AI018\_Interview\_Audio\_Only

Just always want to check. Okay, 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. Okay, and we'll be doing something called a semi structured interview, where I have my plan 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. Okay. You have any questions before we begin?

**Speaker 2**

I don't think so.

Okay, awesome. Yeah. And are there any questions that you find uncomfortable or don't want to answer? That's totally okay. We want to make this a positive experience. Okay. Okay, awesome. Um, could you please start off by telling me about your son's sensory sensitivities and sensory interests.

**Speaker 2**

Um, okay. It's kind of varied. There's different things that affect him. And there are different things that affect them at different points in time. Like when he was a kid, he had a really 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 who wear like the same outfit is only literally the same exact outfit t shirt, it's always a T shirt with a rounded neck, and shorts that are like athletic shorts, they're 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 want any wool or 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, you know, it's the fourth of July. And you know, he kind of goes down and hides, he seems to have a really well developed palette or sense of taste, because he can discern ingredients that I can't even taste and and so he knows when things are in stuff, and he can boost it and no one else can. He has really good vision his vision is like pilot level vision. And try think what what else touch taste sound. Smells. Smells can be a problem because some smells overwhelmed 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 heavier 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 smell and I guess mints your is pretty bad. Because, you know, one day we stood there in the island and like you really need to wear something like and we had you sniffing all of them. He just found that they were very strong. And he didn't really like them. So smells uncertain. Like he can pick out smells of things. Like if somebody makes like muffins or something and he has like, he can tell some of the ingredients that are in it from smelling. It looks something smells is better than mine.

Um, 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 someones touch or

**Speaker 2**

he does. He doesn't like being hugged and stuff unless he says it's okay. He doesn't like as he got older, like he started getting hair in his legs. He doesn't like hair. I was like he pulls the hairs out. um he didn't really he doesn't really cover up a whole lot, either. I mean, he wears Crocs, and that's like, 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 in the crocs

to the kind of like, he doesn't like things that are too too close to his body. Yeah. And then you talked about smell other than like kind of perfumes or like deodorants Are there other smells that he dislikes or likes.

**Speaker 2**

For some reason, he doesn't like the smell of eggplant. I don't really know why. certain foods hillson they can't eat them because of the way they smell. I don't hear sometimes you can't tell me why he doesn't like it. Yeah. I'm not entirely sure.

No, that's okay. And then also with this palette, 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 just Certain things that like your IDE maybe couldn't be able to,

**Speaker 2**

um, he he seems to have a real like penchant for stuff that's really, really spicy. So like a comic peppers and stuff like that, but then other things he doesn't like at all. Um, I'm hard pressed to think of an example off the top of my head, but that's okay. Um, he's not really a kid to be like, Oh, I want something like super sweet. He tends to be more of like, chips, salty pretzels. Um, eat stuff that's weird. Like octopus, he really likes. But it also has to be a very specific type of preparation. So the key loves octopus, he'll eat octopus, but like, he wants octopus done a certain way. Like, he wants to get it from one restaurant and not like, it's not just you 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 so it's like he can get very picky and challenging about you know, I can't taste differences in a lot of things. But he can and like he can taste the differences in the soy sauce. To me, it just tastes like soy sauce. will say oh, no, it's not right. It's not the right one. It's about the right kind. Gotcha. You know, he somehow can taste. These vary. I mean, I can't tell at all.

Yeah, no, totally. And then what the noise is other other things other than fireworks that he dislikes.

**Speaker 2**

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 they'll kind of put his hands over his ears. I did get him noise cancelling headphones. But he doesn't seem to feel like they work very well. Um, gotcha. I don't know.

That's great. Thank you. And how does he like handle or manage the sensitivities?

**Speaker 2**

We try to work. We've done some like desensitising therapies, in terms of like trying to get him a little more flexible. closes like I just I gave up that battle because I'm just not going to win it. I buy him the same t shirt and like six different colours, in the same shorts, with different colours, occasionally will wear socks for me. But it's always the short socks that don't come all the way up. And their cotton and the crocs. He had to wear sneakers for chemistry classes here because he had to have like the covered toe. And it was really difficult. I mean, oh my god, I really thought he's gonna get kicked out of class. So I was like, Can we put like bags over the crocs? Can you like work with me? Um,

was able to go Sorry, go ahead.

**Speaker 2**

It's, 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's only eat like white foods like macaroni and cheese and potatoes and stuff like that. Like I think I've developed since that he's eating other things. But now he's very picky about the preparation of 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 desensitising of you know, like, just try a little bit just try once Bing, calm, no kidding. And then he the noises with the noise cancellation headphones, and sometimes the noises keep them 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 anything 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 gonna react. Sometimes it depends on his mood. But he did start trying some new things like with the desensitising and you know, he he still skinpack system picks the hair that was 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 they're loud and like they take up a lot of energy. But he joined the room to me he's he really liked it. He said he felt a sense of calm doing that. Oh, it's great. Sticking with that, and like it's a smaller group of people, so I think it's a little bit more manageable. 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 talking to him, and he's trying to focus on what they're saying. 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. Mm hmm. 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, oh, when I'm walking down the hall here, the water from the water fountain, I hear the people walking by here their clothes, making noise. I hear people talking, I hear you know, this not 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 worse.

Yeah, I can imagine that being really challenging if you have to, you're paying attention to everything. Yeah. What you said you listen to other parents to try to see if you can use some of their tactics, what have you tried, and what has worked and what hasn't worked?

**Speaker 2**

Um, let's see, what have I tried? Well, when he was only eating white food, I was trying to like get him to 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 who might be okay with like nuts, then we can get 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 to vegetables, he's still a little 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 made. But he does, like a pretty decent variety of stuff now, whereas before, it was like three things.

It's great. It's definitely great. Um, other than a de sensitization, have you tried other therapies or interventions to help him?

**Speaker 2**

So we 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. He does speech ot PT, which is pretty normal, I think for autism, he had a little bit of a issue speaking and it's gotten way better, so much better,

right.

**Speaker 2**

And now he's very verbal. Like, there's some autistic kids that aren't verbal at all. And I would actually say my kid can't write, but he can talk leaves off the trees. That's 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. Um, 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 them 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 works. So hey,

you know, whatever it gets he gets you there.

**Speaker 2**

It is really, it is really hard for me to get him to wear clothes like consistently like he's still just doesn't really even want to do it wants to wear like 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, I'll be like, I'm not cold. And it's like, well, I don't care that you're not cold. To wear something that covers yourself need to wear socks. It's it's been really challenging. You just want to wear boots. You didn't want to wear pants he doesn't want to wear you know. So we're still working on that. I would say either that or we'll have to move to a sunnier state.

Yeah, geez. Do you think he truly isn't cold or he doesn't want to wear those clothes later some people just don't feel cold genuinely are don't realise that Cold?

**Speaker 2**

Um, 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, I'd say, so there's gonna be old me if your lips are blue, super cold. But even snow wasn't.

Did any of that ot help him with any other sensory sensitivities?

**Speaker 2**

I think it did with some touch. I mean, he does, like, allow me to, like, hug them sometimes say to him, like, Can I have a hug? It's not all the time. Like, sometimes I'll just be like, I'm done with people. 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 was has a good message says the right thing. Hmm. He is trying to sort of be aware of other people and their needs a little bit more, which is good. Absolutely. Artists, there's a kind of very internalised. And he made me think, hearing, he's done better with sort of, instead of just sitting there and letting everything bother him, like, he will say stuff now or he'll be like, Can I move? Or can I cover my ears? Or can I, you know, put my earbuds in or stuff like that. So I think that in terms of, I don't know that the sensitivity of the hearing has changed, I think the coping mechanism has changed.

Absolutely. Um, and then, how have these sensitivities changed over time? Like, were they more severe or less severe when he was younger?

**Speaker 2**

Um, I think they were more severe when he was younger. Was it like in all domains? Oh, sorry, I didn't mean to cut you off. Well, I was gonna say, too, I think sometimes his perception of the situation, and other people's perception of the situation is very different. Um, 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 is 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 dealing with other people in general. Does that make sense?

Yeah, absolutely. I mean, it's hard when there's like,

a gap between how you feel and someone else feels about a situation? It's kind of, is that kind of what you're talking about?

**Speaker 2**

Yes. And also, just, society has certain expectations. And they're not necessarily like, you must wear this, but you must do this. But I think because people expect it, it's hard. And I think that when they don't get the behaviour that they expect to get angry. Um, 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 disability, and that they're willing to like help or scaffold. So I think sometimes they get angry at him. And it's difficult. It's hard to, for him to decide, like, do I want to disclose to this person that I have a disability because this is escalating? And I think a lot, I think there are times when he has situations where it escalates out of control, just because he doesn't understand the situation. So like, part of you were saying sensitivities, or we have emotional sensitivities to some extent. And, you know, like, he wanted to go and hang out with this kid. And he 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 is like, very threatening, because like, why is this kid asking for my mom's email address? He didn't explain. My mom wants to talk to your mom, so we can hang out. He just said, Can I email? It was it just, it was an unexpected behaviour. So we talk about unexpected, unexpected behaviour a lot to try and make him understand how, how other people feel. 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 gonna, like, go and tell his mother that he did something or something like that. Or been. So like, there's also those emotional sensitivities in terms of like,

**Speaker 1**

yeah, if you don't ask someone like for their mom's email address, they might think that's strange or not appropriate or whatever. Yeah, no, absolutely. Thank you for sharing that. And you had just said that you felt that his sensory sensitivities were more severe when he was younger, was it in all sensory domains or just in one or two?

**Speaker 2**

I think his not wanting to eat freak out. I think he's gonna 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.

**Speaker 1**

--Oh, no, it's fine.

--Sorry.

**Speaker 1**

--You're fine. Don't worry about it.

Hi!

**Speaker 1**

No, you're fine, don't worry.

**Speaker 2**

I --I think he's he's starting to develop more coping mechanisms. I guess that's what I would say. I don't think that this ... 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.

--Yeah.

**Speaker 2**

--Can you hear me? Can you hear my voice? If you hear me calling you please respond stuff like that?

**Speaker 1**

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

--Um,

**Speaker 2**

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? Um, --Absolutely. It could be. --I'm not sure.

**Speaker 1**

--No, that's okay. That's perfectly okay. Um, and then these sensitivities, um, does that cause or increase anxiety for him?

**Speaker 2**

Yes.

--Yes.

**Speaker 1**

--How so?

**Speaker 2**

Um, 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 up the collar, pull up 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 just sat there, he didn't do anything.

**Speaker 1**

--Mm hmm.

**Speaker 2**

--And they were like, what's going on, like, didn't know how to react to him. So basically, they just left him there. Well, you want to play and he didn't finish the concert. But it is disruptive to some sense, because that, again, is an unexpected behaviour. And people don't know why he's doing it. And it upsets them. But he was really sort of responding to like, he didn't want to have the loafers and the pants and the collared shirt. I mean, I can see it. He starts pulling, like I can see it. Yeah, 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 work a little bit. So...

**Speaker 1**

--And how does ... go ahead, sorry.

**Speaker 2**

--It's just part of like, I have to tell him like that this is this is what people expect. They don't want you to be running around half naked, you know, like. And they'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 expression to do that. Because nobody wants to have the guys, look, running around with nothing on.

**Speaker 1**

--Absolutely. And how does he like manage or handle this anxiety that he experiences?

**Speaker 2**

--I think a lot of it if it gets overwhelming for him. I think if the anxiety gets really overwhelming, he shuts down.

**Speaker 1**

--Mm hmm.

**Speaker 2**

--It's hard for him to come back.

**Speaker 1**

--Uh huh, absolutely. And has this anxiety changed over time as well?

--Um,

**Speaker 2**

I think he's a little bit more able to hide it. I don't know that it it goes away. even if that's not unexpected behaviour, it's a more acceptable behaviour than yelling, screaming, stuff like that.

**Speaker 1**

--Yeah, absolutely, that makes sense.

**Speaker 2**

--I think what we're trying to do is move towards more acceptable behaviours, 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, it's a February, please don't have the hood up, don't have your hands, make sure your hands are where everyone can see them and cooperate as much as possible. And if the you know, if they come in and stop you, that kind of thing, then you just need to cooperate. Don't bite, argue or..." But I could very easily see that happening. I could very easily see that happening. And I always worry. you know, I'm always concerned about what happens if you do follow me around. And he runs into someone and it escalates and he doesn't handle it well. 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?

**Speaker 1**

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

**Speaker 2**

--Okay, I think that what we're trying to do is move him towards socially acceptable behaviours. 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.

**Speaker 1**

--Absolutely, thank you. Um, and now kind of shifting gears, although you've touched upon this already, um, as he has grown up in age, how has his and your community reacted to his sensory sensitivities?

**Speaker 2**

--How are you defining his community?

**Speaker 1**

--However you want to, whatever makes sense for you? Like, what is your community mean to you? Is it like your family? Like it could be his school, like a religious group, your neighbours, friends?

**Speaker 2**

--Okay. So how have ... how have people reacted to his sensitivity? Our group? Or?

--Yeah.

**Speaker 2**

--I think that people who have kids with special needs have a better understanding of some of the challenges of dealing with him. 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 can't beat the autism out of him. Sorry, just doesn't work that way. 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 need them but I want him to try and do the best he can. And and sometimes he just doesn't want to do it, needs to want to beat me up. 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 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. Yeah, if his dad was living in the house, I doubt his behaviour would change. 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, it sucks everything out of me," I still think they want that connection to other people. And I, 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.

--Absolutely.

**Speaker 2**

Absolutely.

Thank you, um,

**Speaker 1**

and then thinking again about the community. Was it more or less accepting when he was younger?

**Speaker 2**

--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.

--Aww.

**Speaker 2**

--I can't believe this.

--That's rude.

**Speaker 2**

--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, and and you might not be an athlete in any way. 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 you 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 it. And like sports is a huge thing in this country, too. And he's just ... he has completely no interest in sports whatsoever.

**Speaker 1**

--Mm hmm. Absolutely. I'm sorry those parents were not nice. That's that's upsetting.

**Speaker 2**

--We work on it. --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 them all the time, it's going to be harder for you. But you got to remember, there's always somebody who's going to criticise, it's easy to criticise, it's hard to do something original, it's hard to be yourself. So just, you know, don't worry about it.

--Yeah.

**Speaker 2**

--Um, where there are certain, like, parts of the community, like different spaces or places that were more or less accepting or accommodating of him? --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 car. 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 call 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 recognise that it's not easy, and to be tolerant of it. 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. We hope that other people come to our house with the same way or at least try.

**Speaker 1**

--That's beautiful. That's really lovely. Um, 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?

**Speaker 2**

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 have that passion for what you like. And it's not always easy, and some people, it takes them 20 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 and 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, 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.

**Speaker 1**

--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?

**Speaker 2**

--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 organisational skills. 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.

**Speaker 1**

--Yeah, absolutely.

**Speaker 2**

--And it just maturity wise, like he still needs to be 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.

**Speaker 1**

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

**Speaker 2**

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. 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, it 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.

**Speaker 1**

--Absolutely. Does he have like a social life to some extent that he manages?

**Speaker 2**

--Well, now that COVID came around? Not really No, no.

**Speaker 1**

--I know. Pre-COVID?

**Speaker 2**

--Pre-COVID, 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's ever done that, because, he used to always say that this kid who was like in his first grade classes was his best friend. I mean, he hasn't seen that kid. They haven't gone to the same school for like six years. --Mm hmm. --So I think he's working on it. I think it's hard for him.

--Yeah, absolutely. COVID also makes us so much ... A lot of things feel kind of impossible right now, I think as well.

**Speaker 2**

Yeah.

**Speaker 1**

Um, 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?

**Speaker 2**

No.

**Speaker 1**

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?

**Speaker 2**

He's doing better doing a transaction.

**Speaker 1**

That's good.

**Speaker 2**

You know, he's gotten to the point where he can go up to the 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.

**Speaker 1**

That's awesome. And then ...

**Speaker 2**

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.

**Speaker 1**

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?

**Speaker 2**

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 organisations, charitable organisations, 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.

**Speaker 1**

That's awesome. That's a really great opportunity.

**Speaker 2**

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.

**Speaker 1**

That's great. I mean, it's still a great first step, though.

**Speaker 2**

Yeah.

**Speaker 1**

And then, do you think he'll be able to achieve more independence in the future?

**Speaker 2**

I hope so.

**Speaker 1**

Yeah.

**Speaker 2**

I really hope so. I think, 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 and hoping that he will be able to live on his own. Like, that's really what we're trying to focus and work towards.

**Speaker 1**

Absolutely. Mm hmm. You said you're worried about driving? Are you worried about 'cause he's ... struggles to pay attention? Or like, what's that ... what's driving your worry?

**Speaker 2**

Um, 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.

**Speaker 1**

Oh, it's true.

**Speaker 2**

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 it'll be like, "oh, my God, a noise, woah woah woah!" and, you know, hit someone.

**Speaker 1**

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

**Speaker 2**

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.

**Speaker 1**

Mm hmm. Well, that makes complete sense. And now kind of putting these two things together um, sensory sensitivities and this transition to adulthood. How do they intersect for Thomas?

**Speaker 2**

Um, 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 behaviour. 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, if you feel 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 behaviour, the older you get.

**Speaker 1**

Yeah.

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

**Speaker 2**

I think he's developed some of them into strengths, like his his palate 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?

**Speaker 1**

Yeah.

**Speaker 2**

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.

**Speaker 1**

Mm hm.

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

**Speaker 2**

Um, oh gosh, that's a hard question.

**Speaker 1**

I know, I'm sorry.

**Speaker 2**

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. 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. 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 behaviour, like if they don't get that expected behaviour, 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.

**Speaker 1**

Yeah.

**Speaker 2**

Does that makes sense?

**Speaker 1**

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

**Speaker 2**

Um, well, the coping mechanisms for sure. They change sometimes to like, as he gets older, like, just because he's changing as well, like with the hairs where he's picking them out. Yeah, we'll leave that alone. They're not going away. But just giving him an adequate tool. So let's say he's all right, you know. I always worry. I'm always gonna worry. But I'm hoping that he can get to a point where he'll be okay.

**Speaker 1**

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

**Speaker 2**

Um, I think, I think he's continued to go to speech to to learn expected speech behaviours 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 behaviour. 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.

**Speaker 1**

Yeah.

**Speaker 2**

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 he's not like paying attention to 50,000 things at once and doesn't have any idea what's going on.

**Speaker 1**

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

**Speaker 2**

Absolutely. School ... school is only required, according to school, to provide the bare minimum of a benefit for a kid. That's not appropriate my opinion. And I think that we need to increase the the state plan goal of 13% reading, um math, and 19% reading, because that's not really acceptable, 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 him in first, second and third grade, I wouldn't be where I am with him now. It wouldn't be as challenging.

**Speaker 1**

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

**Speaker 2**

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 gonna have a good life. I'm sorry, there was expectations. What was the other one?

**Speaker 1**

Um, expectations, hopes or goals. And you can just hope ... sorry, go ahead.

**Speaker 2**

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 ...

**Speaker 1**

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?

**Speaker 2**

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.

**Speaker 1**

And has this perspective changed over time?

**Speaker 2**

Mine or his?

**Speaker 1**

Yours.

**Speaker 2**

My ... yeah, my personal ... I mean, when he was born, I was like, "yeah, he's gonna 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.

**Speaker 1**

Yeah, I can imagine that. It's understandably hard. It's hard to change expectations.

**Speaker 2**

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.

**Speaker 1**

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

**Speaker 2**

I don't really know. I think that's the biggest question I have. Because I worry a fair amount about can you do this? Can you 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 gonna have to worry too much? 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. 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.

**Speaker 1**

That makes sense. And then, final question, um, how has his sensory sensitivities impacted this current perspective that you just articulated?

**Speaker 2**

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 sensitive 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 criticise 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.

**Speaker 1**

You do not seem like a bad person in any way.

**Speaker 2**

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 2000 pound animal that has its own brain. 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.

**Speaker 1**

Yeah, you can't force it.

**Speaker 2**

Yeah.

**Speaker 1**

Absolutely. Um, so that's really it for all of my formal questions. Would you like to add anything?

**Speaker 2**

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 you can be a food taster and maybe he could 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.

**Speaker 1**

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.

**Speaker 2**

Well, he can't drink yet, but

**Speaker 1**

Well, no, obviously, when he's of legal age ...

**Speaker 2**

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.

**Speaker 1**

I mean, that's an incredible skill. I think he could definitely use that to his advantage. 100%. But yes, it's actually it on my end. Those are all of my questions. Thank you. Ahem. 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.

**Speaker 2**

No, thank you for doing a 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.

**Speaker 1**

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

**Speaker 2**

I don't remember seeing it, but I got a few things. So I'm not sure.

**Speaker 1**

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.

**Speaker 2**

Okay, yeah, thank you.

Yeah, of course. No, thank you. Um, 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.

**Speaker 1**

I can't see you anymore. Hello? Are you still there? Hello, can you hear me?