friends online and things like that. And at school, sometimes we’ll arrange parent dinners where we get the class together and we’ll just all meet at Silver Diner, or something like that, watching him interact with his friends, **[00:48:00]** he’s a really good friend. He’s a very nice person.

**Interviewer:** That’s nice.

**Interviewee:** I can watch him, like, he’s taking care of everybody and making sure everybody is happy. If somebody is not talking to someone, he’ll go over and talk to them. If somebody looks upset, he’ll go over and make sure they’re okay, just a really nice person. And the kids like him. I can see that he has friends and they like him.

**Interviewer:** That’s excellent.

**Interviewee:** So, he’s very social, and the pandemic has definitely made it to where he has had to get more organized about actually connecting with people...

**Interviewer:** Mm-hmm, you have to...

**Interviewee:** ...we can’t do it any other way, so that’s been a learning process for him, but he’s definitely getting better about it. Like now, it used to be he was just like, *“Oh, I miss Kyle so much,”* and I was like, *“Well, call Kyle, arrange a time to hang out with Kyle,”* and he resisted that for months, but now he’s doing it I’d say at least weekly, just calling Kyle up and talking to him, so that’s been nice.

**Interviewer:** That sounds awesome. And then again, thinking ahead to the future, do you think he will be able to achieve more independence when he’s older?

**Interviewee:** Than he has now?

**Interviewer:** Mm-hmm.

**Interviewee:** Oh yeah, absolutely, yeah, yeah.

**Interviewer:** Like, what type of independence do you see for him? How do you think he will achieve that, when?

**Interviewee:** Well, he wants to live independently and I want him to be able to do that. We’re in the middle of applying for SSI because I do think he’s going to need that kind of support, and honestly I worry about healthcare with him to be really blunt about it. So, if we can get SSI, he can be on Medicaid, and then he has insurance covering things. So, we’re definitely worrying about that. I would love for him to have a job, you know, but as I said earlier, I just don’t know what’s going to be possible for him. He is working on it, and I think he’s developing maturity and insight around what he needs, and so I think as he experiences different things, he’ll find his place. But, you know, I have to think he will find something to do, and a way to contribute to the world.

**Interviewer:** Oh yeah, absolutely. And what do you think will help him move into adulthood?

**Interviewee:** A lot of support, and a lot of pushing. His default strategy, like I said, is to run away or to hide, that is his strategy and that’s not a good strategy for moving forward. So, we are constantly having to figure out how to give that gentle push while still being supportive **[00:51:00]** and we just keep working at it with his therapist, with him, I keep hoping that at some point, I mean, I’ve seen kids who do cognitive behavior therapy who don’t have autism, and once they learn the skills for managing their anxiety, it’s like, they take off. That is not the experience we are having with Oliver at all. For him it’s just very gradual changes and so I keep just hoping that he learns the strategies to face what he needs to face and decide what he can handle, but we have to keep pushing him, because that anxiety, and it’s not sensory anxiety necessarily, it’s all these kinds of anxiety, we just have to keep pushing him forward bit by bit and expressing our confidence in him. The thing that’s painful about it is, you know, he’s 18, so developmentally, he wants to be separate from us, and he knows he can’t be. A friend of mine calls this “hostile dependence.” That’s a very accurate term.

**Interviewer:** It is, that’s great.

**Interviewee:** And that’s where we are. He knows he is dependent on us right now. He wants to be independent, I want him to be independent, but I’m not going to just throw him out there to fall apart at the seams.

**Interviewer:** Yeah, about.

**Interviewee:** So it’s a constant very gentle push.

**Interviewer:** And other than therapy, or just perhaps therapy, do you see other services or interventions in his future to help him move towards adulthood?

**Interviewee:** He’s on a waiver program, a Medicaid waiver program for kids under 21, and what they are giving us, and he asked for this, was a peer mentor. So, he wanted somebody who he could talk to about a job, somebody who is a little bit ahead of him who could say, *“Here are the things I’ve faced in trying to get a job. Here’s advice I give you based on my experiences.”* And so right now we’re in the middle of getting the Developmental Disabilities Administration to approve the funding, and then we’ll hire somebody to do that. So, that’s a support he identified as wanting. I honestly think, you know what I really wish? I wish boarding houses still existed, because I actually think he would do great living in a boarding house, where somebody else fixed the meals, he would have them ready at a reasonable time, he doesn’t need much, he just needs a room to sleep in. As far as relationships go, we haven’t touched on that, but he’s very clear, he does not ever want to get married, and he does not ever want kids. And the reason about the kids is they’re too loud and unpredictable, and it’s definitely a sensory thing. **[00:54:00]** He says he doesn’t want to get married because of, honestly, sensory issues, to be really blunt about it.

**Interviewer:** Absolutely. Do you think he would want it from like a social part of it, though? You mentioned how social he was.

**Interviewee:** Absolutely, and I keep trying to say, marriages are different, you just have to be honest with your partner. You might find somebody who actually doesn’t want the physical side, you know, like they may be similar to you, but you have to be honest the people, don’t pretend to be something you’re not, you just tell them what you need and if they’re not a good match for you, they’re not a good match for you. But, people are all different, and so I’m working with him on that, because I do, the social of it I think having somebody, a partner in life, oh, he would be so happy, he would love that. Like I said, he’s such a social guy. He does have these really close friends that he enjoys talking to and learns from. The reason he figured the thing out about gaming is friends of his online were like, *“We don’t think that might be the right career for you. Maybe you should think about this other thing.”* It was his friends who helped him with that. So, I think he understands the value of friends and he does really love other people, he loves people.

**Interviewer:** Absolutely, that makes sense. We’re going to shift again, now kind of putting these two things together, sensory sensitivities and the transition to adulthood, how do they intersect for him?

**Interviewee:** I think he’s going to have to find a career that allows him to be who he is without stressing him out all the time, and it’s going to be a process of trial and error, I think. He’s just going to have to try something and see if it works for him. I was thinking as we were talking, I used to work at the University of Maryland here, and there was a guy who did a lot of coding for our projects, he would design software for us, and I’m pretty sure he had sensory issues. You would go into his office, which was this interior office, and he had a halogen light on, it was like the dimmest light imaginable, we called him the mole **[both laughing]** and he was a super sweet guy, but he really couldn’t stand it, when he would walk out into the hallway he would start crying, it literally was that overwhelming. And so if my son could find a situation like that where people are like, that’s just how he is, and let him structure things so that he would be productive there, I think he would be fine, and I think he would be a very good employee, I mean, he really does want to please other people when it doesn’t get in the way of his mental wellbeing. **[00:57:00]**

**Interviewer:** Yeah, absolutely. And then do you think his sensory sensitivities interests are a vehicle, an obstacle, or a bit of both for him in terms of independence?

**Interviewee:** I think it’s mostly an obstacle.

**Interviewer:** How is it mostly an obstacle?

**Interviewee:** Because he’s oversensitive, he spends a lot of time trying to protect himself from exposure, so that is work for him. You know, it’s funny, you’re going to think I had like 10,000 jobs, which I probably did, but one of the things in a past life was I did a lot of audio engineering, and I have very sensitive hearing, and so I would do things like I would work with recordings, splicing things together, I was very, very good at that job. That is an example of a job where being sensitive to the audio is an enhancement, it made me good at my job. I keep saying to him, *“If you could get a job where you were required to listen carefully for things,”* that could be for him. He is not interested because I suggested it, I’m his mom, and I don’t know, he may come there, I don’t know. So, if he could find something like that, I actually think it would be an enhancement, it would be a gift to him. But right now, the things he’s interested in, I think it feels to me like he’s just trying to protect himself from being overwhelmed.

**Interviewer:** That makes perfect sense, thank you. I was going to ask you why it was only “mostly,” so you answered my question. And so what do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities and sensory interests?

**Interviewee:** I think that his awareness, he’s very good at self-advocating, I will say that, he’s totally got the self-advocacy piece down, so that’s good. But I would say he’s not terribly aware of what’s driving him at times. And so until he develops that awareness, I think it could be a real obstacle. As we’re talking, I’m thinking I need to start working on that and just pointing out to him, *“You know, the reason you’re shutting down right now is because,”* whatever. Or, I could ask him, *“Is it too loud right now?”* Just getting him thinking about it, so he can start developing and doing more of that.

**Interviewer:** Absolutely, I’m sorry, if you hear noise in the background **[01:00:00]** I’m in the living room and the microwave is now going, so, I’m sorry. **[both laughing]**

**Interviewee:** It’s a pandemic, and we’re all in our houses.

**Interviewer:** So, my apologies.

**Interviewee:** Don’t apologize.

**Interviewer:** What do you think will help him in this realm of how sensory sensitivities intersect with his independence?

**Interviewee:** That’s a long complex answer, I’ve given you some parts of it. I feel like educating the world about this difference, especially it is very invisible. I think during our last interview I mentioned that book, The Out-of-Sync Child Grows Up. So, because my other son wrote a chapter or two in there, we went to the book launch party, or whatever, and they had adults who had contributed to the book talking about their sensory lives as adults, and I’ll tell you what I walked away from that with is that it’s not that you ever get less sensitive, it’s that you develop good coping strategies, so you learn how to structure your own environment so that it is not overwhelming to you. That was just one of the biggest messages of that launch party and I do think that’s the secret to Oliver’s success, being aware and being able to say this is what I need, and if an employer can’t do that, he needs a different employer.

**Interviewer:** Mm-hmm, that’s so well phrased, thank you. Do you think there are services or interventions that could help him in this realm?

**Interviewee:** You know, I find myself wondering as we’re talking whether going back to an OT or somebody to help him develop, the thing is, I mean, honestly, I do this for a living. I work with parents and help them figure out how to help their kids. And I’ve done everything I can for him, and some stuff is just really impervious to intervention and for him, I think I mentioned when I was talking about my other son. My other son did the listening therapy. We tried the listening therapy with Oliver, it absolutely did nothing for him. Now, I don’t know if that’s because he was so busy fighting it that he couldn’t take advantage of it, I just don’t know, and I’m wondering if now that he’s older, if we could retry some of those things and see if they would help him. So, you know, maybe I should retry the listening therapy, maybe we should retry the Wilbarger Brushing Protocol, **[01:03:00]** who knows? But those are some things that might be worth it. But maybe, maybe not. We can say this is what we got here, and figure out how to help and structure his world so he can successful.

**Interviewer:** Yeah, absolutely. And do you think there are gaps in the available services for him?

**Interviewee:** Oh god, don’t even get me started. **[both laughing]** The service cliff when you hit adulthood is so ridiculous. I’ll just tell you a story about my older son who had a significant language delay, and when he turned 8, when he turned 13, and when he turned 18, so we had him in speech therapy all that time, and at each of those boundaries, insurance stopped paying, there were just like, nope, we’re not, he doesn’t need this. Which was not true. So, we had to appeal, my husband is a government employee, we had to appeal in all cases, all the way up to the Office of Personnel Management, and get them to tell the insurer that they were denying him services that he was entitled to, and most OT stuff for adults is really focused more on fine motor skills and job readiness skills, which are very necessary, and I honestly think he could benefit from that. But the ones who work with adults tend to not deal with sensory stuff, it’s just not their world. And so I don’t know, I could probably find somebody who be willing to work with him, but in my experience, the pediatric OT people very often do get the sensory piece, but the adult OT people tend not to focus on that. I don’t know if they get it or not, but they tend not to focus on it. So, I’ll just offer that.

**Interviewer:** Yeah, that’s really helpful, thank you. And how did his sensory sensitivities and interest impact your goals, hopes, and expectations for him as he is navigating adulthood?

**Interviewee:** When your kids are little, one of the processes that’s hard about getting a diagnosis is giving up on your totally ill-informed ideas about what your child is going to want for themselves when they grow up and what’s going to be possible for them. So, he was definitely, I mean, he was do reactive and honestly he was a hot mess from the minute he was born, and it was sensory stuff, really, everything, he was incredibly reactive too. It was a very, very hard childhood, and honestly, with him, I’m not kidding you, from probably 6 weeks on, it was like this child **[01:06:00]**needs serious help and I was in the doctors’ offices saying you have got to help me, you’ve got to help me, and nobody will really do anything until they’re about 4 or 5, and so, because kids are different, but he was so different than every other kid I have ever dealt with, that I knew he definitely needed help, but you just can’t get help, and so you basically just kind of hang on until they’re 5, and then you’re like, okay, now people will start prescribing medication, people will allow them to, we did have him in OT when he was little, so during that time you’re just like, I don’t see how this is every going to play out in a good way over the long haul, right? So you let go of those dreams at that point. I had a friend, she’s wonderful, she was a director of the school Oliver was in from 4th grade to 8th grade, and she said, *“All kids take it out of you eventually, kids with autism take it out of you sooner.”* And that is absolutely the case with him. I just had to let go of every expectation I had and say we’ve got him here, we’re going to try to move him here, and we’re just going to keep trying to move in a direction that feels constructive for him, and I don’t think about the future too much. I prepare, you can hear, I’m putting all the supports in place and so on, and that same principal actually said, *“You gotta prepare for the worst and hope for the best.”* And so that’s what I’m doing, I’m preparing for the worst and hoping for the best, trying to move him incrementally towards the best, but yeah, I really have no expectations, I just want him to make progress, I want him to keep making progress.

**Interviewer:** Mm-hmm, absolutely, thank you for sharing that. We’re going to go to the next chunk of questions, we’re almost there. Finally, as a caregiver, as a mom, as a parent who has ASD but also has sensory sensitivities, what does transitioning to adulthood mean to you specifically?

**Interviewee:** As you said that **[laughing]** I thought, if he lives in his own place, I can play music again in my own house **[both laughing]**. So, honestly, our house is so geared towards not triggering him. And I would love to return to my life where I can have pictures on the wall that I like, that I can listen to the radio I want to listen to, I can listen to the music I want to listen, I don’t have to walk on eggshells worrying all the time whether **[01:09:00]** I’m going to upset him somehow, and unfortunately all those things involve him moving out. I feel bad saying that, but I actually think it’s kind of a biological thing, like kicking the little birds out of the nest is a real biological imperative, so yeah, that’s kind of a selfish thing to say...

**Interviewer:** No, that’s a very human thing to say.

**Interviewee:** It’s just the darned truth, I really look forward to being able, here’s an example, my kids are older now, so we don’t have to take them everywhere with us, and my husband and I bought kayaks and we are going kayaking all the time now, kids don’t come with us, because they’re older, they can stay home alone, and my husband and he get to go in the water, right? So this is not an activity Oliver would ever want to participate in, but we get to go kayaking and have a really nice time. So, that’s an example of something I get to do now, because he’s old enough to take care of himself, you know, he’s never going to want to go kayaking, that’s not going to be a thing he wants, but it’s something that makes us happy and so we’re doing it more now that he’s old enough to do the things that make him happy while we do the things that make us happy.

**Interviewer:** Yeah, that’s great, it’s important for you to be happy for you to be happy, too.

**Interviewee:** Well, it’s hard, you know, when your kids are little you really do have to just give up on a lot of stuff, and that’s just the way it is, and I think when you have kids who are a little more than the other kids, you give up more, you really do. You know, you do it willingly. I always say they didn’t choose to be brought into this world, you chose to bring them into this world, so you do your best for them and help them through it. But I’m not saying it’s not hard, because it is definitely hard.

**Interviewer:** I’m sure. And has this perspective changed over time for you?

**Interviewee:** Yes, very much so. When the kids were little, I really just thought this was the way life was going to be forever and as they’ve gotten older, I’ve realized I cannot, cannot do it anymore for my own mental health. I need to do the things that make me feel okay, and I have just honestly had to give up on some things for them that might have been ideal for them that were not ideal for me, and my own mental health started mattering in a very fundamental way. And so I just had to get real about it, I had to say, you know what, I know it might be better if he had an hour of OT a week, but I can’t handle one more appointment in the week, he’s already going to three appointments a week, and adding another one, I can’t do it. Okay, if that would have been good for him, too bad, I can’t do it, I just can’t. And so it feels selfish, and when he was littler, I absolutely would have just moved heaven and earth to make it happen, **[01:12:00]** and I can’t do that, I just can’t do it anymore.

**Interviewer:** You can’t do other things if your mental health is gone.

**Interviewee:** Yeah, I actually teach a class for parents called “First Put On Your Own Oxygen Mask.”

**Interviewer:** It’s important, absolutely. And then what do you see happening in his future, unless you don’t think to the future too much, though.

**Interviewee:** Yeah, I’ve learned not to because all that happens is it’s not right. So, there’s not really much of a point to it. To honest with you, I do see him being in a long-term relationship with somebody, I definitely see that as a possibility for him. I think it will happen, I think he’s just in that teenage place of, you know, I’m never going to get married, whatever, he just hasn’t met the right person yet. So, I do see him in a long-term relationship, I do see him living independently. I do not know what his job prospects are, and I have to say, filling that form out last night made me less sure that he could hold on to a full-time job, that was so hard, it was like wow, if I were a supervisor, I would not put up with this, so, anyway.

**Interviewer:** Absolutely, well, I have one last formal question for you. How has his sensory sensitivities and interests impacted this perspective that you have?

**Interviewee:** I think it’s driven my perspective. It defines him in a way that I don’t think most of us, if you don’t have sensory issues, you don’t really think about smell or taste, or whatever, you don’t think about if I go to that restaurant is there going to be something on the menu I can eat? You don’t think about is it going to be so loud in there I’m going to have to leave? You don’t think about any of those things. And it literally defines every moment of his day.

**Interviewer:** Mm-hmm, absolutely. Thank you. Well, that’s all I have, would you like to add anything else?

**Interviewee:** Nope.

**Interviewer:** Awesome, thank you.

**Interviewee:** I’ve unloaded on you.

**Interviewer:** No, it’s been so helpful, it’s so interesting to hear every parent’s perspective, and you’re the same parent, but you have a different perspective, and it’s so interesting to hear, thank you.

**Interviewee:** Yeah, I told you it was going to be a really different interview.

**Interviewer:** Yes, it’s great. I do have one nonformal question, I was looking at your demographic form and in the current services you checked the ‘other’ box, but you didn’t say what other. Is that the relational development intervention?

**Interviewee:** Yeah, that was the RDI, yes.

**Interviewer:** Okay, and how many hours a week does he have that currently? **[01:15:00]**

**Interviewee:** Well, so, that’s a parent mediated intervention, so basically I get the intervention and then I do things at home, it basically changes how I interact with him. And I honestly, the thing about RDI is that it teaches you to just do, grab every moment that you can during the day to use the strategies, and so on. So, I meet with my consultant once every two weeks for an hour, but we’re kind of grabbing those little RDI moments any time we can.

**Interviewer:** Gotcha, awesome, thank you. I’ll change it on the form, that way it’s not blank.

**Interviewee:** Yeah, I remember thinking, I can’t enter the ‘other’ something happened and I remember thinking, this is weird, I really need to indicate this here, but I can’t, so I don’t know what that was.

**Interviewer:** Yeah, it should work, but I’ll check it.

**Interviewee:** User error. **[both laughing]** I’m pretty sure it would be user error.

**Interviewer:** Well, I’ll check, I mean, it could be design error, so you know, who knows.

**Interviewee:** I would suspect user error.

**Interviewer:** No worries, thank you. Do you know anyone else who might want to participate or be eligible? We’re still looking.

**Interviewee:** I have to tell you, if you’re willing, I have some list serves here that I am part of, that I would love to forward this to them.

**Interviewer:** Yes.

**Interviewee:** It would definitely, you know, they serve a large part of the DC Metro area.

**Interviewer:** Great.

**Interviewee:** Okay, you’re okay with that?

**Interviewer:** Yes, we want everyone, and it’s all remote, so as long as I know the time difference, it doesn’t matter where you are.

**Interviewee:** Okay, that’s great.

**Interviewer:** I can send you an email with all the recruitment materials.

**Interviewee:** Yeah, send me the email you would like me to forward to the list serves, and then I can just say I participated in this study, it was really interesting, and do it that way.

**Interviewer:** Beautiful. I will do that, thank you, that would be so helpful, you are my last interview lined up, so I need to get more.

**Interviewee:** Yeah, this time of year is hard because people are, especially during the pandemic, they’re a little burned out on summer.

**Interviewer:** Yeah, it’s rough.

**Interviewee:** Oh my goodness, these poor families, right before you I was one with a family who was like, we have to figure out what we’re doing for school next year, and they just literally like three days ago announced that it’s all remote learning, and so many families are like, this is not a go for my kid, I can’t do it, and so they’re all scrambling to figure things out.

**Interviewer:** Yeah, I can’t imagine what it would be like to be a parent right now with any age child, with any type of child.

**Interviewee:** Well, I’ll tell you what, I am so glad my kids are older right now, because parents of young kids, it is bananas, it is absolutely impossible. I feel so bad for them, it’s so hard, it’s so, so hard, and honestly, I’d just have to quit my job if **[01:18:00]** if this was 10 years ago and my kids were younger. There’s just no way.

**Interviewer:** Yeah, my siblings have little ones, and they’re superheroes, they’re doing everything.

**Interviewee:** It is so hard, it is so hard, I wish there was a way as a society we could take care of them and help them, it’s just so hard.

**Interviewer:** Absolutely, it is, it is really hard. But, on a positive note, this is great and you’ve been so helpful.

**Interviewee:** I’m so glad, I love your study, I really love your study. Is this your PhD work? Or is this just a project?

**Interviewer:** No, this is just my job. I’m applying to doctoral programs in the fall, but not a student yet, so hopefully I will be.

**Interviewee:** Oh, okay, what field are you applying in?

**Interviewer:** I’m looking at child clinical psychology with a neuroscience focus.

**Interviewee:** Okay, yeah, yeah, this is a great time to be doing that, we’re learning so much right now, it’s super exciting.

**Interviewer:** Yeah, I’m really excited.

**Interviewee:** Are you hoping to say in Boston? Are you looking nationwide, or what?

**Interviewer:** Ideally, I would stay in Boston, I did my undergraduate out in Seattle and I loved it, but I missed my family and so I want to stay closer.

**Interviewee:** Yeah, I highly advise that, my family is in New Mexico, and the educational opportunities there are just pretty limited, you know, but every day I’m like why don’t I live in Albuquerque, I really miss it.

**Interviewer:** Yeah, yeah.

**Interviewee:** Well good luck.

**Interviewer:** Thank you, yeah, I appreciate that. Do you have any final questions for me? Can I help you with anything?

**Interviewee:** No, no, I’m good, it’s been really fun.

**Interviewer:** Thanks. Do you want to see the report? Yeah? Okay, I’ll send you that.

**Interviewee:** Absolutely.

**Interviewer:** I sent you them last time, right? I sent you all the forms, did I? For your other son?

**Interviewee:** I don’t think I got them.

**Interviewer:** Would you like them?

**Interviewee:** I would, I would.

**Interviewer:** I’m happy that parents have been asking, so I will send all the forms to you.

**Interviewee:** That would be great. I actually have been talking, I am working on getting SSI for my son, but during the pandemic, it used to be that you would go to the SSI office and they would meet your child, and then they would sort of figure out what’s going on, but that’s not an option anymore, and so the way you have to prepare your case file, has to make them look, in writing, like what they are. And it is hard. So, this woman I met with yesterday basically said, *“You know, you should get the Vineland done on him,”*

**Interviewer:** Yeah, you did the Vineland, so I’ll send you both Vinelands.

**Interviewee:** That would be awesome. Yeah, she wanted the Vineland and then she wanted him to do an IQ test thing.

**Interviewer:** Yeah, we don’t have any IQ test, because they’re not great remotely, so go figure.

**Interviewee:** Yeah, it’s not easy. **[01:21:00]**

**Interviewer:** Awesome, and then you mentioned the cliff, I read the cliff in terms of drop-off for services, I read a paper recently about how it changes, I don’t know if you...

**Interviewee:** I would love to see it.

**Interviewer:** I wrote it down, so I’ll send it all to you, it will be a big email.

**Interviewee:** That sounds great, thank you for everything, it has been so good to know you and I love this study, so I hope you will pass on to your team members how much I as a parent appreciate that you are doing this work, because I think that raising awareness and the breadth of what our kids experience, is so enormous. And you know, when people talk about sensory processing disorder, I’m always like, well that’s so vague as to be almost unhelpful. But it does indicate that there is an invisible challenge that is driving behavior, so that’s helpful. It’s just nice to see people thinking about these issues in a really thoughtful way.

**Interviewer:** Yeah, well, thank you, that means a lot, we’re trying our best. I’m glad it’s what you want to see as a parent, that means we’re doing some good.

**Interviewee:** Yeah, you are definitely doing good stuff, so thank you.

**Interviewer:** Okay, well I have to hop off to another meeting, but it’s been so lovely to talk to you and I look forward to talking to you in the future.

**Interviewee:** Yes, likewise, great.

**Interviewer:** Bye.

**Interviewee:** Bye.

**[End of transcript]**