**[START OF TRANSCRIPT]**

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

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** Mh-hmm

**Interviewer:** OK. And if there any questions that you don't want to answer for whatever reason, it's perfectly fine. ‘I don't know’ is a perfectly fine answer as well, and you're welcome to bring things up as they come to mind.

**Interviewee:** OK.

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

**Interviewee:** Right now, as they currently are, or like his history?

**Interviewer:** I'll be asking about them in the past, so you're welcome to start however is easiest for you.

**Interviewee:** Well, right now his biggest thing that we have the problem with is stuff on his hands. And I think that really started with the pandemic, that like escalated big time. And then stuff in his eyes, he's gotten really weird about. Like, he freaks out about things getting in his eyes. And then noise. Noise he's gotten so just touchy about, it's really…and any kind of…and clutter **[chuckles]**. We went from living in a 2600 square foot house to a 1000 square foot apartment when we moved here 'cause we're building a house here. And so, he is really, I mean like he’s very hyper-sensitive about his space and any kind of clutter, moving other people's stuff around.

**Interviewer:** Got you, thank you. And when you talked about stuff on his hands, is it that he doesn't like the feeling of things on his hands?

**Interviewee:** It's that, like he gets up a couple of times to wash his hands with soap and water *during* a meal. Like he will finish a portion of the meal or in the middle of the meal when he's still eating something, he will not use a napkin, or he'll use a napkin *and* he'll get up and go wash his hands and then continue eating. I mean, he is like…like I had to take him to the doctor and get prescription cortisone cream for his hands and talk to him about, *“OK, you really need to start using lotion afterwards, you need to chill on the hand sanitizer. You're going overboard, we're going into OCD land here, OK? We need to chill.”*

**Interviewer:** Got you. And I think on the form you also said there are certain fabrics he didn't like?

**Interviewee:** Yes, he's your typical sensory kid in that the tags bother him, any kind of fabric that is rough, *“it's too itchy, I don't like that,”* we get all that mess. So, we've always had that issue. And then, he has rules about clothes, like shirts have to be buttoned up all the way to the top when he has them on. And he doesn't tolerate going to bed without pants on of some kind, even if he's wearing underwear, he must have pants on top of that.

**Interviewer: [00:03:26]** Got you, thank you. And you just said that noise is a little touchy for him. Could you talk about that a little bit more, provide some examples?

**Interviewee:** Well, he like his brother, who may or may not be on the spectrum, dunno, that's a completely different can of worms **[chuckles]**, but he makes little noises and sings to himself and stuff when he's in a good mood. Matthew gets very upset whenever he makes any kind of noise, *“can you stop making noises! You need to stop making…be quiet.”* He just fusses at him anytime he makes any kind of noise. But he likes to listen to music and he likes to watch music videos and he just doesn't tolerate any kind of noise that *he's* not making, let's put it that way.

**Interviewer:** Yeah, OK. And does this translate to other non-human noises like trucks or sirens or alarms, things like that?

**Interviewee:** Yeah, we'll get a lot of, *“what's that noise? What's that sound coming from?”* Like, *“I don't know what quote that noise is, you need to describe it, you need to tell me.”*

**Interviewer:** Got you. Awesome, thank you. What about smell? I think you also mentioned that.

**Interviewee:** Yes, we get that all the time, *“what's that smell?”* But I'm like, *“OK, I don't know what that smell is.”* It's like living with a pregnant woman.I swear to God, he's got the pregnant lady sense of smell **[sighs].**And he just…I'm sorry, sometimes it gets exhausting.

**Interviewer:** Oh no no, don’t apologize, not at all.

**Interviewee:** You know, we've had so much togetherness during this pandemic and then a cross-country move. And now we're living in this small apartment and it's like, *“oh dear God, get me out of here!”* **[Both laugh]**

**Interviewer:** That's a lot.

**[Interviewee makes screaming, frustrated noise and laughing]**

**Interviewee:** Yeah, he's real weird about that. I forgot that he's also…I have a scented candle burning right now, and he would blow that out the minute I lit it. I mean, he would just, you know.

**Interviewer:** So, it sounds like he notices smells that you don't notice right away. Does he dislike those smells as well as just being more aware?

**Interviewee:** Yes.

**Interviewer:** OK. Is it a particular smell, like candle smells versus like food smells?

**Interviewee:** Food smells he finds very offensive. Food, it's usually food that bugs the crap out of him. Candles he's generally OK with, he seems to be OK with…he says that I smell good when I come out of the shower or from getting ready and I'm like, *“well, that's girly stuff, it's supposed to smell good.”* But food smells he really wigs out about. But he has a diagnosed sensory feeding disorder, so.

**Interviewer: [00:06:26]** OK, got you. Does he then have sensitivities to certain tastes and different foods?

**Interviewee:** Yeah, I mean, he's…basically the description of my kids, both my kids have a sensory based feeding disorder, they both got OT for it. And the description of their eating habits is beige, breaded and bland. There you go, the 3 Bs. If it's dry and carby, they're going to eat it, or if it is a breaded meat product that is fried, they will eat. Otherwise, no.

**Interviewer:** Has he been able to articulate what he doesn't like about things that are not the 3 B’s?

**Interviewee:** He doesn't like the way it looks, it's yucky. The only thing that has ever gotten him to branch out is seeing a peer eat something different. Or an attractive typical female that he likes, he wants to try something for her.

**Interviewer:** Fair enough.

**Interviewee:** Yeah, I’m OK with it, whatever works.

**Interviewer:** What about sight or vision, any sensitivities to visual stimuli?

**Interviewee:** No, not that I've seen, no. He plays really obnoxious video games that make me motion sick. So, I mean, no, he's alright there.

**Interviewer:** Got you. And how have these sensitivities changed over time?

**Interviewee:** When he was a little kid, he used to vomit and gag at the sight of anything green, when he was an infant, and it was totally weird. He went through that phase, which really sucked. I mean, he was your typical autistic infant, I guess you could say. I mean, he wouldn't touch grass, wouldn't touch sand. I made the mistake of putting a toe in a pool and he freaked out for 5 hours afterwards about that. He had gravitational insecurity, leaning him back, oh hell no. Putting him in a car seat or stroller was not happening, we had to bounce him on the ball and do joint compressions and brushing just to get him in a high-chair so he could eat. We went through a year where he wouldn't get in a bathtub, so we had to do water therapy at OT. Just oh my God, so much, so much, so carboy much.

**Interviewer:** I'm sure. And so, he isn't as sensitive to those types of touching experiences anymore?

**Interviewee:** He still really walks on his tip toes all over the place, he might be, but he's just not telling us about them. And he's not as…I mean, when he was nonverbal, when he was a baby, he had no other way to do it. He's 17 now, so maybe he's just processing it in a different way, I don't know. But he walks on his tip toes everywhere, all the time. I don't know.

**Interviewer: [00:09:27]** That's OK, you don't have to know.

**Interviewee:** Yeah, I don't know.

**Interviewer:** That's alright. And has he always disliked sounds that he isn't the one like making or in control of?

**Interviewee:** Yeah.

**Interviewer:** Got you. And these changes that you just alluded to, do you think any of those changes might be related to any independence that he's gained over time?

**Interviewee:** Like him getting better with his sensory sensitivities, you mean?

**Interviewer:** Mh-hm.

**Interviewee:** Yes and no. I think the independence helped. I also think being in the classroom has helped because he has always been either the highest functioning or one of the highest functioning kids in the classroom. And so, he's had to be around some kids who were pretty severely affected who had a lot of very loud vocal stimming and then had one little girl who she – God bless her – did menstrual blood smearing in the room. So, he has had to acclimate to some pretty severe behaviors, he's been exposed to a lot. Of-course they got him out the room when stuff like that happened, but his exposure level has…so, yeah.

**Interviewer:** Awesome, thank you. That was a great segue to my next question **[both laugh].** So, my next question is, how does your son manage and cope or handle his sensitivities?

**Interviewee:** Well, I mean one of the things we have encouraged, like he went through a period when he was just very violent, we had a lot of violence, we had a lot of temper tantrums. As he’s gotten older, what has helped him is us telling him that, *“you're allowed to be angry, you're allowed to not like something, but you need to tell us. You need to use these words, this is what you need to say, this is how you need to communicate that,”* giving him the tools that he needs to communicate. The fact that he's verbal is a blessing, he can tell us this stuff. So, being able to state his likes and dislikes and knowing that he is safe to do so.

**Interviewer:** Absolutely. Is there anything that you do to kind of help him in this process besides give him those communication tools?

**Interviewee:** When he says he likes or doesn't like something, we say OK and we change it if it is appropriate and it's OK to do so, it's not like ridiculous. If we do something that offends him, we apologize, we respect his boundaries, you know. Like he went through a period where he did not want me to touch him, he did not want me to hug him, he did not want me anywhere near him. And I mean, that's fine, those were his boundaries and I'm not going to be Marie Barone and force myself on a child. I mean, that's his body, that's his boundary. So, we've always respected his autonomy, respected his boundaries.

**Interviewer: [00:12:31]** Absolutely, thank you. You just mentioned OT a couple of sentences ago. What else? What other specific therapies or interventions has your child received regarding his sensory sensitivities?

**Interviewee:** OT was the biggest one. We have like the best occupational therapists on the planet, she was actually on 2020. I mean she was…

**Interviewer:** Yeaah! Nice!

**Interviewee:** Yeah **[chuckles]** She's really, really good. But she was taken out of commission when one of her clients, a little autistic kid, went to run out into traffic and she grabbed him and tore a rotator cuff.So, we had to stop, but she was awesome.He also went to teach at the University of North Carolina, we did teach with them, we did social work with him for a long time.God bless them, they're worth their weight in gold. And then there was a camp – I don't know if you're familiar with Raleigh Durham area?

**Interviewer:** Mh-hmm.

**Interviewee:** OK, we were there for 24 years, so we just moved to Texas. So, Raleigh Durham, we were right there with Teach and, you know, you can't swing a toy train without smacking somebody autistic in Raleigh Durham, that's how it is. So, they have a *big* summer camp for autistic individuals there, and it's an overnight camp and it's weeklong. And it's one to one camper-counselor ratio, and they were awesome, very trustworthy. The Teach counselors had to browbeat me into sending him there the first time **[laughs].** But he would go there, and it was awesome. That really helped him too because they went swimming three times a day, they went on hikes, they had this *huge* sensory gym there, it was amazing, amazing.

**Interviewer:** Yeah. Did the OT and Teach also help him with the sensory needs?

**Interviewee:** Oh yeah, like Teach, oh my gosh! One of his counselors, in particular, she's just, oh God, I love her, she’s a saint. She would sit there, she would hold my hands in the session and say, *“you know, Christina, you need to use less words, you need to do this.”* **[00:14:33 inaudible]** she would coach me and go, *“yeah, oh yeah!”*

**Interviewer:** That's awesome. And how did his sensory sensitivities change throughout these therapies and interventions?

**Interviewee:** He didn't change, I did.

**Interviewer:** How so?

**Interviewee:** We learned to bend around him. I mean, that's just how it's gotta be, your kid isn't going to change, not when they're autistic. I mean, it's just…he trained us, which is how it has to be. I mean, that's just how it has to be. You learn how to shape yourself around your child and adjust your expectations, adjust your reactions and to kind of chill and take a step back. So, yeah.

**Interviewer:** Awesome, thank. And then when your son is in an environment that has sensory experiences that he finds aversive, like say a bad smell or sounds he doesn't have control over, does that cause or increase anxiety for him?

**Interviewee:** Sometimes it does, yes. I mean, like when we went to Disney World, we were kind of worried about that, but we brought my sister along for that specific reason. I mean it can, but we always…I mean, we're so…I guess it's like we don't even think about it anymore, because we're so kind of trained that we just always operate in that way of thinking, we always have a Plan B, always have an exit plan. I don't know.

**Interviewer:** And do these exit plans and Plan B’s kind of negate the anxiety of your child?

**Interviewee:** Usually. I mean, we're just so…it's automatic now, we don't even really think about it, it's just how we are as a family, it's just what we do.

**Interviewer:** And has that always been a case where it hasn't really caused anxiety for your son?

**Interviewee:** Oh no. I mean, there have been *many, many* times when we've had to cut and run and bail. I mean, it’s just he was our first kid, our kids are 4 years apart. By the time the second one came around, he was 4 years old, so we were broken in. We were well trained and then the second one came along and lightning struck twice and we had another one with sensory issues, so the whole house is freaky, so it's alright, that's just how we roll **[laughing],** it doesn’t matter.

**Interviewer:** Got you, thank you. Thinking more specifically about your son's reactions to sensory experiences that he has, has anxiety related to that changed over time?

**Interviewee:** I don't know. I mean, like he used to tantrum a lot, and I know that every behavior has a function, behavior has a function, OK. And so now, as opposed to tantruming, he will go into his room and seek alone time. So, I guess how he expresses it. We're dealing with a lot of actual expressive anxiety now as opposed to tantrums. So, I guess it's probably not changed, just how he expresses it that’s different. Does that make sense?

**Interviewer:** Yeah, totally, absolutely, 100%, thank you. And so now thinking a little bit more broadly, what goals or hopes do you have for your son in terms of his sensory sensitivities?

**Interviewee:** I just want him to be comfortable in his own skin, that's just all I want. I read that book, *The Fabric of Autism* by Judith Bluestone. Have you ever read that book?

**Interviewer:** Mh-hmm

**Interviewee:** Oh gosh…

**Interviewer:** Recommended

**Interviewee:** Yeah. Well, she's an autistic woman and she talks about what it's like to have to pass as typical all day and what it's like to have to make eye contact with people and deal with the sensory bombardment and then come home, and what it's like to feel like in her body. And it talks a lot about the Physiology of it, and since I'm a nurse, I nerd out on that stuff. I just want him to feel comfortable in his own skin and to feel safe, like he isn't going to be forced to be miserable.

**Interviewer: [00:18:50]** Absolutely, thank you. We're gonna move on to our next chunk of questions. So, as your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** Well, that's where we're lucky. You know, he grew up in Durham and it is like an autism bubble, I mean, I swear to God it is. And because Teach was right there and we had this huge, huge, huge autism support group and huge autism community, there was a presence there. I mean, we literally didn't have to worry any time we were in Raleigh Durham, it was just like everything was cool. We never had to worry unless we went out of town.

**Interviewer:** That makes sense. Then this kind of answered my next question, but was the community more or less accepting when he was younger?

**Interviewee:** Oh yeah, they were, they were great, more accepting. When he was younger…yeah. I mean, we never had to worry. It was always just, I mean, that little bubble, that was a big…that factored into our decision leaving, how supportive it is there.

**Interviewer:** Were there specific aspects or are there specific aspects of your community and his community that are more or less accepting?

**Interviewee:** What Austin versus Durham?

**Interviewer:** You could talk about both, you could talk about where you are now, or you could talk about Durham.

**Interviewee:** Durham was just because there were so many, you know, you had Duke, you had UNC, you had Teach, you had all the, you know, you had research triangle, which of-course, I'm a big proponent of autism is genetic, and it's because the geeks are breeding. So, you had tons of your math and science and tech nerds there, and so you had like this huge influx of your autism clusters. So, it was just because of the atmosphere there with the math and the tech and the medical science and the academia there, we never got the funny side eye looks or people telling us we needed to just beat some sense into him, we didn't encounter those things. And I mean I used to carry these little business cards around with me and I put them in my pocket only when I didn't feel safe, when I was worried that somebody was going to make comments about his behavior, and I usually only carried them in my pocket with me when we were out of town. Not when we were in Durham, because people generally were cool with it. I mean yeah, it's very granola there, very crunchy **[both chuckle]**. So, places like that tend to be more accepting of not the norm, and so that was…yeah, that helped.

**Interviewer: [00:21:55]** Are you finding where you are now a different experience for your son?

**Interviewee:** Well, we were very deliberate in our choices to move. I mean, that was a huge factor. You know, Austin is the little granola center of Texas, which just is, and you wouldn't…I mean, Texas is Texas, God bless it **[both laugh]**. But where he is now is just…it's unbelievable, we're even in a suburb of Austin. And you would think it's kind of rural, but they're extremely accepting here. Very, very focused on…why can't I think of the word? I keep wanting to say ‘integration’, that is such the wrong word. What’s the word I wanna say…? Inclusion! There we go. Hello, sorry.

**Interviewer:** It's OK, it’s almost Friday.

**Interviewee:** OK, yeah, they're very inclusion minded here, it's really weird. I mean, not weird, but it's really good. He's had way more inclusion here than he had in Durham, which is bizarre.

**Interviewer:** Hmm.

**Interviewee:** I know! So, yeah.

**Interviewer:** And is that in schools or is it in other aspects of the community?

**Interviewee:** Both.

**Interviewer:** That’s wonderful.

**Interviewee:** So, it's really bizarre.

**Interviewer:** What about family, how is family with his sensory sensitivities?

**Interviewee:** They're good. I mean, when he was a little baby, we didn't know what the crap was going on with him, everybody was just kind of sympathetic and puzzled and confused, and he was a really hard baby. But once he was diagnosed, which was of course really young, they've been fine. I mean, they always…they bend around him. And they've always…they work with his quirkiness and he says blunt, kind of rude things sometimes and they just laugh like, OK.

**Interviewer: [00:24:00]** Yeah, got you, thank you. And so now again, thinking a little bit more broadly, do you have worries or hopes for how the community will continue to react to your son sensory needs?

**Interviewee:** Absolutely, yes, of course. I mean, it's reality, he's gotta grow up, he's going to become an adult, he has to function within society. I'm in the process, I've got paperwork sitting on my desk I gotta give for a summer job program for him. And it's through the Texas Workforce Commission and it's pairing with Goodwill, and he's going to be, you know, it's *for* special needs people, but still. And he's had vocational training. But I'm always afraid, I'm always afraid. I can't help it. And you hear and you see stories about special needs people encountering law enforcement and not reacting correctly, and I've had long talks with him about that and how he needs to act and everything, and it just, yeah. Yeah, I worry, of course.

**Interviewer:** Yeah, thank you for sharing that. We're going to go to our next chunk of questions again. So, in the transition to adulthood, quote unquote, where do you see your child?

**Interviewee:** Well, my husband and I have always assumed that he would not be independent because he is developmentally delayed. I really don't think he'll ever have the intellectual capacity to manage his own finances, to manage a household or things like that. Hold a job, certainly. *Maybe* drive, I don't know. There are two organizations here that teach developmentally delayed people to drive. God bless them, let them do it, not me **[both laugh].** Maybe he'll drive, I don't know. Baby steps. But my husband and I have always planned for him to live with us always, and both his parents and mine have trusts for him set aside, and we've got…our wills are set out so we have the financial thing…we've had it planned out for him to be dependent on us and or somebody else for the rest of his life.

**Interviewer:** Got you, thank you. Thinking a little bit more about his stage of independence, could you describe things where he needs a little more support versus some things that he's able to do more independently?

**Interviewee:** He definitely needs support with financial decisions and making any kind of an adult decision – well, actually any kind of an older adolescent decision, he needs help with. He's great with activities of daily living, he cooks his own meals, I mean, easy stuff, putting a frozen pizza in the toaster oven and stuff. He does his own self-care. If you teach him how much medication to take, I put their meds out for them and they know how to take what. He's fairly independent, he's functions probably at the level of about a 12- or 13-year-old maybe, maybe a little younger.

**Interviewer: [00:27:19]** Yeah, absolutely, thank you. You talked about cooking for himself simple things. In a perhaps pre-Covid world, was he able to help you with shopping to get those items or like household items?

**Interviewee:** Oh yeah, yeah. And he still does when he wants to. I mean, we haven't…we restricted him a little at the beginning, we kept him locked down and didn't let him go out with us, but, you know, they're both in in-person school. I'm a school nurse for crying out loud, if I'm not bringing cooties home, they’re bringing cooties home. So yeah, he’ll be alright.

**Interviewer:** Yep, super Fair. How is he with helping with household chores and things like that?

**Interviewee:** He loves to vacuum. We have a Dyson Stick vacuum that he's in love with.

**Interviewer:** I have one too, they're great.

**Interviewee:** OK, so you know the Dyson Stick love, OK! So, I asked his brother to vacuum the throw rugs in the house the other day and he said, *“well, when I started to do it, Matthew asked if he could do it instead, so I let him.”* Like, *“OK, whatever.”* I can't get him to clean a bathroom properly to save my life, but he is a teenage boy, so whatever. But he's really weird about if people leave dishes or cups or anything sitting around where it's not supposed to be, this is the OCD organization thing, the clutter thing, he gets really weird about that. And he always picks stuff up and moves it and puts it in…oh, it drives me crazy.

**Interviewer:** I'm sure, I understand. You talked about how he will need support for money and things like that. Does he understand the concept of money or does he just struggle with…?

**Interviewee:** Oh yeah, yeah. He doesn't always get his math right, and they're teaching him about banking and credit cards and stuff at school. At his summer work program, he will actually get paid, so maybe we should open a bank account for him.

**Interviewer:** That's wonderful.

**Interviewee:** We’ll cross that bridge when we get there.

**Interviewer:** It's in the summer **[chuckles]**. And you talked about his job. Does he want a job?

**Interviewee:** Yes, yes he does.

**Interviewer:** And I know you said that you do plan on him living with you later, but does he *want* to live on his own? Does he want to be more independent?

**Interviewee:** Yeah, he does. He does, but I mean, a group home over my dead body. Sorry, no. I mean, the most I would ever allow would be for him to live with like a para or an aide or something, or maybe like…there's a famous author who she writes books about autism, and her son lives with another autistic person and it's like she and that mom got together and they put their sons together, that may be it. But mh-mh, I'm just not comfortable.

**Interviewer: [00:30:29]** Nope, and you're allowed, it's totally your prerogative. And does your son manage some sort of a social life to some extent?

**Interviewee:** Yes…meh…we’ve been having difficulty with that. He just got his first cell phone this Christmas. We arranged this volunteer thing for him. I forgot the name of the organization here in Austin, where they hook special needs teams up with typically developing peers and they have a Zoom chat once a week.

**Interviewer:** Fun!

**Interviewee:** Yeah, and it's for social interaction. Well, Matthew got a little bit stalkerish, a little overly attached to these girls. They're real cute little girls, little cute little 16-year-old girls. He was messaging them excessively and kind of pushing the boundaries, so we had to get intervened with their boss and me and kind of tell him how to back off and these are their boundaries. And I had to talk to the girls about how, *“it's totally OK for you to say to my son, you need to back off, you're driving me nuts, play it down,”* ‘cause I think they were afraid to be stern with him and it's like, please go there, it's OK. But now that he has his own cell phone, he's actually texting other people and stuff. But he's very funny about it, he'll bring his cell phone to me and say, *“this strange number texted me and tried to call me, is it going to put a virus on my phone, is that OK? Am I safe? Am I safe?”* And I'm like, *“yeah, you're safe, you're fine.”* He’s really worried about predators and viruses, so yeah.

**Interviewer:** That makes sense. They do exist, unfortunately.

**Interviewee:** They do, and I'm glad he's afraid of them instead of he doesn't care.

**Interviewer:** Absolutely. Do you think your son will be able to achieve more independence in the future?

**Interviewee:** I do, we're actually gonna…there's this institute here in Austin, it's…I guess the only way I can describe it is a private junior college for autistic people. That's the best way I can describe it, is what it is, 'cause there's a tuition, it’s $16k a year, and it's only for autistic people, and they do computer and software and vocational training. And so, we’re going to send him there.

**Interviewer:** That’s great.

**Interviewee:** Yeah. They teach job skills, they teach life skills, social skills in addition to vocational skills.

**Interviewer:** That's awesome.

**Interviewee:** Yeah. I mean, I have…we want him to have whatever he can, whatever is possible for him, we want him to have it. Does that make sense?

**Interviewer: [00:33:25]** Yes, absolutely. And again, you gave me a wonderful segue, so, thank you. So, my next question is, what do you think will help move him into adulthood and move him into more independence?

**Interviewee:** Honestly, vocational training and exposure to…I mean, typical peers have been great for him and he loves the inclusion that he's got, typical peers have been awesome. However, this junior college thing, it’s called the Nonpareil Institute, and avocational experience with peers on the spectrum who are his same level of functioning. I think he needs more friendships that way, because he needs to grow a friendship circle of people who are his true peers, he really needs to grow friendships that way and make a circle of friends who aren't going to age out and away from him. People who are going to remain where he is and who are going to be in the same life experiences with him, who can share and stay in his orbit.

**Interviewer:** Yeah, absolutely, that makes total sense, thank you. Beyond this kind of peer support that you're describing, or this institute, are there particular services or interventions that you think could help [him] gain more independence?

**Interviewee:** Well, the vocational thing and then the places that do teaching driving to [the] developmentally delayed. I've never heard of that until we moved here. I was amazed that there are two, independent private places that do that. I was like holy crap, that's amazing. Offering…like for his job, the summer job thing we're doing, one of the big problems they have is transport, do we have transport for these people? And yes, that is a big problem. I mean, my husband and I are very fortunate, we’re upper middle class, we’ve got the income, I don't have to work full time, so I can drive my kids there, but what about these parents who don't have it? And then you’ve got the vocational training, social groups. Like one of the skills that they're doing at this junior college thing is teaching them office interaction skills, like professional interaction skills, like how to talk to your boss and stuff like that. I mean, they need to learn how to do things like, I mean, I know ADL’s, yeah, ADL's are important but also so is washing your own clothes, learning how to take care of a household, frigging home-ec, I guess. I mean, bring back home-ec, for crying out loud.

**Interviewer: [00:36:19]** Absolutely, thank you, that was wonderful. And so now putting these two things together, your son's sensory sensitivities and his transition to adulthood, how do they intersect?

**Interviewee:** Well, right now, I guess his sensory sensitivities and his sensitivities in general are manifesting as big-time anxiety. And the transition to adulthood, one thing I just talked about was home-ec, which made me think, because a lot of people would say, well, that's your job as a parent to teach that to your kid. Yes, that is correct. Here's something, let me just tell you this little anecdote. When Matthew was like 7 or 8 years old, me and my girlfriend, one of my best friends, she's an autism mom too and her son is about on par with Matthew. We were talking one day about how other kids, typically developing kids had been taught to not interrupt their parents when they were talking and how our children still interrupted us all the time in the middle of a conversation, and we would always turn and address them and how we needed to *stop* that. But we had been so trained through speech therapy that every time they spoke to us to always answer them back. But these were little things, because we had so many other fires to put out, so many other fires to put out in our house that we didn't think about things like teaching them basic manners of not interrupting and teaching them basic things like, this is how you make a bed, this is how…I didn't teach Matthew to ride a bike until he was 14, I had other fires to put out, I had too much. Like, the dentist one time asked me about flossing, and I burst out laughing at her and I said, *“we* just *now reached the point where I don't have to pin him to the floor to brush his teeth. Are you kidding me?”* I mean like, we had…autism parents have had so many other friggin fires to put out our whole life, we haven't had time or even *thought* about teaching the very basics, because it hasn't occurred to us, it just hasn't even been on our radar.We were like, *“what?”*

As far as the sensory sensitivities, now those are manifesting as extreme anxiety, so, we've got anxiety right now.So, what we need to do at this point, my husband and I, our families, we’re actively trying to manage his anxiety with meds and therapy – psychotherapy to get those under control.So, that's what we have to do.And then teach him realistic expectations, because he has a lot of unrealistic expectations of what real adult life is actually going to be.Like he's afraid if he breaks even small rules that the police are going to show up **[sighs]**.I don't know.Oh yeah, and I was talking to…he got very upset about something, about something his brother was doing.And I told him, I said, *“when you're in the workplace, when you're in a job, you can't react that way, you need to learn how to control this reaction.”* So, yeah, as he gets older, it's going to have to be more about when he has a sensory overload or he's having [one], he's got to learn how to channel that into something that is socially acceptable and safe.

**Interviewer: [00:40:02]** Yeah, absolutely, thank you. And then, would you view his sensory sensitivities as an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** An obstacle.

**Interviewer:** In what way?

**Interviewee:** Because they do tend to…because he already has a lot of resistance to change to new situations, to trying things, just because that comes with the whole package of autism. And then you add on top of it and aversion to smell, an aversion to the way that looks, the way that sounds, the way that tastes, the way that feels, and it's just going to be a roadblock to new experiences, to new people, to new things, to new places.

**Interviewer:** Absolutely, thank you. And then, relatedly, what do you anticipate as being challenging for your son as he does gain more independence in relation to his sensory sensitivities?

**Interviewee:** Really, he's going to have a hard time tolerating noise. I think he's going to have a hard time tolerating the noise and the idiosyncrasies of other people. People make noise, they tap their pens a lot, all that noise. That's going to be the number one challenge for him.

**Interviewer:** That makes total sense, especially when we're all stuck at home **[laughs]**.

**Interviewee:** Oh good Lord!

**Interviewer:** Do you think there's anything that could help your son at this intersection of sensory and transition?

**Interviewee:** Just exposure and just gradual exposure and training, you know, just like – I hate to use the analogy – boil the frog. I mean, he just needs to gradually get more and more exposure and more and more used to it, and the only way to do that is with vocational training and gradually increasing the level of…yeah.

**Interviewer:** Yeah, absolutely. Besides vocational training, are there other particular services or interventions that you think could be helpful at this intersection?

**Interviewee:** I think that social outings, like going out with typical peers to baseball games, noisy, loud places, having to interact *with* society at large without mom and dad there because we helicopter, we can't help it. Having to be with his peers and to be in a public place, you know, go to shopping malls, go to baseball games, go wherever, just be in society and have to learn how to interact and be in those…be in the messiness that is our world.

**Interviewer:** Absolutely, thank you. And do you feel like there are gaps in these available services and interventions?

**Interviewee:** For older kids, heck yeah! For adults, good God, yes, yeah. People forget that cute little 3-year-old autistic kids grow up to be 18-year-olds. They grow up.

**Interviewer:** Yeah. Do you see those gaps in any particular spaces or places?

**Interviewee:** Meaning?

**Interviewer:** Like, you talked about how they don't exist as kids age. Is it like, are they lacking in a particular modality, like occupational therapy or something like that?

**Interviewee:** Oh. Well, from what I see, I mean again, this is different for my husband and I because we're privileged, we can pay for a lot of stuff. And also, Matthew is higher functioning, so, we haven't had to deal with that. One of the things that I know a lot of parents say they really need are things like respite, respite is a *huge* one. And things like, yeah, they don't have OT for all the sensory stuff. OT for older kids, heck no, that doesn't exist, it doesn't exist. Like, well, I know a mom was talking about a sensory gym, and they just don't have those for older, bigger people, and Matthew I know would *love* that kind of stuff. They don’t have it. I mean, it's once you get past a certain age and height, it just doesn't exist anymore. And social groups, any social groups they have are usually towards higher functioning or Asperger’s. Not everybody who wants to be social has Asperger’s or high up on the spectrum, OK. The middle ground people have been completely forgotten.

**Interviewer: [00:44:42]** Got you, thank you. I appreciate that. And now looking back, how have your son's sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Well, that's a hard one to answer. I mean, he shifted our entire life, but he did it so early on that I don't remember what I thought and wanted before the shift. I try to think about what I used to think I would have as a son, but I can't remember.

**Interviewer:** Yeah, that makes sense, he's your son. Thank you. Last chunk of questions, we're almost done and it's related. So finally, as a caregiver, as a mom, as a parent of someone with autism, but also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** It means that he's gaining independencies or going to actually…I don't know, I guess the…we're gonna peek behind the curtain finally and see, the question will be answered – who is he going to become? We've been waiting all these years and kind of holding our breath. And I don't know, all the hard work that we've put in is finally paying off, I guess. Transitioning to adulthood means that we can exhale.

**Interviewer:** Thank you. Has this perspective changed over time?

**Interviewee:** Yeah, oh yeah. I mean, when your kid is first diagnosed, I mean, when your kid is really young, oh dear God! Yeah, when you're in the throes of new autism, geez. Oh dear God, no. Yeah, yeah, way way better now **[Rachel chuckles]**. Well, it just is, I mean, yeah. When your kid is…when you have a kid that…he didn't sleep through the night till he was 3, and breast fed every hour, an hour and a half the first nine months of his life. My God, I was a zombie. So, yeah.

**Interviewer: [00:47:17]** Thank you. What do you see happening in your son's future?

**Interviewee:** I'm not sure. I'm not sure even where we're going to be, I mean, everything has just…I never thought we'd be in Texas, I never thought we would have moved during a pandemic, I never thought we would have left Durham, everything has changed. We’ve had a major cross-country move, we've had deaths in the family.

**Interviewer:** I’m sorry.

**Interviewee:** It’s alright. I don't know anymore. There's been so much upheaval in our family I don't have a road map anymore. I don't know.

**Interviewer:** That's OK, none of us really know.

**Interviewee:** Yeah. I just wanted to be happy and know he's loved, that's it. And safe.

**Interviewer:** Absolutely. But you mentioned that you think he'll stay at home with you. Is that right?

**Interviewee:** Yeah.

**Interviewer:** Do you think he'll hold a job even though he will be at home with you?

**Interviewee:** He will absolutely murder us if we don't let him hold a job. My gosh, that child will call an Uber and run away. He’ll call my sister, he's very close with my sister, his aunt. He'll call his aunt, his aunt will call him an Uber. She'll come and get him out of the house, she’ll take him away from me. She's like, yeah, yeah yeah, he'll be fine.

**Interviewer: [Laughs]** That's good. And do you see him finishing that school program you mentioned?

**Interviewee:** Yes, yeah. Absolutely, yeah.

**Interviewer:** Do you see him ever having a partner or a family of sorts, whatever that may mean?

**Interviewee:** God, I hate that question.

**Interviewer:** I’m sorry.

**Interviewee:** No, it's OK, 'cause my sister is…she's so obnoxious, she's my older sister, so she's really annoying. So, she's like a huge proponent of him having a girlfriend and all this other stuff, and that just makes my stomach turn, and I'm like, dear God, no. I don't know. We made him take a human sexuality class just for the developmentally delayed, they had one of those in Chapel Hill at Teach. It was very comprehensive, it went over consent and LGBTQIA and birth control and all the other good stuff. So, it was beautiful, it was wonderful. We're using the binder for my 13-year-old 'cause it is so comprehensive, it's fabulous. So, he's been educated. If he has a partner, that's fine, I will freak out. I don't know if he will have a partner, I don't know.

**Interviewer:** That is OK, you don't have to know.

**Interviewee:** I will need to be sedated **[Rachel laughs]**. It'll be OK though.

**Interviewer: [00:50:13]** Absolutely. Last, final question: how have your son's sensory sensitivities impacted this perspective you described in terms of what it means for him to transition?

**Interviewee:** Well, he gets upset like when we talk to him about how when he has his outbursts, or when he had them – he hasn't had an outburst, like he had one outburst two weeks ago and he hadn't had one in a long time. When he would have his outbursts, we would sit him down and say, *“you talk all the time about wanting to be a grown up and wanting to have your own car and wanting this kind of independence. You cannot do these things and you cannot react this way if you want…”* We told him that. So, it seems like he has almost really taken that to heart.Maybe that's why he's learned, didn't even think about that until just now.Maybe that is why he started being more vocal and reigning it in, it’s because he really…I mean, he really does want independence, yes, he wants it badly. And so, we started using that as currency with him, telling him, *“you need to start using this, being more productive and how you express yourself when you are upset, when something bothers you and something drives you crazy. Rather than exploding, you need to say or you need to walk away or get away from whatever it is that's bothering you.”* So yeah, in regards to his independence, I think that must have been the impetus for that.

**Interviewer:** That's wonderful. So, it's actually all I have, that's it for my formal questions. Would you like to add anything else?

**Interviewee:** Nah.

**Interviewer:** OK, thank you. This was wonderful, I truly appreciate all the time and effort, it's been great to learn from you.

**Interviewee:** I'm really glad you're doing work for older people on the spectrum, so thank you, appreciate it.

**Interviewer:** Thank you, my pleasure, of course. And as soon as this audio and video renders, I will send you a final email and it'll include a gift card as compensation for your time and effort.

**Interviewee:** Oh, thank you, I appreciate it. Encourage your colleagues to do more research on the older autism community because we need it.

**Interviewer:** I will. I think people are, I think it's a positive trend that's happening. I can send you some other resources. I think people…

**Interviewee:** We so need it, we so so need it, it's a high need area.

**Interviewer:** Yeah, I think people are learning that.

**Interviewee:** Good, thank you.

**Interviewer:** Of course. And that email, I'll probably get to you on Monday. I'm not working tomorrow, but it will be in your inbox very soon.

**Interviewee:** Yeah, no worries. OK, thank you.

**Interviewer:** Thank you. Have a great day.

**Interviewee:** Bye.

**Interviewer:** Bye.

**[END OF TRANSCRIPT]**