**[Start of transcript]**

**Interviewer:** **[00:00]** Just always want to check. OK, we are recording. And I’ll be asking you questions about your perspective about your son’s sensory sensitivities in relation to his transition to adulthood.

**Interviewee:** OK

**Interviewer:** And we’ll be doing something called a semi-structured interview, where I have my planned questions here, but I’ll be adapting my questions to follow our conversation and to actually make sure they fit for what we’re talking about.

**Interviewee:** OK

**Interviewer:** Do you have any questions before we begin?

**Interviewee:** I don’t think so.

**Interviewer:** OK, awesome. Yeah. Now if there are any questions that you find uncomfortable or don’t want to answer, that’s totally OK. We want to make this a positive experience.

**Interviewee:** OK

**Interviewer:** OK, awesome. Could you please start off by telling me about your son’s sensory sensitivities and sensory interests?

**Interviewee:** OK. It’s kind of varied. There’s different things that affect him and there are different things that affect him at different points in time. Like, in … when he was a kid, he had a real **[1:00]** aversion to things touching his skin, and it went away for a little while, and now it’s back again, where I have to cut all the tags out of his clothes and he prefers cotton and he’d rather wear cotton and he’ll wear, like, the same outfit. It’s almost literally the same exact outfit: T-shirt—it’s always a T-shirt with a, a rounded neck—and shorts that are, like, athletic shorts, that are, like … move with him a certain way, like, where he doesn’t feel constricted. He hates jeans. He hates anything that’s, like, he feels is touching him or irritating him. He’s allergic to wool, so he doesn’t wear any wool, but any type of fabric that’s, like, scratchy or itchy or uncomfortable. If he hears loud noises, that bothers him: usually, Fourth of July, times when I know that it will be loud outside, we have, like, air going and noise machines and noise-cancelling machines and all this stuff in the house and, you know, he knows, because I taught … You know, he’s knows it’s the Fourth of July and, you know, he kind of buckles down and hides. He seems to have a really well developed palate or sense of taste, because he can discern ingredients that I can’t even taste in things, and so he knows when things are in stuff and he can taste it and, and no one else can. He has really good vision. His vision is, like, pilot-level vision, and … I’m trying to think: what else? Touch, taste, sound, smells. Smells can be a problem because some smells overwhelm him and bother him and I try to be really careful about smells, like, I don’t wear anything, like, no perfume, nothing that’s, like, heavy or over the top or anything like that. And he, he really doesn’t like wearing deodorant because of the smell, because it’s, like, a strong smell and I guess men’s cologne is pretty bad because, you know, one day we stood there in the aisle and I was like, *You really need to wear something* and we had a huge sniffing all over them and he just found that they were very strong and he didn’t really like them. So, certain smells and certain, like, he can pick out smells of things, like, if somebody makes, like, muffins or something and he’ll, he’ll, like, he can tell some of the ingredients that are in it from smelling. Like, his sense of smell is better than mine.

**Interviewer:** In the beginning, you just talked about … he doesn’t like things on his skin. Is it just, like, clothing related, or is it other things, like, maybe someone’s touch or, like, a seatbelt?

**Interviewee:** He, he doesn’t like being hugged and stuff, unless he says it’s OK. He doesn’t like … as he gets older, like, he started getting hair on his legs. He doesn’t like hair on his legs: he pulls the hairs out. **[crosstalk at 3:53]** He doesn’t, he doesn’t really cover up a whole lot either, I mean, **[4:00]** he wears Crocs and, like, that’s pretty much the only thing he wears on his feet. He doesn’t like wearing sneakers. He doesn’t wear socks, you know, doesn’t wear underwear, just the T-shirt and the shorts and that’s it, pretty much, and the Crocs.

**Interviewer:** So the kind of, like, … he doesn’t like things that are too, too close to his body?

**Interviewee:** Yeah.

**Interviewer:** And then, you talked about smell. Other than, like, kind of perfumes or, like, deodorants, are there other smells that he dislikes or likes?

**Interviewee:** For some reason, he doesn’t like the smell of eggplant. I don’t really know why. So certain foods, he’ll … that he can’t eat them because of the way they smell. I, I don’t …

**Interviewer:** OK.

**Interviewee:** Sometimes he can’t tell me why he doesn’t like it.

**Interviewer:** Yeah.

**Interviewee:** I’m not entirely sure.

**Interviewer:** No, that’s OK. And then also with his palate, you said he’s, like, has a really, really keen sense of taste. Are there things he doesn’t like because of that or is he just able to discern things that, like, you or I maybe couldn’t be able to?

**Interviewee:** He, he seems to have a real, like, penchant for stuff that’s really, really spicy, so, like, atomic peppers and stuff like that, but then other things he doesn’t like at all. I’m hard pressed to think of an example off the top of my head, but …

**Interviewer:** Got you. That’s OK.

**Interviewee:** He’s not really a kid to be like, *Oh, I want something, like, super sweet.* He, he tends to be more of, like, chips, salty pretzels. He eats stuff that’s weird, like octopus. He really likes octopus, but it also has to be a very specific type of preparation. It’s like, he loves octopus and he’ll eat octopus but, like, he wants octopus done a certain way, so, like, he wants to get it from one restaurant and not, like, it’s not just he can go into any place and get octopus. Like, it has to be done … like, he wants the vinegar to be a certain way, he wants it, you know, with a certain type of soy sauce. He can be very picky and challenging about the … I can’t taste differences in a lot of things but he can taste the differences in the soy sauce. To me, it just tastes like soy sauce. He will say, *Oh no, it’s not right; it’s not the right one, it’s not the right kind.*

**Interviewer:** Got you.

**Interviewee:** You know, he somehow can taste these very … I mean, I, I can’t tell at all.

**Interviewer:** Yeah, no, totally. And then with the noises, are there things other than fireworks that he dislikes?

**Interviewee:** Sirens, alarms, bells, he hates bells, like, in his school, they don’t use actual bells, they use a tape recording of bells and a lot of times he’ll kind of put his hands over his ears. They did get him noise-cancelling headphones, but he doesn’t seem to feel **[07:00]** like they work very well.

**Interviewer:** Gotcha.

**Interviewee:** I don’t know.

**Interviewer:** Yeah. That’s great. Thank you. And how does he, like, handle or manage these sensitivities?

**Interviewee:** We try to work … we’ve done some, like, desensitizing therapies, in terms of, like, trying to get him a little more flexible. Clothes **[inaudible at 07:14]** … I gave up that battle because I’m just not going to win it. I buy him the same T-shirt in, like, six different colors and the same shorts in six different colors and occasionally he will wear socks for me, but it’s always the short socks that don’t come all the way up, and they’re cotton and the Crocs. He had to wear sneakers for chemistry class this year because he had to have, like, a covered toe and it was really difficult. I mean, oh my God, I really thought he was going to get kicked out of class. So it was like, *Can we put, like, bags over the Crocs? Can you, like, work with me on this?*

**Interviewer:** Was he able to …? Oh, sorry, go ahead.

**Interviewee**: It, it, it’s … I kind of have to pick the battles. Like, I think I’ve developed him with food, like, he used to have, he used to only eat, like, white foods like macaroni and cheese and potatoes and stuff like that. Like, I think I’ve developed him so that he’s eating other things. But now he’s very picky about the preparation, how it’s done and stuff … and he’s really not flexible about, like, new or different or change, but he does eat a wide variety of food, I think. And that, a lot of that had to do with the desensitizing of … you know, and, like *Just try a little bit, just try it once,* bribing, crying—no, kidding. And then he … the noises with the noise-cancellation headphones and sometimes the noises keep him up, like, he has a hard time sleeping. The sleeping thing has really been kind of challenging because he doesn’t really sleep that well but we’ve added melatonin to try and get him to calm down. And I do a lot of talking to other parents to see what methods they’ve tried, to see if any of them was successful, and try it with him. And sometimes it works and sometimes it doesn’t. But it really kind of is trial by fire, because just, because you just don’t know how he’s going to react. Sometimes it depends on his mood. But he did, he did start trying some new things like, with the desensitizing, and, you know, he, he still skin picks, he still picks the hairs out of his legs. But he was on the rowing team last year and I really thought that would be difficult for him because he does not like interacting with other people. He thinks that they’re loud and that they take up a lot of his energy. But he, he joined the rowing team. He really liked it. He said he felt a sense of calm doing that.

**Interviewer:** Well that’s great.

**Interviewee:** He’s been **[10:00]** sticking with that. And, like, it’s a smaller group of people so I think it’s a little bit more manageable for him. Like, he tries to control his environment, in terms of, like, he goes to school and he deals with kids in class, but then when he has a free period, he doesn’t want to talk to anyone, so he sits by himself. And they were, like, telling him, you know, *Go be with other kids*. And I said, *You know what, it takes him so much effort and energy to interact with kids in the class. Just let him have the time to decompress. And then he’s better when he comes back, instead of feeling like he’s overwhelmed because people are constantly like, seeking his attention and, and talking to him and he’s trying to focus on what they’re saying and, and ….* He actually has told me numerous times that focusing on what people are saying is difficult, because he’s hearing so much background, a lot.

**Interviewer:** Absolutely.

**Interviewee:** And I tried to get him to explain it to me. And he kind of just says like, he hears so much that to him it’s very overwhelming. And he’s like, *When I’m walking down the hall, I hear the water from the water fountain. I hear the people walking by. I hear their clothes making noise. I hear people talking. I hear, you know, this and that and the other thing.* And he said to me that basically, like, trying to discern between all those sounds is very difficult. And then, on top of it, trying to focus on a conversation is, is worse.

**Interviewer:** Yeah I can imagine that being really challenging if you have to … if you’re paying attention to everything.

**Interviewee:** Yeah.

**Interviewer:** What … you said you listen to other parents to try and see if you can use some of their tactics. What have you tried and what has worked and what hasn’t worked?

**Interviewee:** Let’s see, what have I tried? Well when he was only eating white food, I was trying to, like, get him to, like, try different things, just to get him to eat different things. So, like, if he’s eating potatoes and macaroni cheese, obviously the main objective is just get him to eat and get calories in him. I actually went and saw a nutritionist for him. And she said, *Well, if we incorporate little things that he might be okay with, like nuts, then we can get him to go to other things.* Like, we started with the nuts, then we moved into different kinds of fruit, and then from the fruit, we went into vegetables. He’s still iffy on the vegetables, but he’ll eat like, breads, different types of breads. And she was able to, like, grow his … what he could tolerate. Now, there’s some things he still won’t touch at all. And he really is very picky about preparation and how things are, are made. But he does eat, like, a pretty decent variety of stuff now, whereas before it was, like, three things.

**Interviewer:** That’s great. That’s definitely great. Other than the desensitization, have you tried other therapies or interventions to help him?

**Interviewee:** So I tried to do ABA therapy with him. That was difficult because that’s, like, a 40 hour a week commitment, and for him to go to school six and a half hours a day and then have 40 hours a week on top of it, that was really hard. **[13:00]**

**Interviewer:** Totally.

**Interviewee:** He does, he does speech OTPT, which is pretty normal, I think, for autism. He had a little bit of an issue speaking, and it’s gotten way better, so much better.

**Interviewer:** That’s great.

**Interviewee:** And now he’s very verbal, like, there are some autistic kids that aren’t verbal at all. And I would say, *My kid can’t write, but he can talk the leaves off the trees*.

**Interviewer:** That’s excellent.

**Interviewee:** He, he, he likes to listen to shows on the radio, like, where people talk about their lives and things they’ve done and he finds it very interesting. So he’s very, like, … he couldn’t, he couldn’t read in the beginning, and I was having a lot of trouble getting him to read. So what I ended up doing because he was so interested in listening to the radio, I ended up playing CDs in the car of stories, to get him interested in the stories, and then I had him follow along with the book and that’s kind of how he learned how to read. That’s not really a conventional method. But it worked, so hey.

**Interviewer:** You know, whatever gets you there, gets you there.

**Interviewee:** It is, it is really hard for me to get him to wear clothes, like, consistently. Like, he still just doesn’t even want to do it. Like, he wants to wear shorts and T-shirt all year, doesn’t care if it’s snowing out, doesn’t care. A lot of times, even if, if he’s … even if it’s, like, three, negative three degrees, he’ll be like, *I’m not cold*. And it’s like, *Well, I don’t care that you’re not cold. You need to wear something that covers yourself, and you need to wear socks.* It, it’s been really challenging. He doesn’t want to wear boots, he doesn’t want to wear pants, he doesn’t want to wear, you know. So we’re, we’re still working on that, I would say. Either that or he’ll have to move to a sunnier state.

**Interviewer:** That’s an option.

**Interviewee:** Yeah.

**Interviewer:** Do you think he truly isn’t cold, or he doesn’t want to wear those clothes? Because I know some people just don’t feel cold genuinely, or don’t realize they’re cold.

**Interviewee:** Well, it’s hard, you know, it’s hard to say because I feel like, if it’s negative three out, it’s cold enough that you’re …

**Interviewer:** I’d say so.

**Interviewee:** You’re going to be cold. I mean, if your lips are blue, it seems to me you are cold. But he would insist no, he wasn’t.

**Interviewer:** Did any of the OT help him with any of the sensory sensitivities?

**Interviewee:** I think it did with some touch. I mean, he, he does, like, allow me to, like, hug him sometimes. I will say to him, *Can I have a hug?* It’s not, like, all the time, like, sometimes he’ll just be like, *I’m done with people today*. But, but sometimes he will do it, and it’s nice and he tries to, like, I think he tries to, like, sort of measure other people’s … if they’re feeling bad or whatever, he tries to say something uplifting. But I don’t know that he always has a good message or says the right thing. He is trying to sort of be aware of other people and their needs a little bit more, which is good.

**Interviewer:** Absolutely.

**Interviewee:** Autistics are kind of very internalized.

**Interviewer:** Absolutely.

**Interviewee:** And he … let me think, hearing, he, he’s done better with sort of … instead of just sitting there and letting everything bother him, like, he will say stuff now like, *Can I move?* or *Can I cover my ears?* or *Can, can I, you know, put my earbuds in?* or stuff like … So, I think in terms of … I don’t know if the sensitivity of the hearing has changed. I think that the coping mechanism has changed.

**Interviewer:** Absolutely. And then, how have those sensitivities changed over time, like, were they more severe or less severe when he was younger?

**Interviewee:** I think they were more severe when he was younger.

**Interviewer:** Was it like, in all domains—oh sorry, I didn’t mean to cut you off.

**Interviewee:** Well I was going to say too, I **[17:00]** think sometimes his perception of the situation and other people’s perception of the situation is very different. Because sometimes he, he thinks that what he’s doing is fine or whatever, if he’s not sitting with other kids, or if he wants to wear the same outfit every other day, but then other people’s perception of this is, it’s sort of odd. And he doesn’t care and that’s wonderful, like, I feel like, that’s a great thing that he doesn’t care. But I think that it makes it challenging for him to sort of cope with other people in general. Does that make sense?

**Interviewer:** Yeah. Absolutely, I mean it’s hard when there’s, like, a gap between what you feel and how someone else feels about a situation. It’s kind of … is that kind of what you’re talking about?

**Interviewee:** Yes, and also just society has certain expectations, and they’re not necessarily like, *You must wear this* but … or *You must do this*, but I think because people expect it, it’s hard. And I think that when they don’t get that behavior they expect they get angry. And the thing is, he doesn’t have an obvious disability. It’s not like, he has, you know, something where they know it’s a disability and they’re willing to, like, help or scaffold. So I think sometimes they get angry at him and it’s, it’s difficult. And it’s hard too for him to decide: do I want to disclose to this person that I have a disability because this is escalating? And I think, I think there are times where he has situations where it escalates out of control just because he doesn’t understand the situation. So, like, part of, you were saying with sensitivities, is that we have emotional sensitivities to some extent. And, you know, like, he wanted to go and hang out with this kid and so I said he could if he … if, you know, I could talk to the mom, the parent. And so he was asking the kid for his mom’s email address, but the kid perceived that as, like, very threatening. Because like, why, *Why is this kid, asking for my mom’s email address?* He didn’t explain, like, *My mom wants to talk to your mom so we can hang out,* he just said, *Can I have your mom’s email address?* It was, it was an unexpected behavior. So we talk about unexpected and expected behavior a lot, to try and make him understand how other people feel. But, but, like, he doesn’t understand that. He thinks very differently and he thinks very differently about things in his environment. So it kind of escalated because the kid was, like thinking that my son was going to, like, tell his mother that he did something or something like that. And I actually had to intervene. So, like, there’s also these emotional sensitivities, in terms of, like, yeah, if you go and ask someone for their mom’s email address, they might think that’s strange or not appropriate or whatever.

**Interviewer:** No, absolutely. Thank you for sharing that. You had just said that you felt that his sensitivities were more severe when he was younger—was it in all sensory domains or just in one or two?

**Interviewee:** I think his not wanting to eat a lot of food was very **[20:00]** severe and he was underweight, so that was really a problem …

**Interviewer:** Totally.

**Interviewee:** … because he didn’t want to eat things and then, I think, the noise issues …. He didn’t have good coping mechanisms for them, so he would just kind of freak out. I think he’s getting, I think he’s getting, like, a little more control over, you know, able to control his reactions a little bit more, even if it’s not, like, what he likes? Oops.

**Interviewer:** Oh, no, it’s fine.

**Interviewee:** Sorry.

**Interviewer:** You’re fine. Don’t worry about it. Hi!

**Interviewee:** Sorry.

**Interviewer:** No, you’re fine, don’t worry.

**Interviewee:** I, I think he’s starting to develop more coping mechanisms. I guess that’s what I would say. I don’t think that the ... it’s possible that the sensitivity hasn’t changed, but the change in response, because when he was a kid, if he didn’t like something he might just sit there and scream or misbehave or hide or whatever. I’ve always had issues with him wandering. And, you know, I try to make him cognizant of, like, if you wander off, it’s scary for me. So don’t do that.

**Interviewer:** Yeah.

**Interviewee:** *Can you hear me? Can you hear my voice? If you hear me calling you, please respond*. Stuff like that.

**Interviewer:** Gotcha. And, like, these changes over time, and this change in response and change in coping mechanism, do you think that’s related at all to any independence that he’s gained?

**Interviewee:** That’s a tough question. And the reason it’s a tough question is because I don’t think he has the same level of independence other people his age?

**Interviewer:** Absolutely.

**Interviewee:** It could be. I’m not sure.

**Interviewer:** No, that’s okay. That’s perfectly okay. And then these sensitivities, does that cause or increase anxiety for him?

**Interviewee:** Yes.

**Interviewer:** How so?

**Interviewee:** So, just as an example, like, I know that the school required that they do a band concert, and it’s required to take music. So he had to wear, like, pleated pants and a dress collar shirt. And it was really difficult for him to even get through small stretches of time doing that. And he would, like, like, pull and pull at the collar, pull at the pants. And one time when he was up there, didn’t know what he was doing. Because he was so bothered by the outfit and the shoes and whatever that, like, he just stopped playing. So he just sat there and he didn’t do anything. And they were like, *What’s going on?*, like, they didn’t know how to react to him. So basically, they just left him there. Well, they wanted to play and he didn’t finish the concert. It is disruptive to some sense, because that, again, is an unexpected behavior. And people don’t know why he’s doing it. And it upsets them.

**Interviewer:** Yeah.

**Interviewee:** But he was really sort of responding to, like, he **[23:00]** didn’t want to have the loafers and the pants and the collared shirt.

**Interviewer:** Yeah.

**Interviewee:** I mean, I can see it. He starts pulling, like, I can see it.

**Interviewer:** Yeah.

**Interviewee:** I don’t really … the clothes is a battle I feel like, I’ve lost because, you know, as much as I try, like, even if he goes home, he’ll, like, be just in his shorts and nothing else. He won’t, he doesn’t care. He doesn’t really want to wear them. He only wears them because I insist that when you go out of the house, you must wear clothing. So ...

**Interviewer:** And how does ... **[crosstalk at 23:34]** go ahead, sorry.

**Interviewee:** It, it’s just part of, like, I have to tell him, like, this is what people expect. They don’t want you to be running around half naked, you know, like. And you’re older now. And it’s, it’s not cute. You’re not a little kid running around and it’s funny, you know, as he gets older, obviously, it is more of an expected behavior to do that. Because nobody wants to have the guys, look, running around with nothing on.

**Interviewer:** Absolutely. And how does he, like, manage or handle this anxiety that he experiences?

**Interviewee:** I think a lot of it … if it gets overwhelming for him. I think if the anxiety gets really overwhelming, he shuts down. It’s hard for him to come back.

**Interviewer:** Yeah. Absolutely. And has this anxiety changed over time as well?

**Interviewee:** It’s poss …. Well, I guess, I never directly asked him, but I suppose that, rather than being on the floor and kicking and screaming or refusing, or, you know, having defiant behavior, I think he just sort of gets quiet instead and is kind of in his own stuff. I think, even if that’s not an expected behavior, it’s a more acceptable behavior than yelling, screaming, stuff like that.

**Interviewer:** Yeah, absolutely. That makes sense.

**Interviewee:** I think what we’re trying to do is move towards more acceptable behaviors, so that he can sort of fit in because the worst thing, every parent’s nightmare is that their kid does something unexpected and it ends up involving a police officer or something, and that the police officer doesn’t understand because the kid has autism. And, you know, that it escalates. So I’ve often told him, you know, because when it gets … when it does get cold out, he will wear a hoodie, and he’ll pull the hood up over and have it over his face. And I’ve told him, *You cannot wear a hoodie, you can’t wear your hood over your face. You can’t hide your hands, you know, if you’re ever with a police officer, please don’t have the hood up, don’t have your hands … make sure your hands are where everyone* ***[26:00]*** *can see them and cooperate as much as possible. And if the … you know, if they come in and, and stop you or something, then you just need to cooperate. Don’t fight or argue or* …. But I could very easily see that happening. I could very easily see that happening. And I always worry and I think that’s why he doesn’t have the freedom, because, you know, I’m always concerned about what happens if he’s roaming around. And he runs into someone and it escalates and he doesn’t handle it well.

**Interviewer:** Absolutely.

**Interviewee:** We work on that constantly, all the time. But I just ... you never know, it’s a wild card. You said, you know, *My kid’s gone out to do, like, science projects and stuff in schools*. And you know, I just don’t know how they’ll react sometimes, you know?

**Interviewer:** Yeah, absolutely. Thank you. It’s actually a really nice segue into my next question, kind of already answered it, but what are your goals or hopes for him in terms of his sensory sensitivities into the future?

**Interviewee:** OK. I think that what we’re trying to do is move him towards socially acceptable behaviors. So he can kind of navigate his environment, and mitigate risk in terms of avoiding escalation with other people. And, and to enable him to live as independently as possible.

**Interviewer:** Absolutely, thank you. And now kind of shifting gears, although you’ve touched upon this already, as he has grown up in age, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** How are you defining his community?

**Interviewer:** However you want to, whatever makes sense for you? Like, what does your community mean to you? Is it like, your family? Like, it could be his school, like, a religious group, your neighbors, friends.

**Interviewee:** Okay. So how have ... how have people reacted to his sensitivity? Our group or our …

**Interviewer:** Yeah.

**Interviewee: …** community? I think that people who have kids with special needs have a better understanding of some of the challenges of dealing with them. I know that there are some people who have told me like, *Well, you’re just not disciplining him enough. If you, if you discipline him more, then he would, he would be a certain way.* And you can’t beat the autism out of him. Sorry, just doesn’t work that way. It can be difficult with people—especially, like, older generation people, who just think he lacks discipline and don’t really understand this is a very real thing for him. And it’s difficult for him too, because the thing is, I always have to make sure he’s not using it as a crutch, to not perform. And I always have very high expectations of him and he doesn’t always meet them, but I want him to try and do the best he can. And, and sometimes he just doesn’t want to do it, **[29:00]** he just doesn’t want to **[inaudible at 29:02].** And it’s frustrating to me, because I want him to be the very best he can be. But sometimes he just doesn’t want to do it. It, it’s challenging. It’s hard. It’s really challenging. Someone ... some people have said to me things like, *Well, if his dad lived in the house, he wouldn’t be like this,* or, you know, and I basically said, *Yeah, that’s just not true.* It’s ridiculous. But it’s kind of like I tell my son all the time, like, everybody has an opinion and they feel like they need to share it with you. And it doesn’t really matter what they think or say, because at the end of the day, you’re judged on what you do. So you have to focus on what you do and not worry about the other stuff because, yeah, if his dad was living in the house, I doubt his behavior would change. **[phone call in the background]** Maybe, but really, I think that would be so low. And I think, you know, I think it is challenging for him. And as much as I try to, to work with him on his issues, I also try to get him to start coping with his issues. So he can sort of fit in a bit better. We, as much as, as much as we like to say *We’re all individuals* and this and that and whatever, people are social, they want to be in groups. And if you don’t want to be in a group, you’re kind of the odd man out. And I still feel, even though autistic kids say, like, you know, *I want to be alone, because I’m tired of dealing with people and their energy sucks … sucks everything out of me,* I still think they want that connection to other people. And it’s just harder for them. Like, I don’t think they don’t want it. I just think it’s just harder for them. So.

**Interviewer:** Absolutely. Thank you. And then thinking again about the community. Was it more or less accepting when he was younger?

**Interviewee:** I think it was more accepting. It gets worse every year in terms of, like, when he was in kindergarten, they were all kind of the same. And I saw it very clear, like, when he played sports, like, the next year, the other kids were getting better and he wasn’t and the next year, they were getting even better and he wasn’t. And by the time he was in third grade, like, he was upset, because, like, the parents were telling him he sucked.

**Interviewer:** Aww.

**Interviewee:** I can’t believe this.

**Interviewer:** That’s rude.

**Interviewee:** It’s horrible, but he doesn’t ... One of the, the facets of autism is your, your coordination is not as good as ... you’re not an athlete, you know, but you might not be an athlete anyway. But it was a struggle for him because he really felt like parents were calling him out on his failures and, you know, and that was the end of sports for him. And that was too bad. I mean, that’s why I’m kind of glad that he went back to rowing because it is something he can actually do and not have as, as much coordination. But baseball, soccer, football, stuff like that, nope, he won’t even go near it, he won’t watch **[32:00]** it. And like, sports is a huge thing in this country, too. And he’s just ... he has completely no interest in sports whatsoever.

**Interviewer:** Absolutely. I’m sorry those parents were not nice. That’s, that’s upsetting.

**Interviewee:** We work on it.

**Interviewer:** Yeah.

**Interviewee:** But even, even as an adult, there are people who ... you go out in the world, they don’t like what you do, they don’t like the way you drive, where you park your car or whatever. And you have to deal with it. So you just, you ... I tell him all the time, *It’s going to be harder for you. But you got to remember, there’s always somebody who’s going to criticize. It’s easy to criticize. It’s hard to do something original. It’s hard to be yourself. So just, you know, don’t worry about it.*

**Interviewer:** Yeah. Where there are certain, like, parts of the community, like, different spaces or places that were more or less accepting or accommodating of him?

**Interviewee:** So I think the parents of kids with special needs are more accepting of issues with kids. I think other people are not as accepting. I do know that when he was a kid, you know, if he was acting up or misbehaving, like, there were times when I just had to walk out of a store and leave everything behind. And not … I mean, one time I left my purse in the supermarket because it was in the cart. And I had just walked out because he was just not behaving. And it was so difficult. And some people come up and be like, *Your kid’s a brat and a jerk.* And other people come up and be like, *You know what, I understand. I have kids, it’s really hard.* So I try to be, like, really nice to people with kids, to recognize that it’s not easy and to be tolerant of it. So, like, when we go out on Halloween, like, he got dressed up in a dinosaur costume and he was dancing for the kids. And we put out stickers for kids who couldn’t have candy and candy for kids who couldn’t have nuts and other candy for other kids. We try to make our home open and accepting and we hope that other people come to our house would the same way or at least try.

**Interviewer:** That’s beautiful. That’s really lovely. And then again, thinking to the future, what are your hopes or worries in terms of how his community will react to him and his sensory sensitivities?

**Interviewee:** I’m, I’m hoping that he can be independent. I’m hoping that he can figure out a way to navigate and to disclose his disabilities in a way that will not make him feel like he’s less than and have people be supportive of him. And I’ve told him like, *You’ve got to find your people.* I, I said, you know, *Go to school ... the only thing you really have in common is geography. If you have other things in common besides geography, that’s great, but you may not.* And I said, *You might have to wait until you join a science club where everybody likes science or robots or, you know, whatever, history, or you have to find those people that* **[35:00]** *have that passion for what you like. And it’s not always easy and some people, it takes them twenty years or more. But when you find them, like, it’s so much better, because then you’ve got, you know, you’ve got your group and you feel accepted.* And it’s unfortunate, because the way the school is set up right now … but kids with disabilities don’t get proficiency ratings that are good in our state. I think they’re only required to get 13% proficient in math, 19% in reading, which doesn’t give you the skills to get a really good job and a job where you can be self-sufficient. But the other problem is, if I’m a person who can’t get a job, because I don’t have the proper skills, or I’m flipping burgers at Burger King, like, I’m not connecting with people from my community, like, he would be at that point. Like, if he got out of school and he was like, 22, you know, you don’t want to work at Burger King anymore, because that’s where there’s, like, 15-year-olds, you want to be with, like, people more your age, connected with them. Because when you feel like you belong and work is a big part of how we belong. Because it sucks up so much of our time, you know, people at work, we talk to them, we have water cooler gossip, that’s really a connection that, that draws you into your community. If you don’t have that, I feel like you’re at such a huge disadvantage. So, like, I’ve been pushing him to try and develop skills and do better in school because I was ... my feeling is, if he can’t have that work connection as the starting base to make friendships, and I think that when you don’t have that connection, it can lead to, like, depression and isolation and mental health issues.

**Interviewer:** No, absolutely. Thank you for sharing that. I’m now kind of, like, switching gears or shifting gears. In the transition to adulthood, where is your son?

**Interviewee:** So, my son is 16. So theoretically, he would become an adult in 18 months. Theoretically. He’s not ready for that yet. He doesn’t have the maturity. He doesn’t have the organizational skills. I think he thinks he’s going to be in school forever because, from his perspective, it’s going to drag on and on and on. It’s not going to be forever, though, and I really …. He’s very in the moment and long term is very difficult for him. I’ve done a lot of work with vocational rehabilitation to try and get exposure to different kinds of job opportunities—careers, I guess. I’m hoping that he’ll continue to do work with them. It has to go through the school. And sometimes it can be hard to get the school to cooperate. But I really think he needs that because I was thinking about it and I was, like, if he’s really not ready to go to college, and it would be difficult for him because college is all about writing papers. And he really can’t write papers. He needs to try and start finding his community. And if he doesn’t have the necessary job skills, I, I’m really concerned. I’m really concerned about that.

**Interviewer: [38:00]** Yeah, absolutely.

**Interviewee:** And just, maturity wise, like, he still needs to make … in terms of decision making, critical thinking, stuff like, that ... doesn’t ... he doesn’t think about stuff like that in the way I think an adult would.

**Interviewer:** Absolutely. In terms of, like, levels or stages of independence, like, where is he? Like, you mentioned that he kind of practices jobs, what about, like, taking care of himself on a daily basis, things like, that?

**Interviewee:** So it’s difficult because, like, his responsibility is to go to school every morning. And what he has to do is he has to get up, he has to shower and he has to get his stuff ready for school. But that’s pretty much it. A lot of times, I get him up, he fights me on getting up, he doesn’t want to get up. I get him in the shower, he falls asleep in the shower, I have to go in there and, like, bang on the door. He eventually comes out, he’ll get dressed, he’ll eat breakfast in the car because he’s usually running late. He takes his meds in the car. He has had something like 80 tardies last year, which is not great. He’s not good at managing his time. And he’s not really super independent. Like, I’ve been teaching him how to do his laundry. He knows some basic cooking things, like, with a microwave. I’ve been working on him with doing transactions like going to Walmart and buying something and trying to budget, like, if you only have $20, can you make a meal with that? What can you get if you need to get these things? So we are putting a lot of time and effort and energy into trying to, to get him more prepared for that.

**Interviewer:** Absolutely. Does he have, like, a social life to some extent that he manages?

**Interviewee:** Well, now that COVID came around, not really, no. No.

**Interviewer:** I know. Pre-COVID?

**Interviewee:** Pre-COVID, yeah, he had a friend in school he was talking to that he really wanted to hang out with. I think he was working on it. It’s really kind of the first time that he’d ever done that, because he used to always say that this kid, who was, like, in his first grade class was his best friend. I mean, he hasn’t seen that kid and they haven’t gone to the same school for, like, six years. So I think he’s working on it. I think it’s hard for him.

**Interviewer:** Yeah, absolutely. COVID also makes us so much ... a lot of things feel kind of impossible right now, I think as well.

**Interviewee:** Yeah.

**Interviewer:** Does he ... so he only lives at home with you now ... does he express interest in wanting to, in wanting to live on his own eventually?

**Interviewee:** No.

**Interviewer:** And with your trips to, like, Walmart and teaching him about budgeting, is he gaining a sense of, like, what money means and, like, budgeting? How is that going?

**Interviewee:** He’s doing better doing a transaction.

**Interviewer:** That’s good.

**Interviewee:** I told … he’s gotten to the point where he can go up to the **[41:00]** register, he acknowledges the person. He tells them, you know, *I’m buying this*, they bring it in, he gives them money, he gets change, he makes sure it’s correct. He will ask them if he thinks there’s a question about a price. So he’s made a lot of progress.

**Interviewer:** That’s awesome. And then ... **[crosstalk at 41:19]**

**Interviewee:** Sometimes he does get confused. And they’ll be like, *Uh* and, like, he’ll ask me to, like, help him, but it’s getting less. I mean, it’s definitely getting less.

**Interviewer:** That’s awesome. That’s great that he’s learning that. In the form that you filled out, the first one, you indicated that he does some computer repairs for a job. Could you talk a little bit about that?

**Interviewee:** So, through vocational rehabilitation, he told them that he wanted to do something with computers. So they found a place where he can do for $7.75 repair of computers that get resold to, like, organizations, charitable organizations, schools, stuff like that. He goes in, he’s learning about how to take stuff off the computer, reinstall software on the computer, sort of some basic repairs. So he will be continuing doing that into the fall.

**Interviewer:** That’s awesome. That’s a really great opportunity.

**Interviewee:** He does, I should, I should counter that: he does do that with a job coach. It’s not independent. So the job coach will just go in there just to make sure that the situation is okay. But her plan, which from what she told me is that she’s going to start pulling back and letting him do more of it. She thinks he’s ready.

**Interviewer:** That’s great. I mean, it’s still a great first step, though.

**Interviewee:** Yeah.

**Interviewer:** And then, do you think he’ll be able to achieve more independence in the future?

**Interviewee:** I hope so.

**Interviewer:** Yeah.

**Interviewee:** I really hope so.

**Interviewer:** Abso…

**Interviewee:** I mean, it’s something I worry about, but I hope so. I mean, I think he’s … in our state, you can drive at fifteen and a half. And I haven’t taken him to drive and I’m ... that’s something I’m worried about. But, like, I’m hoping at some point that he will be able to drive. I’m hoping that he will be able to live on his own. Like, that’s really what we’re trying to focus and work towards.

**Interviewer:** Absolutely. You said you’re worried about driving? Are you worried about because he’s ... struggles to pay attention? Or, like, what’s that ... what’s driving your worry?

**Interviewee:** There’s a lot of factors in driving in terms of you have to observe your area, there’s a lot of noise, there’s a lot of other people, other people can be unpredictable. I guess that I think the main worry’d be, like, getting into an accident and not knowing what to do or something like that. And it just, it, it’s not something that … I know … it’s a lot of people drive, but, like, it doesn’t mean they drive well.

**Interviewer:** Oh, it’s true.

**Interviewee:** I don’t know. I actually think that he’s kind of lucky, because with automatic cars, that might be a huge advantage for him. But, you know, manual driving is a worry, just because I don’t know if he’ll be like, *Oh my God, a noise! Woah, woah, woah!*, you **[44:00]** know, and hit someone.

**Interviewer:** No, that makes total sense. And then what do you think will help him move into adulthood and move into more independence?

**Interviewee:** I would really, really love it if he got more executive functioning support from the school. I would love it if he could strengthen that. I think if he could that his life would be a lot easier. I found that, you know, trying to manage all the sound and the touching in terms of the clothing and ... it’s overwhelming for him. And, you know, it’s difficult for him to cope and that makes it difficult for him to pay attention.

**Interviewer:** Yeah, that makes complete sense. And now, kind of putting these two things together—sensory sensitivities and this transition to adulthood—how do they intersect for Thomas?

**Interviewee:** I think it’s a big deal because in terms of becoming an adult or even just getting older, like, people are less accepting of your behavior. And sometimes you can’t control it. Like, he doesn’t mind it if bugs or bees fly on him, but, you know, I bet you if they did on me, I’d be screaming and freaking out. So, like, the opposite is true of him. Like, he you feels that people are overwhelming him or the noise is overwhelming him or the situation is overwhelming him, he can’t, he can’t, like, just check out. I mean, he just did an internship. Last week? Last week. And the teacher told him, like, basically like, *You’ve got to get it together because you’re just, like, not functioning*. And I’m kind of glad she said that because it wasn’t me, because I have zero credibility with him whatsoever. But he needs to hear it in some level, just so that he can start to try and move forward and understand that people are less and less tolerant of that behavior, the older you get.

**Interviewer:** Yeah. And then would you say these sensitivities are an obstacle, a vehicle, a bit of both or neither, towards his independence?

**Interviewee:** I think he’s developed some of them into strengths, like his, his palate, I think, can be an obstacle. I think he really needs good coping mechanisms. And I think that can be challenging, because sometimes if he doesn’t want to engage coping mechanisms, he can be very difficult to deal with. I mean, there have been days where he, like, just hasn’t wanted to leave the house and given me such a hard time and a fight. And it’s, like, you know, you know?

**Interviewer:** Yeah.

**Interviewee:** And it’s not cute, if you’re arguing, argumentative or, you know, you just don’t want ... you’re checking out or whatever, people, people don’t want to invest time in you because they think you don’t care. And it’s not necessarily that he doesn’t care, it’s that he’s not adapting well.

**Interviewer:** And then what do you anticipate as being challenging for him as he does gain more independence in terms of his sensory sensitivities?

**Interviewee: [47:00]** Oh gosh, that’s a hard question.

**Interviewer:** I know. I’m sorry.

**Interviewee:** I guess, I guess the biggest thing is just I’m hoping he has a good set of tools to cope. Because I feel like, if he doesn’t cope, things can escalate. And I just, I worry about escalating issues. And if he ever had an encounter with a police officer, if it escalated. Like, I heard one mom tell me a story about how her kid, like, you know, got upset that a police officer was being obnoxious with him. And, you know, he escalated and the cop escalated and it ended up in a high-speed chase and the kid ended up getting arrested. And this was, like, a 19-year-old kid. Now, 19-year-olds is an adult.

**Interviewer:** Yeah.

**Interviewee:** But it’s the lack of understanding and communication, which is very tough, because the police officer doesn’t know, but the kid can’t articulate it. So how do I get my kid to be able to articulate it? I mean, there are moms who’ve had business cards made up that say, like, *I have autism, please be patient*. But as an adult, if you gave something like that out, they might then think you’re not capable.

**Interviewer:** Yeah.

**Interviewee:** So it’s really this huge catch-22 of how do you get the coping skills? And how do you make sure that you’re not escalating? And how do you make sure you’re controlling your environment in a way that’s acceptable, that you’re, you know, operating and not, you know …? Essentially, like, unfortunately, people … with the expected behavior, like, if they don’t get that expected behavior, they do sort of get agitated, because it’s unexpected. And people don’t really like change or unexpected. So, really, giving him that toolset to, like, transition, not just to transition but, like, to survive it. Because, like, realistically, he’s trying to operate in a world that he doesn’t understand or belong to because it’s not his world.

**Interviewer:** Yeah.

**Interviewee:** Does that makes sense?

**Interviewer:** No, that, that makes complete sense. Yeah, no, that, that was crystal clear. Thank you. And then what do you think would help him in this intersection of sensory sensitivities in this transition to adulthood?

**Interviewee:** Well, the coping mechanisms for sure. They change sometimes too, like, as he gets older, like, just because he’s changing as well, like, with the hairs where he’s picking them out.

**Interviewer:** Yeah.

**Interviewee:** We’ll leave that alone. They’re not going away. But just giving him adequate tool sets, so that he’s all right, you know. I always worry. I’m always going to worry. But I’m hoping that he can get to a point where he’ll be OK.

**Interviewer:** Yeah, absolutely. And do you think there are particular services or interventions that could help him get to that point of, like, being okay?

**Interviewee:** I think, I think he’s continued to go to speech to, to learn **[50:00]** expected speech behaviors and idioms and stuff like that. So when people say like, *Oh, that person has that other person’s ear*, he doesn’t think they cut their ear off. So that, that’s good. He continues to do PT and some OT at home on his own. I really want to incorporate an ABA therapist. ABA therapists engage in Skinner, and it’s kind of, like, teaching expected behavior. But I want them to kind of help guide him to, like, some better executive functioning techniques. My son is a kinesthetic auditory and that’s a more rare learning style. Because a lot of times people say *Oh, your kid is autistic, he must be visual. Let me give him a chart.* And it’s like, *He doesn’t respond to a chart. He’s a kinesthetic auditory.* So he’s got the added challenge of being, like, in a really different category. So I wanted them to come in and work with him on that kinesthetic auditory. Sort of, like, getting it to work for him. Because, I mean, if you give me a chart, I can do it. But I have a different learning style than he does. And I can’t see to my learning style because it’s not his.

**Interviewer:** Yeah.

**Interviewee:** So, the person who I got in touch with is an expert in kinesthetic auditory and she does a lot more hands on and physical manipulation of things. So I’m hoping that that will help him sort of get some of his executive functioning components more manageable. So that he’s not, like, paying attention to 50,000 things at once and doesn’t have any idea what’s going on.

**Interviewer:** Absolutely. And then do you think there are gaps in the available interventions and services for kids like your son?

**Interviewee:** Absolutely. School, school is only required, according to school, to provide the bare minimum of a benefit for a kid. That’s not appropriate in my opinion. And I think that we need to increase the, the state plan goal of 13% reading, **[corrects herself]** math, and 19% reading, because that’s not really acceptable—and that’s embarrassing. These kids don’t have IQs of 50. A lot of them are, like, well over 120. They’re capable of so much more. And I really feel like it’s kind of a failure of society in a way because, if we’re not setting them up to fail … if we’re setting them up to fail. I’m sorry, I misspoke. If we’re setting them up to fail by not giving them the correct tools and education, like, we end up failing in the end, too, because we need them to be working, we need them to be contributing to Social Security, we need them to be paying taxes, the whole nine yards. So, like, I really wish they would change their attitude on that. And I find it very stressful and challenging because they don’t want to. I think if they had gotten someone in to work with him as kinesthetic auditory and to get his spelling reversals and stuff like that, way back when I was complaining about them in first, second and third grade, I wouldn’t be where I am with him now. It wouldn’t be as challenging.

**Interviewer:** Absolutely, that makes complete sense. And then again, how has **[53:00]** his sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** I think I had to, to not have any expectations. I have to play it by ear because he is limited in certain aspects with certain things that he will not be able to do. Like, he just, he’s never going to be able to do certain things. And you have to accept that. And that’s, that’s not an easy thing. Because you want your kid to be able to go out and do anything. I have to accept the fact that he may not go to college. That’s really hard. Very hard, incredibly hard. But that doesn’t mean that that’s not … he’s not going to have a good life. I’m sorry, there was expectations. What was the other one?

**Interviewer:** Expectations, hopes or goals. And it could be… you can just **[crosstalk at 53:40]** ... sorry, go ahead.

**Interviewee:** I hope he has a happy life and that he’s successful enough that he has what he needs. And he’s not, you know, living under a bridge in Manchester. But ...

**Interviewer:** Yeah, absolutely. I think a lot of parents just want their kids to be very happy. And I’ll kind of as, like, an end to our interview … we have a couple more questions that were towards the end of it. As a caregiver, as a mom, as a parent of a child who has ASD but also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** I would say that transitioning to adulthood means being able to live independently or as independently as possible. Being able to connect with your community, to work and function in your community. And, you know, starting to do the things that you want to do. I mean, you spend a lot of time in your life doing things that other people want you to do. Time for you to start doing the stuff that you want to do.

**Interviewer:** And has this perspective changed over time?

**Interviewee:** Mine or his?

**Interviewer:** Yours.

**Interviewee:** My ... yeah, my personal ... I mean, when he was born, I was like, *Yeah, he’s going to be the next president.* Now I have to deal with, like, he may never go to college. That’s a huge shift in thinking. And it’s hard. It’s very hard.

**Interviewer:** Yeah, I can imagine that. It’s understandably hard. It’s hard to change expectations.

**Interviewee:** I don’t want him to have limitations. I want him to have every opportunity in the world. And it just … it isn’t the way it is.

**Interviewer:** Yeah, absolutely. Well, thank you for sharing that. And what do you see happening in his future?

**Interviewee:** I don’t really know. I think that’s the biggest question I have. Because I worry a fair amount about can he do this, can he do that? Do I have to worry about him driving? Do I have to worry about him? You know, if I send him to Boston to do something, like, am I going to have to worry he’s mugged? And I think that’s why he doesn’t have as much independence as maybe other kids, he definitely doesn’t have as much independence. He’s not driving around. He’s not ... you know, but I still want him to be happy. **[56:00]** But, like, it’s been difficult for me even to, like, leave him in the house for 15 minutes. So we’re, we’re slowly working up to that, you know.

**Interviewer:** Yeah, no, that makes sense. And then, final question, how has his sensory sensitivities impacted this current perspective that you just articulated?

**Interviewee:** It’s kind of like that saying, *You can lead a horse to water, but you can’t get them to drink.* When your kid has sensory issues, like, you cannot get them to do things, some days, no matter what you try to do. And it’s just, it’s not going to happen. It’s very, very hard, because there are people who will criticize you and tell you that, like, you’re bad and you’re defective, because you can’t make them do something. But they forget, this is an entirely different person with their own brain and feelings. And you just can’t control that.

**Interviewer:** You also do not seem like a bad person by any means.

**Interviewee:** Well, it’s kind of, like, if you ever ... I don’t know if you ever rode a horse, but I’ve ridden horses and, like, when you ride a horse, this is a 2,000 pound animal that has its own brain.

**Interviewer:** Oh yeah.

**Interviewee:** And if it decides it’s not going to jump over a stick, then it’s not going to do it. It’s going to stop and you’re going to go over its head and that’s it.

**Interviewer:** Yeah, you can’t force it.

**Interviewee:** Yeah.

**Interviewer:** Absolutely. So that’s really it for all of my formal questions. Would you like to add anything?

**Interviewee:** I guess the only thing I’d add is, I definitely think that parents want to see their kids be productive and, and be able to use whatever they have in a positive way. So, like, my son does have an advanced palate. It’s very advanced. I mean, it’s ridiculous. He ... I’m hoping that maybe he can parlay that into something, like, where he can be a food taster and maybe he can just dictate what he wants to say. Or maybe he could, I don’t even know. I just hope that he has a place and he feels connected. And he’s happy.

**Interviewer:** Absolutely. Absolutely. That makes complete sense. And I do think people do seek that out, like, super tasters for wine, you know, like, people want people with those skills. So you ... I think you could definitely leverage it.

**Interviewee:** Well, he can’t drink yet, but … **[crosstalk at 58:10]**

**Interviewer:** Well, no, obviously, when he’s of legal age ...

**Interviewee:** He can definitely discern things. Like, we had burgers the other day and he said there was lemon in them. And I went back and looked and there was lemon in them. And I didn’t taste it at all.

**Interviewer:** I mean, that’s an incredible skill. I think he could definitely use that to his advantage. 100%. But yes, so that’s actually it on my end. Those are all of my questions. Thank you. Sorry. Thank you so much for giving your time and your insight and sharing about you and your family and your son. It’s, it’s so, so helpful for us. We really, really appreciate it.

**Interviewee:** No. Thank you for doing the study. And, actually, if you want to send me information to the study, I asked if I could post it in the group and they said yes, and there were a couple of people interested. So if you do that, I will post it.

**Interviewer:** Oh, yes. Did that link work for you? I think I might have sent it. I can resend it.

**Interviewee:** I **[59:00]** don’t remember seeing it, but I got a few things. So I’m not sure.

**Interviewer:** I’ll resend it: not a problem. Easy peasy. I’ll send you a link to our Facebook page. But I’ll also send you the flyer and just the blurb so that we can copy and paste if it’s easier for you.

**Interviewee:** Okay, yeah, thank you.

**Interviewer:** Yeah, of course. No, thank you. And as soon as this audio is done rendering, I will send you a thank you gift card as compensation for all of your time and effort. We truly appreciate it. I can’t see you anymore. Hello? Are you still there? Hello? Can you hear me?

**[End of interview]**