**[Start of transcript]**

**Interviewer:** Alright, we are recording. And I will be asking you questions about your perspective regarding your child’s transition to adulthood in relation to his sensory sensitivities.

**Interviewee:** OK.

**Interviewer:** And we’ll be doing something called a ‘semi-structured interview,’ which means I have my planned questions, but I’ll also be adapting them to fit our conversation, so they actually fit for what we’re talking about.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** No.

**Interviewer:** OK, wonderful. And if there’s anything that you don’t want to answer, for whatever reason, perfectly fine. “*I don’t know*” is a perfectly fine answer. And if anything pops up from earlier later on in the conversation, feel free to jump in. It doesn’t have to be linear.

**Interviewee:** OK, perfect.

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

**Interviewee:** Sure. My son is 17. And as he has gotten older, he’s been able to adapt better with his sensory limitations. However, storms are still terrifying to him, thunderstorms, the anticipation of storms. So that really gets to him. It’s very hard for him to even function when he’s getting ready for those. Loud noises are also scary. If someone is shouting, then he does not react to that well. And that … he shuts down quickly. And by him shutting down … he’s a very passive kid, but, you know, you can see him really, you know, trying to retreat a little bit the best that he can, and he tries to exit the situation. Some sporting events are difficult to attend. Concerts are something that we haven’t really been to. He does better with earphones, like, headphones or even earplugs. That’s been good. And then light isn’t a significant sensory issue for him, although he doesn’t particularly care for the dark, but it’s not something that is as pronounced as sound is for him. And texture: he’s particular about his clothes, but he’s never, like, refused to wear anything because of the way it feels, but he doesn’t want to … if he doesn’t like it, he doesn’t want to wear it for a period of time, like, church clothes that he … he’s very happy once the church is over to take his clothes off. But that’s also, I think, kind of typical for any boy. So, but other than that, he’s done great. He started working with me, I think I said that in a couple forms, and that has actually greatly improved his self-confidence, which has helped some of his sensory constraints as well.

**Interviewer:** How so? That’s wonderful, though. But how so?

**Interviewee:** Oh, yeah. Well, I think just because his self-esteem is **[3:00]** growing, you know, and then now that we’ve … since, it’s a catering company, a friend of mine owns it, so I started working there as, like, a side hustle thing and so he’s doing it too. And it’s been great. And … but then he’s forced to have to go to different places. So we’re having to … at new events, to be around a lot of people that he’s never met before. You know, some weddings have music, and there’s a lot of talking, so I mean, he’s … but he’s done well, but he’s also been able to, with some maturity, to tell me when he needs a break, because when we work events, we do them together. But he is able to tell me, like “*I need to go outside*” or “*I need*,” you know, “*a break for a minute*.” So that’s been very good that now he’s actually able to recognize that it’s OK to ask for one, you know, and that it’s OK to remove yourself from the situation and he always comes back, which is great, too. So that’s improved a lot as he’s gotten older.

**Interviewer:** That’s wonderful. I’m glad he’s having this experience then.

**Interviewee:** Oh, yeah, me too.

**Interviewer:** For sounds: is it mostly people talking or is it also, like, mechanical sounds that are bothersome for him?

**Interviewee:** Well, he’s … mechanical sounds, he’s OK if he knows what it is. If he does not know what the sound is or where it’s coming from, then that’s very scary. But, like, if he can see a train and he can hear the train, that’s OK. Same thing with planes. But if there’s a noise that there’s, like, a piece of equipment that’s outside, he doesn’t know what it is, then that’s very bothersome. But once he’s able to visualize it, and then he can, like … there’s lots of times, if somebody’s out in the … outside our house and he’ll need to look out the window or we’ll need to look outside and see what it is and then he’s OK. But if he doesn’t know then that … he doesn’t like not knowing what it is, he gets fearful. Which isn’t that **[inaudible at 4:48]** really.

**Interviewer:** Oh, yeah, absolutely. **[crosstalk at 4:52]** Absolutely. And then for texture: you said he’s particular about certain clothes, what type of clothes does he prefer or not prefer?

**Interviewee:** He prefers elastic waists. He’s not a big fan of belts. He prefers soft fabrics. He’s not a big fan of corduroys. He always wears socks. He does not like … he doesn’t like the feel of the floor. He’s never barefoot and even in summertime he’s always wearing socks. He’ll take his socks off, like, if we’re going to go swimming. But even, like, flip flops, he’s not a big fan of, so he’s just got to … he loves socks. So he just really doesn’t like … I just moved in so … you know, and it’s hot here. That’s all anybody ever talks about. But, like, he’ll wear … it’s been better that …. as he’s gotten older that he’ll wear dress clothes, but, again, he doesn’t want to wear them for very long. And he’s particular about colors. Green is his favorite. So he **[6:00]** prefers to wear most things that are green and shoes really need to have some green in them or he doesn’t like them.

**Interviewer:** Got you. Excuse me. What about other sensory modalities like perhaps smell or taste?

**Interviewee:** He has a very restrictive diet. So he only eats five things. So for taste … that he doesn’t … he’s … will not try anything new. So it’s the same things. But that’s been, you know, since he was very, very young.

**Interviewer:** What is he … ? **[crosstalk at 6:30]** Oh sorry.

**Interviewee:** Go ahead.

**Interviewer:** Oh no, you go. You go, please.

**Interviewee:** Oh, for smell: he is more sensitive than I am with smell and more sensitive than my daughter is with smell. So and he … like, if there’s a new fabric softener, he needs to smell it first before I wash his clothes in it, you know, and then he’s OK, if he knows what it’s going to be, you know, but, like, even any cleaners or anything in the house. If I’m washing anything, I’ll have him smell it before I wash the floor. He’s never, like, said … got upset about it, but he won’t like if he doesn’t know. Like, as long as he knows what’s coming up, then he’s OK. Same thing with smells. Like, if he knows, you know, butif I’m cooking something new, then he’ll want to know, like, what is that? And he’ll come downstairs. And then, when he knows what it is, then he’s OK, but he picks up on it quicker than I do or my daughter.

**Interviewer:** Got you. So it’s, like, an uncertainty thing, he wants to understand what’s happening kind of across modalities it sounds like.

**Interviewee:** Exactly, yes. Once he knows, then he’s fine. Same thing with his schedule. I know you haven’t asked this yet, but, like, for his sensory limitations, with schedule changes … he likes a routine. And if something changes, then it doesn’t always go well, but if you tell him about it in advance, then he’s OK. But if the change happens without any notice, then that could just really just ruin his day. So there was … before he was a virtual student, I’d be picking him up lots early from school because of the schedule change or if there was a fire drill, or if there was something out of the ordinary, he just couldn’t stay and I had a doctor’s form for him so that, you know, in case he needed because he always missed more than the 10 days. But his teacher was great at understanding that he’s really not productive anymore once, you know, he’s, you know, kind of defeated for the day. So it’s really, it’s not beneficial for anyone for him to be there. But he’s done great with anxiety and then with sensory stuff, but, you know, he’s just with me or, you know, here at my work so that’s been easier to do this year.

**Interviewer:** Got you. Thank you for sharing that.

**Interviewee:** That was way more than you wanted. I’m sorry.

**Interviewer:** No, nope. **[crosstalk at 8:44]** That’s the beauty with these interviews: the more the merrier, so don’t apologize. You mentioned that your son has a restrictive diet and only eats five things. What are the five things he prefers to eat?

**Interviewee:** Plain Cheerios. He’ll eat that with milk if it’s time for school, **[9:00]** otherwise, he’ll just have dry. Goldfish, strawberries, Chips Ahoy chocolate chip cookies and apple juice and chocolate ice cream at night after a shower, in his pajamas.

**Interviewer:** Got you. Do you … is he able to explain or, like, are you able to figure out, like, what about those five things are good for him versus the other things that are not good for him?

**Interviewee:** What do you mean?

**Interviewer:** Like, do you know why those five things are his five things he eats, like, have you been able to figure that out.

**Interviewee:** Oh, no ... he’s just very … oh, and he eats cheese pizza, but cheese pizza only from a certain vendor’s. So that’s … but he’s a huge kid. I mean, he’s six feet, 190 pounds. So eating that restrictive diet apparently is fine.

**Interviewer:** Apparently it’s enough calories.

**Interviewee:** Yeah, because he’s a big kid, so. But he … you know, you’d think it would be boring, but, like, and he eats the same thing for lunch every day. And that’s just what he wants and he doesn’t want anything different and it’s been like that for years and years and years. And that’s all he wants.

**Interviewer:** That’s OK. How …? Thank you. How do you help him or how does he manage and cope with his sensory sensitivities and sensory interests?

**Interviewee:** It’s a good question. We … I adapt … well, we have learned to adapt so that I don’t try … I try not to put him in situations that I know are going to be hurtful for him or create high anxiety. If we go someplace new, then we look at the pictures on the website. Like, even for these catering events, then, you know, we look up where we’re going and then … so then he knows where we’re going. If we’re doing any travelling, he wants to … we plan a route together, we look at everything together so that he’s aware of, you know, just what to expect. And then, if we’re … like, we don’t go out to eat or anything very much because it’s really—this sounds terrible but it’s, like, it’s kind of a waste just for, like, him and I to go. Just, I mean, the experience is good, but not if you’re not going to eat anything. I mean, it seems sort of silly. But he does, you know … I do take him to different places, you know, just to see what different restaurants are like because it is important for him to be able to know that for him to be a **[inaudible at 11:25]**. But a lot of … really, I’ve just learned what he does … what situations he does well and what do not. And that’s just been over time. So I try not to put him in anything that would create a not positive experience for him.

**Interviewer:** Totally. And you touched upon, like, headphones and even some, like, avoidance behaviors: are there other things that he does to kind of help himself in those scenarios or, like, ask for a break?

**Interviewee:** Yeah, he asks for a break. He has some fidgets that I keep in my purse that he’ll actually get out. So I mean, **[12:00]** that’s been great and he’s able to recognize what he needs. And then when he starts stimming a lot—and that’s usually when he’s very excited, or when his … when he gets very anxious, you know—and then he’s able to self-soothe that way. Or echolalia becomes a lot more present when he is unsure of a situation.

**Interviewer:** Totally. Has he ever received specific therapies or interventions for his sensory needs?

**Interviewee:** No, just the social skills at school and then the early intervention, that was only for speech. But the ABA therapy and a lot of the sensory therapies that are available now were not available 13 years ago. So I think now, if … he would be entitled to much more services younger because of just what’s advanced, but the … behaviors that are available were not available then. And right now … and that’s a bummer with kids and I’m sure that you’ve had this with your other interviews that when you get to this age, like, you’ve aged out of so many therapies and there’s … you get this window, there’s not a lot there.

**Interviewer:** Yeah, that is something that most, if not all, parents have basically talked about, so … **[inaudible crosstalk at 13:10]**

**Interviewee:** So I’m glad you’re doing this study, because it’s so important to see where the gaps are.

**Interviewer:** Yes, I think so. I’m glad you think so as well. You alluded to this a little bit in the very beginning, but how have your son’s sensory sensitive sensitivities changed over time?

**Interviewee:** He’s learned to adapt and I feel that I’ve learned to adapt more as a parent, so that he’s not in situations that I know can be a triggering situation for him to make sensory, you know, to issues. He loves social stories. So now that I know that that helps to communicate new events for him, then, you know, we make those together. So and then, same thing with seeing where we’re going next and then talking about the schedule for the day. That’s very important and that has worked well. So I think that both of us together have learned what has been beneficial for him to have positive experiences each day.

**Interviewer:** That’s wonderful. And the … like, this adapting has made these sensory experiences less impactful?

**Interviewee:** Yes, but also it limits our experiences to what we do. So because, like, that I know … like, football games, like, he’s never going to be able to go in, like, an Alabama football game, you know, and that’s a big deal here in the south. Because it’s just … there’s way too many people, you know, pre-pandemic, it’s way too loud, you know. But so there’s some things that would be a sensory overload, but I don’t have him do that. So yes, they’re less impactful sensory, but he doesn’t do events that I know are going to be … you know, create an atmosphere for him that’s too stressful.

**Interviewer:** Absolutely. Thank you for sharing that.

**Interviewee:** So yes, the adaptation is great. But then there’s also the negativity about, you know, there’s some things that we just don’t do.

**Interviewer: [15:00]** Yeah, that makes sense. And then, this adaptation: do you think that change is related to any independence that he’s gained over time?

**Interviewee:** Can you clarify that a little bit more?

**Interviewer:** Yeah … just … because we’re trying to figure out how do sensory sensitivities impact the transition to adulthood and independence. And I’m just wondering, do you think these changes you’re seeing in your son, if they are related to any independence that he’s gained over time?

**Interviewee:** Yes, I think so because—thanks for clarifying—because as he’s gotten older, he has been able to stay home by himself for a short period of time, so that independence has been good. And for him to know that he needs to separate himself, or if he needs, like, even a time out at home, then, you know, he’s able to, you know, watch a movie or spend time in his game room, you know, so I mean, that’s been good because now that he’s able to do that, so he’s able to, you know, find things that calm himself down. And that’s happened because he’s been older, you know, and that he knows that he needs some time too …

**Interviewer:** And calm himself down from, like, sensory experiences or just generalized experiences?

**Interviewee:** Mostly sensory. Because when he … if we have a really … if we have a lot of activities in one day, then the next day he really needs a lot of alone time because he is so overstimulated. So, like, if we’re working at a catering event, like, the next day, I know that he’s needing a couple hours to himself just to calm down and then he’s in a great mood after that, but there’s so much that he needs to unpack that, you know, he really needs, you know, some time.

**Interviewer:** Yeah, totally. Thank you. And, you’ve kind of touched upon this as well but, when your son is in a scenario or environment that is sensory, like, aversive to him in terms of his sensory sensitivities, does that cause or increase anxiety for him?

**Interviewee:** Absolutely, yes.

**Interviewer:** Yeah. What does that look like for him?

**Interviewee:** Lots of stimming. He gets very red. So he has these physical attributions too, like, his cheeks get really red. Sometimes he’ll cry. And the crying, I think, is tied because of his limited verbal expression. He’s not able to say, “*I can’t handle this, this is too loud*.” He’s very … his communication barriers increase his anxiety a great deal because he can’t express what’s bothering him. And I know that that gets very frustrating to him. He’ll walk in circles a lot. And his echolalia gets more pronounced.

**Interviewer:** How does he or how do you help him manage his anxiety when it does happen?

**Interviewee:** If … then I try to get him out of the situation. So, like I said, like, he’ll get checked out of school earlier. He loves carwashes. I don’t know what it is about carwashes, but that’s … that always calms him down. **[18:00]** So and sometimes we’ll go through, you know, the carwash a couple times, you know, and then he’s OK. I don’t know what it is about it but it just … he loves them.

**Interviewer:** I’ve actually heard that that’s … **[crosstalk at 18:10]**

**Interviewee:** And you know that’s … Oh really?

**Interviewer:** Yeah, I’ve heard of other people, you know, people not on the spectrum finding them calming. So, who knows?

**Interviewee:** He loves the colors. And he just … he really … so he likes those fancy ones when you get like the $15, $18 carwash and then it has a different color **[inaudible at 18:28]**.So but that works well. But he’s … he can’t—which is frustrating for me as a parent and I know for him—that he can’t tell me, like, what it was, you know, what particular thing just made this experience so terrible. I mean, sometimes you can pick it up, if it’s, you know, like, really bright, or if it’s super loud, you know, but if there’s something that seems to be very benign in nature and then, you know, he gets so incredibly distraught, I would like to know, you know, what it is, to try to help to make sure that it doesn’t happen again. And I know that he would like to tell me, but that language barrier is significant for him.

**Interviewer:** That makes sense. Thank you for sharing that. Do you think his anxiety has changed over time, like, how he’s been able to adapt over time?

**Interviewee:** His anxiety is … he was taking an anxiety medication. Now, since he’s not going to school, he’s not doing that anymore. And he’s actually not … he’s not said, but he just stops drinking it when I was giving it to him at night. And then we started talking and then he said he just didn’t want it anymore so for him to say that … because I know that it was helping because he wouldn’t … he was wanting to drink it. Because I have to dilute it because he doesn’t swallow pills. You know, but now that he’s not in school, there’s no pressures with friends or there’s no uncertainty with what the day is going to hold because he knows what’s happening and he’s with me all the time. So I mean, there’s not. So there’s pros and cons to that, you know, because obviously it’s not ideal to be with your mother all day, you know, but he’s … since I work at a school, you know, he’s been … he’s with people all the time. So that’s … the fact I don’t work at home, because then that would really be unhealthy. But this is, you know, but I … but it’ll be interesting to see what next year will look like with him returning to school and then how his anxiety will probably increase. But this past year has been just great for him to grow and to get more independent because he has to, you know, really structure his day and, you know, get his assignments done. And he needs … he can’t do any … he can’t do his assignments independently. But at least he knows that, you know, these have to get done, you know, and knows that this is the time frame to do them in, so.

**Interviewer:** That’s wonderful. That’s great. So that sounded a lot about, like, kind of, like, more social anxiety—has his anxiety regarding sensory experiences, has that changed as well **[21:00]** this past year?

**Interviewee:** Yes, yes. Because we have more control over that now.

**Interviewer:** Yes, that makes sense. Got you. Thank you. And now, thinking kind of broadly, what goals or hopes do you have for your son in regards to his sensory sensitivities, like, in the future?

**Interviewee:** Yeah. I hope that he continues to learn how to adapt to these situations and I hope that he continues to try new things. And, you know, I’m so proud of him that he’s been able to work and do so well, that hopefully this will continue into adulthood. And then that his … that he’s learning that he can do these things and he can be in different atmospheres and that even though some atmospheres are new and scary that, you know, they can also be fun and exciting. And, you know, that the activities that we’re doing there are still the same, even though they’re in different places. So I hope that he still continues to learn and grow and then be able to advocate for himself as well, like, when he needs a break or when he needs to stop.

**Interviewer:** Awesome. Thank you for sharing that. We’re going to move on to our next chunk of questions. Thinking … so as your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** I think that the community that I have and the friends that I have and family have learned how to interact with him in a more positive way. So they’ve learned about, you know, that he’s not a big affectionate guy physically, you know, so these aren’t, like … kind of like, OK, let’s wait until he’s ready, you know, to high five or hug or anything like that, you know, like. And he’s not at all, you know, a kisser or anything like that, he doesn’t like that, you know, so then. Because it’s hard for especially extended family to understand that it’s not that he doesn’t want to or that doesn’t like or care for you. He just cannot, you know. And then to learn about, like, he’s terrified of dogs, so that we can’t have any … you know, we can’t go any place that has a dog, you know, so those kind of sensory things. It’s not like we don’t want to, **[inaudible at 23:06]** it’s just we, you know, we can’t and, you know, learning how to understand that schedules need to be kept to and when … you can’t say things like … and that that’s a sensory thing. You say, “*We’re going to go to the movies today*,” and then you decide … you change your mind that we don’t go, like, that’s not OK. You know, like, that those are … he doesn’t understand that, you know, because that’s … there’s excitement there, you know, and then to, you know, think about just the environment of the house with, you know, lights and noises, just that they’ve become more understanding the older that he’s getting and then more acceptant as well. Not that they weren’t before, but just understanding, like, it’s not that he doesn’t want to spend the time, you know, that they’re becoming more acceptant to the limitations that he has.

**Interviewer:** Got you. Thank you. **[24:00]** Would you say that your and his community was less accepting when he was younger then?

**Interviewee:** I think they didn’t understand. So I don’t feel like it was ever not wanting to accept, but not knowing how.

**Interviewer:** Got you. That’s an important distinction. And what about different, like, spaces or places in your community? You talked about, like, family and friends—what about, like, school or right now where he’s working, how did they understand and accept his sensory needs?

**Interviewee:** They understand his … well, he’s in a self-contained class at school. So there’s lots of students that … most, well, most all have some sort of sensory limitation, so that has been able to be tailored to what works for him. And then when there’s, like, a class party, his teacher knows that he doesn’t particularly care for those because he doesn’t like, you know, like, the singing or the dancing or anything, so they give him alone time. So he has a laptop and he’s able to sit at a different table, that’s away so that he’s still present, but he’s not forced to participate, but he’s still there, which I think is very important that he’s not sent to another room or anything like that, even though he probably … for noises he would be OK with that, but he also would have an understanding that he’s not there. And so I think what they’re doing there is great. And then we’re … where we work … that … he understands that he gets … there are one to two step directions, you know, and that he, you know, needs to understand what’s happening next. And that we need to make sure that he’s not in a place that is, you know, too much. Are you still there?

**Interviewer:** Hi. Yes.

**Interviewee:** OK, I’m sorry. I got cut off again.

**Interviewer:** That happens all the time. Don’t worry about it.

**Interviewee:** So, but, you know, just that he’s … and he likes to be treated the same as everyone else, too. Like, they … now that he … they … we’ve worked for several months and there’s quite a lot of people there that just kind of banter back and forth with him, which is, you know, it’s funny, and he likes to be included. And he, you know, he continues and he plays back, which is fun. So he’s been very accepted, but people seem very willing and want to understand what … how to help, too, which has been great. So, you know, because you can tell with his personality that he’s a pleaser and he wants very much to be involved and wants to, you know, to help and then and to be a part of the community. And you can tell that from him. You know, and that he is so … he’s easy to be with because he’s quiet because he doesn’t have a lot of … his language isn’t great, you know, but he’s, you know, he’s so … he’s very, like I said a couple of times, he’s very passive to be with. So he’s very **[27:00]** … he’s as easygoing, as he can be. Which is … so that’s nice to … and that he’s so eager to learn, you know, that’s helped too with both at school and at work too.

**Interviewer:** Totally. Thank you. And then again, thinking a bit more broadly, what are your hopes or worries for how the community will continue to react to his sensory needs as he does get older?

**Interviewee:** I hope that he will continue to be accepted and then learn how to thrive because, with his sensory limitations, and because, with his physical appearance, that some could think that he is either being defiant to a situation or just being unruly, you know, and with that, he would understand that, you know, because he’s been with his … like, lately, he’s not, you know, he’s not trying to be annoying or he’s not trying to be, you know, bothersome, he just can’t help it, you know, he doesn’t even know he’s doing it, so. And I would love for, at some point, people that, you know, even work at the store not to be, you know, staring sometimes, you know, but that’s what happens, you know, or when he’s stimming, that’s what happens. But I think with the overarching education in, like, social media, and then in, you know, just the articles and that it’s on the news a lot with autism, that the community does seem to be more aware of kids and adults that, you know, that there are some constraints that they have and that it isn’t something that they can help. So I think that’s helped too that just the community by and large talks about special needs more than they did even five years ago.

**Interviewer:** Absolutely. Thank you. We’re going to again move on to our next chunk of questions. We’re about halfway done. In the, like, transition to adulthood where do you see your son?

**Interviewee:** I hope that he continues doing what he’s doing with catering. You know, I think that he’ll do really well with that. This food service is not something that I thought he would be able to do, but he seems to be really good at it. And it’s nice because you’re not … there’s not a lot of … there’s a lot of direct interaction, but there’s not a lot of conversation that needs to be had. So that’s something that he can do. So I see that as a goal. I hope that he can live independently. I don’t know when that would be. But, you know, that would be a goal for him. But right now he’s in the house that we live … we moved last month or last year, sorry. And that … my room is downstairs and upstairs he has his room and a game room. So there’s a lot of privacy and division. So that … and I like that floor plan a lot so that if, you know, he does … if we live, **[30:00]** you know, in the same house forever that there is space …

**Interviewer:** Yes, absolutely.

**Interviewee:** You know, and distinct areas of where he stays and, you know, so that he does have … You know, he’s 17. He needs his own independence and his privacy.

**Interviewer:** Yeah, for sure. Thank you. Thinking about, like, independent skills that your son does have versus some things where he needs some support, could you describe those?

**Interviewee:** Sure. Like, he’s able to do laundry with steps, like, he’s able to, if he knows that, you know, sort it into piles, you know, he’s able to do that. He is able to, you know, do the dishwasher, he’s able to, you know … all of his personal hygiene is, you know … he is able to do all of that. He does pretty well with following recipes. So he likes cooking. He won’t eat any of it, but he does like cooking. So that has been helpful to learn measurements and learn, you know, how to follow steps. So that’s been something that’s been really good because he’s very interested. So any time we’re … I’m baking, he wants to help or any time even, you know, dinnertime, like, he’ll want to help and but he doesn’t want … I love it that he wants to try it, but he doesn’t want anything to do with the food when it’s done. But at least he’s learning, you know, because that’s very important. So those that … and that’s been probably the last year and a half that those skills have grown a great deal for independent living.

**Interviewer:** Totally. What about, like, shopping for food either, like, that the household eats or, like, the five things that he does eat, does he help you with that?

**Interviewee:** Oh, yeah. So when we go anyplace, then I simply give him a couple things to go get. And that he goes by himself and then he gets them and comes back and finds me. So and they’ll be things that … some of them are the things that he eats, some of them are the things that I’ll ask him, like, to go get me, like, four bananas or something, so that he is able to do it by himself and then bring it back to me. So that’s been good.

**Interviewer:** And then, with his job, is he learning about money management, things like that?

**Interviewee:** Yes. He just opened a checking account and he’s learning about money, although he’s not very understanding about how much things cost yet. But he … at Black Friday, he bought a book. So he uses his debit card. So that was, you know, it was very exciting for him to do, so he’s able to do that. But he’s not really understanding yet that, you know, whether the book is $5 or 500, you know, but he’s at least starting to understand about money management and that, you know, when you do a job then you do get the pay.

**Interviewer:** Absolutely. And then, in his own way, does he ever express interest in wanting to live on his own?

**Interviewee:** Not really, no.

**Interviewer:** No. And then does he have friends of any sort, like, a social life that he manages?

**Interviewee:** No.

**Interviewer:** Got you. And then, do you think your son will be able to achieve more independence in the future?

**Interviewee:** Yes, I do.

**Interviewer:** How so?

**Interviewee:** I think that he will know, **[33:00]** I think that he wants to, because I think even with the way that he’s working … And then I’m hoping that eventually within, like, maybe next year, that he’ll be able to do some working events on his own. So that he’ll … not by himself totally, but then if we … because there’s always a team that goes and that he can do some things without me, so that he … because I know that will help gain his self-confidence a great deal.

**Interviewer:** Yeah, totally. That’d be wonderful. What else do you think will help him move into adulthood a bit?

**Interviewee:** I think really just gaining more independent life skills would be good. And the more that he feels confident in himself, that’s going to help a great deal. **[crosstalk at 33:44]** Go.

**Interviewer:** No, no, you go, please.

**Interviewee:** Just when he’s in different situations then he’ll have … he’ll feel like he can be successful instead of being fearful.

**Interviewer:** Absolutely. Are there any services or interventions that you think could help him gain that confidence or increase his repertoire of life skills?

**Interviewee:** I think more job coaching would be helpful. I think some more community outreach would be helpful. I think exposure to different jobs would be good.

**Interviewer:** Yeah, absolutely. And now putting these two things together—his sensory sensitivities and his transition to adulthood—how do they intersect for your son?

**Interviewee:** They more than intersect because they are very much the same. Like, he wouldn’t be … he’s not going to be able to, you know, go to a transition to adulthood if he has to, you know, figure out his own transportation and get there or if he’s going to have to travel different places, or, you know, if he gets to work and then there’s a bad storm, then, you know, he’s not going to be successful there. You know, if he’s going to have to talk to too many people and it’s too loud then, you know, that’s not going to work. So his transition and then different experiences very much … they’re not even just intersecting, they’re more like they are, you know, one item. I don’t even know the big … the word for it, but it’s just … it’s one … they’re together.

**Interviewer:** Yeah. It’s one thing for him.

**Interviewee:** Yeah.

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

**Interviewee:** Obstacle.

**Interviewer:** Obstacle in what way?

**Interviewee:** Because if he’s not able to enter a building, if he’s not able to talk to someone, if he’s not able to advocate for himself because of that, then it’ll prevent him from going further, it’ll prevent him from going to the store, it’ll prevent him from going into in any place of business. It’ll prevent him from, you know, buying the shoes he needs for a uniform, you know, like, all of those things are significant obstacles for him.

**Interviewer:** Totally. Thank you for **[36:00]** clarifying. 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:** Language barriers because of his significant delay in language, that goes over all aspects of sensory too because, you know, like I said, when he gets overly sensitive then he can’t say what’s wrong, he can’t … so if he’s employed and then there’s something that is bothersome, like, you know, maybe somebody next to him has really strong perfume and he can’t say like, “*You stink*,” you know, then, he can’t … so then he’s not going to be successful, he’s not going to want to go back and he’ll be too distracted the entire day because of the smell of perfume and then won’t be able to … so language is … that is … affects his sensory a great deal because he can’t say.

**Interviewer:** Yeah, absolutely. Thank you. And then what do you think could help him? I know that it’s not an intersection for your son but, like, in this conglomeration of the two things, what do you think would help him?

**Interviewee:** I think learning how to adapt to new situations are going to be the best way for him to grow. And then when he’s in … when he’s able to be exposed to many new events, new experiences, that that helps a great deal with sensory because then he knows it’s not scary and we can do it again. Or he knows that we can’t do this anymore. So that’s … they’re both, you know … but I think that the experiences will help greatly. Because you don’t know if you don’t know.

**Interviewer:** Absolutely, it’s true for everyone.

**Interviewee:** Yep.

**Interviewer:** Experiences aside, are there other … are there services or interventions that you think could help him in this, you know, conglomeration?

**Interviewee:** Speech.

**Interviewer:** Speech therapy? Got you.

**Interviewee:** And social cues and then social, you know, social therapy, so play therapy, that is beneficial, too. But all this really goes along with his sensory and his language deficit because he can’t learn any of those things without being able to express.

**Interviewer:** Absolutely. And then, we touched upon this way in the beginning, but do you think there are any gaps in the available services and interventions for young adults like your son?

**Interviewee:** Yeah. Alabama’s far behind most of the states in the country. I serve on the Autism Interagency Council for the state and that’s something that we talk about a great deal that just, by and large, there’s not a lot of transition services that once you hit high school, then you’re pretty much done. There’s not a lot of places for him to go. There’s not a lot of options. And the services that are available are very minimal. So for, you know, a kid that is this far behind with speech, he’s only allocated a half an hour a **[39:00]** week, which is, I mean, just ridiculous. I know that … and that … but that’s the state. You know, and then there’s … that’s just what he’s entitled to and now it’s a group. So he has half an hour with three friends and it’s just … it’s not, you know … but that’s the services that they’ll be able to provide. So even though … and even to get his end-of-year services, you really have to fight for those, which I think is ridiculous as well.

**Interviewer:** Yeah. Thank you for sharing that. That sounds very frustrating. I’m sorry.

**Interviewee:** Yes. But that’s … every state, you know, is just different … it’s just different the way that each one approaches special education, approaches the services and staffing and I know that’s funding, you know, I know all those things, but then you see that and then you think, “*OK, this … there has to be something better*” and sometimes you have to be like, “*Well, there is, yeah—move*.” That’s the best option.

**Interviewer:** That’s the hard option though.

**Interviewee:** Yeah it is, I know.

**Interviewer:** Again, thinking broadly: how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he has navigated adulthood?

**Interviewee:** OK. They have become, like, to use your word earlier, an obstacle, you know, because then … for him to … because I think that he really needs to experience new things and new places and new ideas and be able to talk about things. But that has to happen by actually experiencing them, you know, and then if there is something that triggers … and, for him, if it’s a bad sensory experience, he will not go back. So if we go to a place that is, like, a haircut place and he did not like the way that that worked, he’ll never go back there again. And it’s a hard no. So, I mean, that’s something that once … if it’s … and sometimes he can’t tell me what it is, but he won’t return to a location because of just what has impacted him sensory. It could be the way that … it could be anything, you know. That has happened. So that is a significant obstacle in his life is that we’re not able to try it over again.

**Interviewer:** And how has that impacted, like, your expectations for his … like, how he is navigating adulthood?

**Interviewee:** It’s … provides me a great deal of fear. That if … first, I’m terrified that if, you know, God forbid, something happens to me, I don’t know, I worry a lot about him. And if, like, my brother is going to, you know, I already have that obviously laid out, but then, you know, just to be able to spend as much time, you know, that’s really needed for him, you know, each day, you know, to make sure that he’s, you know, he’s happy, he’s adjusted and he’s in situations that will work for him. And that’s … so that … it’s fearful to me that, if he is in a situation that he can’t handle, will he be able to say that or will he be able to try it over again? So.

**Interviewer: [42:00]** Thank you for sharing that. We’re going to move on to our last chunk of questions. We’re flying by. We’re almost done. So as a caregiver, as a parent, as a mum of someone with autism, but also some sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** It means for him to have a sense of independence. You know, I want him to be able to experience the transitions of becoming a young adult, you know, I want him to be able to, you know, do some of the things that my daughter’s doing at … in college. You know, I know that he won’t be able to do the majority of those things, but I want him to, you know, to start, see, like, see, I would say, like, be able to hang out with friends. But that’s not something that … he’s never been a social guy and he doesn’t really desire to hang out with peers a great deal. But, you know, those are the things that, you know, I would hope for him to do, you know, for him to be able to, even to go do something if he wanted to by himself, you know. Or if he wants to, you know, take a class someplace, he can do that; if he wants to, you know, join a club, he can do that, you know. I want him to be able to drive, you know, I want him to be able to … he’s got a permit, but I want him to learn to drive a car and then to be able to find things that he’s passionate about and to experience those things, you know, as he’s transitioning to adulthood and then find what it is that he wants to do more than just the things that I’m telling him to do, for him to find what his calling is. And I think right now he is interested in all the things that I like to do because those are what I offer to him, you know, but he might be interested in something completely different. And I want him to be able to experience those things and, you know, begin to advocate for himself and be able to say what it is that he wants to do.

**Interviewer:** Absolutely, thank you. Has this perspective changed over time?

**Interviewee:** My goal for him and for my daughter too, so for both kids: I want them to be happy and I want them to find what makes them happy and I want them to be able to find their own voice and to be able to have the wings to be productive.

**Interviewer:** And this has been, like, a constant perspective that you’ve had? **[Interviewee makes an assenting noise.]** And then what do you see happening in your son’s future?

**Interviewee:** I see him staying with me, you know. I see him working, which is great, which is a lot better than where I thought because I didn’t know if he’d be able to keep a job, but now through—it’s another blessing of Covid that he’s been able to really grow and, you know, get some work experience and some more freedoms for that. So I mean, that’s been great but … so I do see him working. You know, I do see him eventually driving, I think that he will be able to do that. I do see him finishing high school and, you know, hopefully being able to do some more things without me, which would be great. That would be an excellent transition.

**Interviewer:** Yeah. Do you see him having **[45:00]** a family of sorts, in whatever format?

**Interviewee:** I don’t right now. But just because he doesn’t want to hang out with peers. So I don’t know how that would … You know, we’ve talked about that, you know, and we talked about, you know, “*If you want to*,” you know, “*live in an apartment, where would you live?*” And he’s, like, “*Well, with Haley*” (that’s my daughter). And I’m like, “*OK, well, that’s the same*.” So. But I think, like, he likes to do some of those things, but I don’t think he is sure that he … I don’t know if he … OK, that’s bad … I don’t know if he wants to do them or if he thinks he’s supposed to do them. So, you know, that I think will be … time will tell with that.

**Interviewer:** Yeah, absolutely. I have my last formal question. How have your son’s sensory sensitivities impacted this perspective you’ve articulated in terms of what it means to transition into adulthood?

**Interviewee:** I think that it’s provided empathy, but also realism. To know that there’s some things that, you know … because with a diagnosis, then you go through steps of grieving for what your hopes and dreams and how they changed everything, after you knew that you have a diagnosis, but then now, it seems that I’m a lot more understanding and realistic about what it is he can do and, you know, where he can be, and then, like, that … set goals that are actually attainable, and not things that, you know … like, he’s not going to go to college so, like, so let’s not focus on that, you know. And then school, if he’s having a terrible day, you know, like, I need to come pick him up because, like, he’s not … I mean, come on, let’s be real, like, he not going to … he doesn’t need any of this. And it’s more important that he’s well adjusted and happy and wants to go back the next day than to do whatever activity you’re doing right now because it’s not like it’s going to be a make or break for him in post-secondary education.

**Interviewer:** Absolutely. Thank you.

**Interviewee:** OK.

**Interviewer:** You’ve been amazing. That’s it on my end. Would you like to add anything else?

**Interviewee:** Nope, I’m good. But thank you very much for doing this. I’m really happy that you’re advocating for parents.

**Interviewer:** Of course. It’s been my pleasure. It’s been such an honor to, like, learn from people like you, to hear your stories, and we couldn’t do the work without you. So, thank you.

**Interviewee:** You’re welcome.

**Interviewer:** Do you know anyone else who might want to participate? We’re still looking for folks.

**Interviewee:** Yes, I actually passed it on to another friend of mine, so, and then I’ll do that again, so.

**Interviewer:** Thank you. I appreciate that. Would you like me to resend you a flyer or are you all set?

**Interviewee:** If you resend me a flyer, that’d be great.

**Interviewer:** I can totally. Anything else? Would anything else be helpful?

**Interviewee:** Nope, that would be it.

**Interviewer:** OK. Any questions? Can I do anything to help you? Any questions? Can I clarify anything?

**Interviewee:** I’m good. Thank you.

**Interviewer:** OK, thank you. As soon as this audio file renders, I will send you a thank you email and it will contain a gift card as compensation for your time and effort. But again and truly thank you. This has been lovely.

**Interviewee:** OK.Thank you very much.

**Interviewer:** You’re so welcome. If you have any questions, you know where to find me, please reach out.

**Interviewee:** OK. Thank you.

**Interviewer:** Bye.

**Interviewee:** Right.Bye.

**[End of interview]**