**[Start of transcript]**

**Interviewer:** We’re recording. And I will be asking you your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities. And I’ll be doing something called a ‘semi-structured interview.’ That means I have my script with my planned questions, but I’ll also be adapting them to fit our conversation so it actually makes sense for us and for what we’re talking about. Any questions?

**Interviewee:** No. All good.

**Interviewer:** OK. And if there’s a question you don’t want to answer for whatever reason, that is perfectly fine. “*I don’t know*” is a perfectly fine answer as well. And if something pops up, feel free to bring it up. It doesn’t have to be perfectly linear.

**Interviewee:** OK. Great.

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

**Interviewee:** So are you just talking at adulthood or, like, through the journey?

**Interviewer:** I’ll be asking you past and present. So you’re welcome to start however makes most sense for you.

**Interviewee:** So, in the past, he was … you know, so he’s the youngest of four. He has … he was super active once he started moving, was able to climb early, was able to walk early and he never really had great sleep issues. So and he really didn’t … he lost the ability when he was very young to take a bottle. So he was breastfed. And he was, I nursed him the longest and some of it was, we were going away and he was 18 months old and we really had to get him off of the breast. And it was those kind of sensory issues that just didn’t fit into the pattern of the other kids, as well as, I mean, he was walking at nine months, he was climbing, he was climbing up stoves—the higher the better—and he was very quiet. And, you know, looking back, I would definitely say he only ate white foods. So, you know, and again, that sensory piece of … he didn’t do a lot of chewing, he didn’t do … he just … it was in and swallow. So and that extreme, where if it wasn’t going to go past his mouth for whatever reason, he didn’t have the ability to say, you know, “*That’s gross. I’m not going to eat it*.” He just didn’t eat it. He just … he would climb out of the high chair and run away in terror. So and being the youngest of four, just a busy life, busy house, we just adapted. So all of those things, you know, as we went into the journey of diagnosis, and **[3:00]** we were in … we did get into Birth to 3 when he was about two and a quarter, somebody’s like, “*You’ve got to have a sensory profile on him*.”And that’s … you know, he was hyposensitive. He walked outside when it was freezing below without shoes or socks on, walked into things didn’t seem to notice. Dislocated his arm, you know, and pushed it back in himself. It … just all of those pain things that just didn’t make sense. And, you know, he was … and just didn’t need to sleep. And you know, we just didn’t know how. I mean, we just … we ended up … we’d call them parties in the middle of the night where he’d sleep for three hours and he’d be up. He can go 22 hours without needing a break. So we had to sleep deprive to EEG and he was nine and we had him up for 25 hours and he finally said, “*Let’s put on some pajamas*,” and we’re like, “*No, we got one more hour till we get to the hospital*.” Because he doesn’t, he wouldn’t fall asleep in that environment either. So it wasn’t like this kid that would take a nap. So we just always had this high running motor and, you know, now he’s 24 and I do hear him at one o’clock at night. And, you know, up until the pandemic, he was out of bed at 6.30 every day. So still a very short sleep cycle and currently, with the pandemic, like, we walk … we most of the time walk four miles a day with him. So that … and, from my forms, you can see I was a recreation therapist and we just kept him structurally busy. So, like, we just knew that engine needed to be fed and it is a sensory need. He’s the only kid we ever bought a trampoline for, we had no problem saying no to the other ones, you know … just climbing on things and I taught at the YMCA and you know, he was always at the Y, probably five days a week, you know. So those are some … those are the things we’ve noticed. The hearing is … he’s been diagnosed with auditory processing, he definitely has an auditory processing and his hearing is OK, he’s actually had a treatment for some auditory processing. And **[6:00]** he was … like, we started packs, he was nonverbal till he was six, we started packs, he did a device, he was reading by four. His preschool teacher would call me, like, you know, she would write things out on the thing for the class to vote, David would be standing up, because that was what they were supposed to do. So kind of doing those kind of things. And so there’s just a smattering of his sensory piece that … You adapt with the food, so you don’t really notice how odd it is because he’s eating … he’s not … you’d never look at him and say he’s malnourished, but still, we have a visual on our table that says slow down and take dime-sized bites. You know, definitely … and if he has, like, a smell issue, he’s going to run in the room, like, in terror and same thing with the hearing. Once in a while it works and it connects and you know it’s connected, but most of the time, it’s not connected. There’s, you know, I always used to compare it with when I would go speak to classrooms, like those old faulty computer wires, that they’re just not there and you jiggle it and it works. I found it very interesting when we did our last sensory profile, and it asked … he was remarkably accurate on the auditory processing piece because he was nonverbal he had apraxia. He doesn’t hum but I don’t think … I think there might be humming in his head. You know, I think there’s a lot in his head. And it looks more today like anxiety. But it’s … like, he answered all those questions. And I was sitting next … I took pictures of him because I was just like, I wouldn’t have rated him that way. But he rated himself and I was like, “*Who am I to argue?*” So, you know and, like I said, when we started this whole thing with the pandemic, because we’re now together so much, we’re 24/7, I didn’t realize how structured we made his other life to fill that energy proprioceptive drive that he has. So we used to leave our house at seven, we would return at 4.35. He’d do a full day **[9:00]** of classes and then he would go to Special Olympics and do two hours of basketball and that just … it made a better life for him. So now we’ve had to pick up those … we start noticing much more “*What? Huh? What did you say?*”—you know, that piece where he is … I ... he reminds me of the Charlie Brown kid where he’s catching one out of, you know, 50 words that the teacher is saying. But if you write it down and in front of him, he’s got it like that. The Zoom classes have been a godsend for us because it slows everybody down. There’s a pattern to all the auditory input. He’s now in a bedroom secluded doing his closet. He’s taking calculus too. Yeah, so, you know, the classes that he struggled with before … even last … he took psychology last spring and an English class, he just did better because it all was much more planned and more structured. And sensorially wise, you know, you can turn your screen off and, if you need to stand up, it’s not a big deal. That kind of stuff. And not only with college, but with high school, we learned the shorter class periods worked. Forty minutes sitting in one place, and then having to get to the other side of the school was filling that sensory need and all of that jostling was something it … You know, I know some kids on the spectrum are all overwhelmed by that, but, for him, it fills those sensory needs—kind of almost he’s hyperactive, but he’s hyposensitive. So, I think Temple Grandin used to say if you can tolerate Walmart or Costco, you’ve got high-functioning autism. I don’t know, I like that diagnosis, just because it was, like, you know, it’s, like, those environments feed his system in a different way that not everybody does well with. So that’s, you know, but I … you know, he’s 24 years old, we have a visual on our table to slow down and to chew and no swallow and if you were to, you know, like, that’s, like, a tactile piece. He, you know, he still can’t eat anything that looks like applesauce, **[12:00]** yoghurt, soup. Lots of foods can’t touch. No casseroles, and feeding therapy, because of his age, just wasn’t around.

**Interviewer:** Yeah. And are those preferences more texturally based or are they color wise, because you mentioned … or flavor, because you mentioned white food when he was younger?

**Interviewee:** So, you know, we did the gluten- and dairy-free diets at six, because we had tried so many other things with him that had not worked. And his first two weeks after being on the diet for three weeks was “*That’s yucky*.” And then he pulled over his device and typed out, “*That’s yucky*.” So we really have pushed that. And it was gross. There’s no question about it. The fact was that astronaut food looked better. We have pushed him outside, but we still have a very set diet. So last night, we had fish. He’s like, “*I’ll have the leftover pork*,” you know, and I don’t know if it’s a smell issue with the fish or if it’s a texture issue, and at this point, we do have a rule going on right now that we have to eat one new food a week. But, you know, most times we’re pressed and it’s … and it and his diet is very healthy, so it’s … but it’s very rigid. So, one pancake a day, we have a glass of orange juice, then at lunch, we have a sandwich. And that was the other thing because we lost our school schedule and routine, he actually in the fall dropped about at least 15 pounds because of that our schedule wasn’t predictable. So that the fact that, you know, like, he wasn’t making his lunch the night before to take to campus. So he would have, you know, a small piece of chicken and that would be considered lunch. So back to ... he’s more scheduled about eating and he’s more scheduled about using the … it’s like, those two senses don’t ever go in the back of your mind. He’s never thinking in the back of his mind, “*Boy, I’m thirsty*,” or “*I have to go to the bathroom*.” It’s like the light switch goes on. And so then we really started to look at his … and he’s 5’11” and 155 pounds. He got down to, you know, about **[15:00]** 138 and all of a sudden we just looked at him and are like, “*You’re really skinny*.” And it’s all of those other schedules that had been in place to eat. So I definitely think that’s a sensory issue as far as, you know, I don’t know where hunger falls into that

**Interviewer:** But he just, like, won’t realize that he’s hungry.

**Interviewee:** Exactly. So, again, we used to eat lunch at 11.30, because it was scheduled at campus to be at 11.30. And he has snacks in his locker because he knew he needed a snack, and then he’d have a snack on our way to our next activity. And all of those things collapsed and he manages the kitchen and stuff like that. So we just didn’t notice he wasn’t eating.

**Interviewer:** Yeah, that makes sense. Thinking back to his auditory processing: does he have additional, like, auditory sensitivities, like, does he not like certain noises or are certain things, like, aversive for him?

**Interviewee:** So we used to run and tear on the fire alarm days. And he definitely has a music preference. So I don’t, you know, like, now if a song comes on and it’s become popular, he’s already past it, he can’t listen to it. And again, it’s a … you know, you have to change the channel. And because he’s the youngest, we do, but, you know, he used to run and tear if the schools would play Disney movies. Because it was, like, over tired and that was the … when he filled out the form he did say those things bother him, but he’s never verbally told u those bother him. So he would never say, “*Oh, I hate alarm clocks or loud noises*.” But he definitely, like, you know, with the music thing, you know, and that, you know, just weird kind of things like bad singers. He isn’t … you know, he can’t even stand it. He’s like, “*Don’t sing*,” you know, I like to sing, but I don’t sing well, so he’s like, “*Do not sing*.” But my son-in-law’s a great singer, and he has no problem being with him. So, but yeah, so I, you know, I was very surprised when he said the loud noises bothered him because I’ve never heard him, like, cover his ears. And we never did that. Now wears headsets like you have on for his classes, but he … and I do notice when he’s using his phone **[18:00]** or iPad to listen to music it’s louder than it should be. But he hasn’t, he doesn’t have a hearing loss. And I can’t remember … There’s a doctor Mencraft at Pitt. She did some auditory processing stuff. And he was in a sound booth and his ears are unequal. So then she did some therapy with him where, like, the word ‘camp’ and ‘fire’ would come up in the right and the left and they’d have to put it together. Same thing with numbers. And she was able to raise them both to much more of a closer **[inaudible at 18:37]**.

**Interviewer:** Yeah. And you talked about smell briefly—does he dislike certain smells?

**Interviewee:** He does. And, you know, again, fish is a good trigger any of the strong smelling … but he doesn’t, like, sniff things like, you know, some kids, like, smell a lot. You know, again, it just seems to be more hypo than hyper. But strong smells like broccoli, cabbage, cauliflower, fish, he’s like, “*Oooh, what’s that smell?*”—but he doesn’t … and, again, we’ve shaped a lot of that behavior. We wouldn’t allow him to run in terror. But like, you know, like, if I am cooking it, you know, then we’ll open a door or something like that.

**Interviewer:** Got you. And then, does he have any sensitivities to any visual stimuli, like lights perhaps?

**Interviewee:** No. You know, maybe when he was younger, he used to look at the TV sideways and stuff like that, but not really. And, interestingly enough, he got glasses and he said, “*It’s made my hearing better*.” I know, but I’m just telling you. And I was like, “*Hmm. Glasses was just more for the, you know, eye strain*.” But he’s like, “*My hearing’s better*,” like, “*OK, well, we’ll take any gains we can get*.”

**Interviewer:** Right, exactly. And then, what about touch—does he have any likes or dislikes regarding, like, textures or, like, clothing, things like that?

**Interviewee:** So they were very prevalent when he was younger and, like a lot of people, you know, graduated quickly to the sweats, but any tags, you know, like, he used to cut out, he would get the scissors and try and cut, you know, threads, tags. So, he’s, again, the only kid I bought special underwear for, you know. If there was a thread on the inside of his pants, he would cut them. He’s ruined a lot of things because of that. **[21:00]** And, yeah, so, like, they always say stores might go out of fashion. I’m like, we have a touch … I definitely know there’s still a touch piece. In seventh grade, we had a friend who was a teacher who said, you know, middle school, you’ve got to wear jeans. So we started that summer and he calls it his khaki pants and his jeans and he had to work up to that tolerance to wear them in middle school. And again, we put it in rule fashion to get out of sweatpants. So when we go out he has to be in jeans or khaki shorts. And I am buying them on feel. You know, there are certain brands we can wear and there are certain brands … like, I don’t think he owns a pair of Levi’s, but American Eagle has a softer pair. We just bought Bamba socks, he’s happy. But yes, so we definitely … and now he blends … because again, he throws on a pair of jeans and, you know, he can go through the airport, nobody would know. Same thing with, like, his shoes have to be unbelievably tight. So there’s, you can see the tops of his feet that are … like, you can see the criss cross of his tennis shoes. So, like, slip-ons aren’t his thing, but he’s in tennis shoes, like, and the rest of the world’s in tennis shoes. I do worry that … and maybe I shouldn’t but it’s … because it’s gotten so much more casual, but I do worry about, you know, like, if he were to get a job in an office today, he’d have to wear a button down. Because I mean, he used to immediately come in after school and completely strip. Still, when we put on … doesn’t matter how soft the polo is, anything with buttons. He changes immediately if we’re going to an event and then he’s got a second shirt—and he packs it so I really, you know, I don’t have a problem with that. But he’s aware. He’s very aware. And it … and you know, sensorially he’s aware. So, like, he went to his niece’s birthday party and he put on a nice shirt, but he had a shirt to go home in and we were there for two hours. I mean, it wasn’t like we were there. So, yeah, so, you know, every once while I go … if we go back to the banker clothes, he’s going to have a hard time. So, yeah,

**Interviewer:** That makes sense. Thank you. And then how would you say his sensitivities have changed over time, if at all?

**Interviewee:** Well, he’s a great rule follower, so we’ve shaped him. So he likes to travel. So if you’re going to travel, you got to try new foods, you know, we are not going to sit at a table and watch you freak out because there’s something on your plate you don’t like, you just … You know, and it’s gotten very black and white. Same thing with the clothes, “*You’re going to wear these khaki shorts to summer school and then you can come home and change*,” and then it was “*You’re going to wear these jeans*.” And so, you know, “*Monday*,” you know … Now we don’t leave the house **[25:00]** but even if we’re going to run to wherever, he changes quickly, and so we shaped a lot of those behaviors. And we’ve tried to give him … because he is now verbal, we’ve tried to give him the words. And then, lots of times, we … like, the auditory thing with the car, we’re like, “*We’re going to finish the song, too bad you’re tired*.” And we’re not mean. But we’ve also … like, “*If you want to do the things you want to do, you have*” … he has to change is kind of the attitude that “*We can’t expect the world to change. We can work with you as much as we can, we can do whatever we can do*.” And I used a lot of social stories. So like, at the dentist, he didn’t like the dentist. I get that. But we borrowed the X-ray tech, X-ray jacket to put it on him so it was a heavy blanket, so it calmed him down. Like, “*We get that this isn’t fun, but your teeth have got to get cleaned*,” and then we scheduled it. So, up until recently, he was going four times a year. But we started with twice, you know, six times a year, so that it wasn’t infrequent. But those kind of things and a lot of carrots and rewards. You know, “*You get your haircut, you get to do this*.”

**Interviewer:** Absolutely. So it sounds like his behaviors have changed, less so his sensitivities: is that a fair statement?

**Interviewee:** I think that yeah. So like, when the pandemic hit and your thing came across, I was like, “*Oh, my gosh, David still has a lot*.” But because he’s, you know … so many things have happened—the portable music, the, you know, the phones—he puts his headphones in, it all starts to look a lot more normal than, you know, a little kid walking around with some loud tape recorder or something like that. So, yeah.

**Interviewer:** And, thinking about how his behaviors have changed: do you think that is related to any independence that he’s gained over time?

**Interviewee:** You know, independence is a hard one. Yes, and yet, we try and build in a schedule because, like, the movement need is so high. We try and build in a schedule that addresses that because

downtime ends up to be bad time. I don’t know how else to describe that. So yes, like, crossing the street is still a … auditory piece of crossing the street that …. an awareness of space, himself in space. He’s not aware of … I don’t know how else to … So if you were to walk behind him in an airport, he goes in … he knows where he’s going. He goes in and out of people. And they almost bounce off of him like a forcefield. So he’s not aware of himself in that space. But people are like, “*Whoa, that kid just* **[29:00]** *scooted in between us*.” So, like, some of that independence, like, he’s bright enough to get anywhere in Pittsburgh where we live, and he can plan it out, but do we trust him? Does that … I don’t even know if I answered your question. But, you know, so he does have some independence and, you know, like, but kind of, like, he loves to swim and he stays at the bottom of the pool for long periods of time like a shark but then he’ll pop up in front of two people and then that’s what makes it not safe. Because he’s not seven; he’s a man.

**Interviewer:** Yeah. So I guess I was asking more about, like, his changes in sensory behaviors, is that related to any independence and you gave the example of him liking to travel and therefore he must eat different food. Is there anything about his independence that kind of, perhaps, facilitated any changes besides that?

**Interviewee:** Can I think about that one? Can we come back to that one?

**Interviewer:** Yeah, absolutely.

**Interviewer:** You talked a lot about how you have helped your son manage his sensitivities, so, you know, shaping behaviors, using the social stories, things like that or, like, modifying his environment—is there anything else that you do or is there anything that he does to handle and manage his sensitivities?

**Interviewee:** You know, we’ve kept him very busy and he would choose to be busy. So I know he’s really missing … He will say yes to everything, every club that is … he’s in … everything he’s invited to do he would say yes to. So he knows that keeps him healthy. And so … and once it’s part of our routine, it never gets skipped. So it’s really like the four miles walking. We live in a really, pretty hilly area, we take a different path every day. But he doesn’t say, “*Hey, I need a walk*.” He just knows we’re going at … we go at eight or we go at noon, we go at five. And he’s dressed and ready to go out the door. And same thing if Special Olympics were to start tomorrow, he will say yes to every activity and he’s coordinated, which is great. So again, swimming, you know, swimming, bowling, basketball, golf, tennis, he wants to do it all. And he looks for those opportunities to try and schedule that too. So we do have somebody that comes on Tuesdays. He’s like, “*Maybe it will be nice next week and we can go play tennis*,” you know. He does have trouble, like, we have a small social group. He has trouble—and I wouldn’t say slowing down, but you know, like … he’s just … engine is high and he’s fit and he goes, and the rest of the group may not be that way. So he’s, you know, Tuesday **[inaudible at 32:56]**, he goes to yoga, and **[33:00]** Zumba, you know. So, he took a yoga class at college. He then took it again the next semester because he knew it was good. And he’s like, “*Oh, I can’t fit it in again this year, this week*.” So I think he knows that piece. And sensorially, like, you know, he’s independent in his clothes and all of that. And, you know, if he doesn’t like it, it’s just never gets worn, like the rest of us.

**Interviewer:** Absolutely. And what about … how does he manage, like, hi the sound environment or, like, smell, those sensitivities?

**Interviewee:** So the sound environment is more like he just ignores it all. You know, if I hadn’t had his hearing tested a million different times, I’d still think he’s partially deaf. But then, you know, sometimes we whisper or—well, sometimes to grab his attention, I whisper and that, like, grabs his attention in a really negative way and so he’s like, “*Oh, don’t do that again*.” So and now it’s just hard because he’s with two adults. And if he’s happy, we’re happy. And he has a hard time when he … and he … he’s a kind kid, a kind person. And so if he asked you very nicely to turn down your music and you didn’t, he’d find that really hard and he probably go try and find somebody else to tell you to turn down your music. And he doesn’t understand when people don’t immediately respond that way. Sensorially wise I would say, especially with the sound, so, like, again, he has not lived in a lot of environments where you’ve got a shared wall or whatever, but he’d have a very difficult time if somebody next door was loud music, hard rock and—he likes all music. But I think, like, well, I’ll play music when I’m cooking and he’d probably prefer for me not to have music on. Like he really **[inaudible at 35:25]** tunes it out, unless he’s controlling the music.

**Interviewer:** Got you. Thank you. And has he received specific therapies or interventions for his sensory sensitivities?

**Interviewee:** So we’ve done a lot of OT. And I think I told you, I, we … I came at it from … I was a recreation major therapist, and that … if we did something like swimming for an hour, that helped. So when he was in fourth and fifth grade, I took him swimming before school every day. You know, the rough house, the hard, physical contact, he was not … I … like, football would have been great. But I … he didn’t have … like, I didn’t trust that environment, but that, all that jostling would have been good for him. So we’ve kept him involved more in sports, we’ve done OT, we tried some listening therapy, we did Fast ForWord. We’ve done a lot of academic interventions. I didn’t really … I don’t think I told you, he was hyper lexicon, he sounds things out. But it all just doesn’t fit right. Like, Fast ForWord I … like, he’s got a **[37:00]** problem with reading comprehension and so we’ve thrown a lot of different therapies at him, we’ve done the brushing. It just seemed like the more we did … When he was younger, we had a gymnastics academy that opened up for … they had rock therapists, PTs, OTs and speech path run a gym class for kids. And that probably was, like, his favorite class. And so again, you had maybe the speech path with them on the beam. But that whole piece was a … it was a great facility. It was a great experience. Because he also got to jump into the foam pit and all of that crash burn worked, so.

**Interviewer:** Do you think all of those therapies helped him with his sensory sensitivities?

**Interviewee:** Yes. I mean, you know, because again, like, he can have a white shirt on and it’s not the end of the world. When he was five, he would strip down. I mean, and there was … no, it was just it was wet and it was almost like it was on fire. You know, so, like, the water table was not a great place for him in preschool. You know, so yes, I definitely think all of that made a huge difference.

**Interviewer:** And then, when your son is in an environment that has sensory things that are aversive to him for whatever reason, does that cause or increase anxiety?

**Interviewee:** Yes, and I don’t … I’ll be honest, I don’t think we noticed the anxiety until recently. We just thought it was his autism. So I don’t … I can honestly say that we just thought that was him and his autism and not anxiety, and it’s probably more of the quietness that you start to notice it.

**Interviewer:** So he gets quiet when he’s anxious, is that what you mean?

**Interviewee:** Well, I think we noticed it with more the pandemic, the quiet night life, the, you know, that he’s nervous about being wrong. He, you know … it’s probably much more and there’s a lot more thinking going on than we realize. No, but he’s not going to … he would like … again, it’s an emotional issue. He would like everybody to be happy all the time. And he works really hard for him to stay in that happy place and he expects everybody else. So he would say things … when he started to talk, he’d come over, put his hand over your mouth and say, “*Talk nicer*.” And that’s a real, you know, you’ve got four kids, and you’ve got a life. And so then we all worked on trying to keep a happier house. But that’s not life, either.

**Interviewer:** No. And so this anxiety, is it more—that you’ve recently realized—is it more general or is it specific to sensory experiences?

**Interviewee:** I think it’s more general. And I think he thinks he could be perfect. It is hard, you know … and a little bit of that comes out of that ABA. Early on, he was a 10/10 kid, you know, you **[41:00]** put a new drill in, accomplish a … good job, you know, and you forget that, you know, especially through some of the schoolwork, he was getting 10/10s, so you forgot how reinforcing that becomes.

**Interviewer:** Absolutely. And, then thinking a little bit more broadly, what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** I think there’s a lot of great tools out there today to help him manage them really well. For example … and there is that in flexibility or rigidity that is in autism or our form, I would like him to be able to take advantage of things—like, he knows yoga helps him, meditation. You know, and right now we are … he does a schedule, but we talk about his schedule and we have an overlying schedule about doing healthy things every day and healthy … I would like that to become much more his not me. So I would like to be able, since he’s an adult, I’d like to be able to step back and see him take over some of that ownership. That ownership of, you know … he probably would be a great runner. I’m too old to be a runner with him, you know, being able to access so many of the things that are … and right now, it’s more, you know, we have a summer schedule, we have a fall schedule, we have a winter schedule, it’s out there, we talk about good things to eat, we talk about good things for our brain. And it’s all written out. But I would like him to, you know, and kind of, I guess, like, that whole thing for all of us, that we all are, you know, that’s part of the adulthood, you know, mom stops telling you to brush your teeth, you brush them on your own kind of thing.

**Interviewer:** Absolutely. Thank you. So we’re going to move on to our next chunk of questions. So, as your son has grown up and aged, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** Oh, they just don’t know what to deal with them. You know, there are very few people and we’ve moved to … so we started in Illinois, we’ve moved to Ohio, we moved here to Pennsylvania. Nobody really seems to … it’s that misnomer of autism and you don’t want to be around people. He’s a active, I mean, I … first doctor, neurologist said to us, “*I can give you some drugs to calm him down*.” That seems to still be like, “*He’s so active*,” you know, he’s the problem. And again, Special Olympics is full of a lot of people with Down syndrome, and that’s fine. But, you know, they just think it’s the same and I’m like, “*This is not the* **[45:00]** *same. This is, you know, he isn’t going to sit nicely and talk to his friends. This is not our form, you know*,” and so if we go to an event, Special Olympics is never on time, they never do anything quick. They all stand around and do nothing and that’s just really hard to manage. So then we end up walking around the soccer field or walking around the track. And so I would say the community in general has a harder time. Schools don’t know what to do with him, didn’t know what to do with him. You know, it’s … and adulthood’s been better because we’re not all supposed to do the same thing at the same time. So, you know, if you get up at 5 am to take a run, nobody’s going to yell at you. You know, if you choose to exercise at midnight, same thing. So that’s probably the better part of adulthood. And, you know, David is definitely one of those tweeners that’s going to need some support. So if you can scaffold in that support for those sensory pieces, I mean, I’m OK that every Friday night’s probably going to be pizza night for the rest of his life. That’s not, you know … and again, the pizza is going to be gluten,- dairy-free and, you know, pepperoni on it. That’s OK, too. You know, you kind of let go some of that as long as you’re not choking to death.

**Interviewer:** Yeah. Would you say that his community was more or less accepting when he was younger?

**Interviewee:** Less.

**Interviewer:** Less? In what way?

**Interviewee:** Well, because we’re lumped in with a whole bunch of disabilities that … Like, how is Down syndrome? Down syndrome, they mostly are socially intact, though all of those things may be delayed, but they come in traditionally. And in autism, my experience—and it doesn’t matter who’s got it—it’s all scattered. It’s like a pegboard and you might have three things in the red row, but you got nothing in the other two and we keep … are being told to fit together and we have motor planning issues. We’ve got speech and language and lots of times processing issues and then were supposed to … told to be … fit in. And then you’re supposed to be just like joiny and they’re not … and I … We have hearing itinerants and we have blind itinerants, but we don’t have autism itinerants. I think that’s inexcusable. And especially from … like, I have always said this in his IEP meetings, he needs speech and language because that was the … if he didn’t understand what was going on, all of the other things are going to be worse, so.

**Interviewer:** Absolutely.

**Interviewee:** Sorry.

**Interviewer:** Thank you. No, thank you. So, you talked about school a bit: were there other specific, like, spaces or places, like, say, family versus a job that were more or less **[49:00]** accepting of him and his sensory sensitivities?

**Interviewee:** So he’s done mostly, he’s done a couple jobs and a couple volunteer jobs from data entry. He worked one organization for several years, doing data entry for them and it’s an outdoor adventure place, and then he did a summer job where he’s loading people into kayaks. They, you know, because there are no boundaries at a park, it became very difficult. And I don’t, they were very, they were great, but again, you could automatically see that there were no guidelines and there were no space guidelines, the job became harder. But the good thing is they found out he was a great power washer, and there was that detail orientated and that input from the power washer, which I would have never given him, that was good. Plays became a great place because he got involved in theatre in high school, middle school and high school. And that became very predictable, and it’s very scripted. And, you know, lots of good heavy work to be done, things to be moved off and on stage, they had an exact place to go. Everything followed a pattern and a reason. And they were very accepting, a very accepting group of people and embraced any of the skills he brought to the table. So that would be a good example. Families: we have a large family and moving has helped because it makes it smaller, a smaller group, a smaller, just less commotion. And because he’s gluten free, and since then, I think now there’s seven, seven or eight people now in the family members, so he’s not the only one, but the first several Thanksgivings and Christmases trying to accommodate the gluten-free diet, it was a production with everybody else. And we’ve gotten good about bringing things. We don’t ever travel without preparation, we always have a peanut butter and jelly stuck in our thing. You asked about sensorially things like making a peanut butter and jelly, he got in the habit of doing it only on Fridays, but he doesn’t still like getting the peanut butter out of the jar. You can see him physically get nauseous. Same thing with putting his hand into a bag of potato chips. Loves potato chips, can eat them out of a bowl, but putting his hand in there is like … And, you know, aka this bowl, rather not open the bag of potato chips because he had to touch them so wouldn’t eat, so, you know, that, you know …. now we’re practicing back to pouring the chips in a bowl. And again, it’s a conscious effort to have him do that.

**Interviewer:** Yeah. Thinking back to, like, community—you talked about his job, you talked about your family: were those places accepting of his sensory sensitivities as opposed to maybe just not aware of them?

**Interviewee:** I **[53:00]** don’t know, to be honest. Because of his energy drive, I get a lot of exasperation, you know, even sometimes when programs are for people with autism. So he went to a summer program at a school and they’re like, “*Well, he just walked away*.” And I was like, “*You know, and I think it was a sensory piece of, you’re doing too much talking*. *It’s too much*.” It’s … and he hasn’t been taught how to leave a conversation. He’s been only taught … **[to her son]** David, do you need me? No, that’s **[inaudible at 53:48]**. Sorry.

**Interviewer:** No, no, it’s fine. Do you need something? Do you need to go?

**Interviewee: [to her husband]** Al, do you want to start David’s Zoom meeting for … I think you can do it, but if you can’t …

**Interviewer:** We can pause, or we can … we can finish up with you another time if you need to go. That’s perfectly fine.

**Interviewee:** Can we pause for just a second so I can start his …

**Interviewer:** I’ll pause the recording. All right, we’re back on. And if you do need to pause, go, that’s perfectly fine. We can schedule another time.

**Interviewee:** Sorry. I’m wordy.

**Interviewer:** No, that’s OK. Not a problem. I can be flexible. So but if you do have to go, that’s always an option. So don’t feel pressured. Thinking broadly again: do you have hopes or worries about how his community will continue to react to his sensory sensitivities?

**Interviewee:** It’s getting better. Yes, I have worries but it is getting better. And even just the general audience of sensory … unless you were in this field, ten years ago, people didn’t understand it. I listened to something today in the *New York Times* and it was about lack of sense of smell and that’s an actual diagnosis. And so it’s, like, somebody said this when he was first diagnosed in the OT world, or the … you know, it’s an exciting time to be around in the brain. I truly believe it’s getting better and better. So, like, I do have worries. And back to the fact that we’ve been able to shape so much and we’re trying to put things in place for him, like being in it, no matter where he lives, him being in his own room will be important for him. Those are, like, in our long-term directive pieces of “*What does this look like when we’re gone?*” So we are having those conversations. Same thing, you know, we think the diet’s important, that will be continued on, trying to figure out ways—as far as the clothing goes, we’ve kind of tried to take care of all of that. You know, I wrote … my parents took care of David when he was maybe six, seven. And I wrote, like, this, like, recipe, this is how everything goes. And I wrote on there that my dad, you know, David doesn’t wear his coat ever in the car. And—oh, he does need me Hold on. I’m going to have to sign off and jump right back on. I’m sorry.

**Interviewer:** That’s … no, **[57:00]** don’t worry about it. I’ll see you soon. … All right, our recording’s back on.

**Interviewee:** Good, so the question was fears, or theories?

**Interviewer:** I was asking you about your hopes and worries regarding how the community will react to your son’s sensory sensitivities.

**Interviewee:** So we’ve put some of the will stuff together and had a directive in there about some of the care that David needs. And back to … similar to what I said with the earlier question, I’m hoping that he will be able to advocate for himself on those needs and, like, you know, like, travel’s important and all of those things. He will work and do a million things for you, if he’s got a reward, so, to kind of, you know, acknowledge that, but the diet, the clothes, all of that’s important. And hopefully, we’re trying to take care of it. He’s got three siblings and we’ve kind of divided some of the duties and responsibilities as that goes too. We also realize their lives are busy and they will have their own responsibilities. And so we want to try and take it so that it becomes his planning, not theirs. So, yeah, so we … you know, but I do have, you know, concerns that I … like I said earlier, I … the pandemic was just like, “*Oh my gosh*,” you know, “*we just have kept him so busy we didn’t notice some of the other things*.” And the more time we’re together, I’m like, “*Oh my gosh*.”

**Interviewer:** We’re all learning a lot through this pandemic, I think. Shifting gears again: so, in the, like, transition to adulthood, quote unquote, where do you see your son?

**Interviewee:** OK, big hope, big dream, the grand slam for us would be, he’s living in an apartment independently with supports that come in to him. There are a few things that are available that are somewhat supported. He probably is going to need support. We’d like him working a full-time job. He thrives on a 60-week, an hour or more, busy schedule. So, like, him maintaining a full-time job would be our idea of a home run. And, like everybody else, we want him to have a job that he likes more days than not, you know. He’s got some very meticulous skills. So we keep on thinking, this could or should work. Getting there is hard and what it looks like, and we’re still delayed, you know. When I think that he’s not even been verbally speaking 20 years. There’s just, we’re still delayed and so I’m OK with it taking longer, because it’s not meaning that it’s not coming in. So that piece is good. But that would be our … a home run is by … you know, and again, we don’t know, **[1:01:00]** but I’d like him out of the house by 30—that’s six years—and living independently. And a lot of the stuff, a lot of the routine stuff is, like, I don’t think … if he’s paying his own bills, paying a bill late will not be an issue. Because those are the rules we master. You know, first, then this, you know, those are the things that he’ll do well with. He will need some support. And we do worry about him being taken advantage of because he is naive. And he is loving and kind. But we did a transition program from 18 to 21. And they were in the city using mass transportation, you know, and also using the things like Uber, the self-driving cars are here in this area, you know, like, he would be able to use those kind of things in the appropriate good ways. He had a friend hang out with him once a while ago and I get he’d do Uber Eats. Because we do live in suburbia. We don’t have a bus close to us. We’re not on a train route. But all of those things, if he’s in the city, a city he would master. So yeah, so I think that’s our long-term goal. But he’s, you know, he’s still here. So, but that’s my home run.

**Interviewer:** Yeah. Thinking a little bit, like, about his current stage of independence: could you talk a little bit about, what are some things he’s able to do independently versus what are some things he needs some support for?

**Interviewee:** So he just started a job from home, data entry, for a person who, I’d say have had more of an idea of trying to get … he’s a roofer and he wanted to put areas together and approach by name and address and stuff like that. So that structure piece of putting it together, I was much more involved. So David put the Excel spreadsheet together. He’s now keeping track, he’s done probably a thousand entries for the guy in the last two weeks, maybe three weeks, and the guy knows what he wants but he doesn’t really know how to ask. So I’m the intermediary, so, the communication person. The guy’s doing some mass marketing, David’s, you know, able to do that. And the first couple were difficult, but, like, even so he had to do his own. He’s an **[1:04:00]** independent contractor, he has to set up his own invoice. And we decided two weeks ago it was going to be done every Saturday. So Saturday night, David’s like, “*Hey, we got to get this done*.” And so he’s seeking for help. He’s asking for help. He wants help. But some of the communication pieces between him and his employer, he needs some help. But I believe I’ll be out of the equation in the next two or three weeks. And this will be between … and so this will be between those two. I’m almost there. So that’s great … and David was unsure about starting it. He does his laundry every week. He … back to … if things are set up in a routine, then they’re done. So, he does dishes every night, he, you know, does not help much with cooking. We’re working on that. And some of that is, I cook, he does the dishes, so that, you know, it’s that kind of trade off, and he’s usually doing schoolwork. He’s scheduled as far as all his medication he takes. We do it for a month at a time, he … we both fill them together. Like I said about crossing streets, sometimes he’s unaware, so that piece is … And, you know, and, again, I don’t necessarily know if he knows a stranger. So if somebody talks to him, you know, then he knows them, and he doesn’t know them. So we’re doing some of that. So, those … that would be, like, my worry, and especially if they have, like, same memorabilia on, “*Oh, I know you because you’re in Special Olympics with me*.” Sure. No, we don’t know her. You know, manages his money, partially, with some oversight from his dad. He’s taking 14 hours in college, he will have an associates at the end of the semester. He loves math. You know, all of that, setting up the testing, asking for accommodations, getting the letters: once the routine has been set up—he writes an introductory letter to all of his professors. That, you know, was set up with the first class, it’s continued. Goes to tutoring if he needs help, all of that he accesses without any of us. You know, every Wednesday, like I said, he does his sheets and towels and it’s all done by noon. It’s all set and started and, you know, goes to the grocery store with us, cannot drive, would like to drive. I just don’t know if he has that perception piece. We keep on waiting for an academic plateau. I think he’s had the last four semesters straight As. So, you know, like, I didn’t think he’d pass calculus, he got an A, he’s now in Calculus II … so I don’t know what to do with … **[1:08:00]** we don’t know what to do with it. He’s also done well with Java. He does a lot of things. Well, but again, he’s not like my other kids at 24. But once he starts something, he won’t stop. So like, you know, he started volunteering when he was in the transition program. He continued to go every Friday until … you know, until really the pandemic hit.

**Interviewer:** Gotcha. Yeah.

**Interviewee:** So once it adds into his routine, it doesn’t really leave his routine.

**Interviewer:** How is he with, like, taking care of himself physically, like, daily hygiene?

**Interviewee:** You know, no issues, so shower, shaves every day. Again, breakfast, lunch, and dinner can be on his own, you know, like, we do have free choice night. And everybody … and that’s the household I’ve run, too: you eat, you clean up, you know, ask for things that he wants, if I’m going to the store, you know, that kind of stuff. We’ll put it on a list. And same thing with certain recipes he likes to make. So like, he does a baked ziti and cinnamon pear coffee cake that he likes. And so he’ll say like, “*Can we make that?*” And that becomes more of a joint effort. But …

**Interviewer:** But he’s able to make those things?

**Interviewee:** Yeah, yeah, yeah, yeah.

**Interviewer:** And is he able to go to the store with you—like, maybe pre-pandemic—and go shopping for these items?

**Interviewee:** Oh, yeah, yeah, yeah. You know, and so, like, on Tuesday, we have somebody come and she’ll take him to the to Target to get all of his personal hygiene stuff and he has a list and he knows the products he likes and so … And he’s a great, I mean, he’s a wonderful shopper, he’d be a great personal shopper. So, like, nieces and nephews who have birthdays coming up. He’s like, “*Oh, we got to stop and get so and so a present*.” And, you know, like, that kind of stuff he’s very good at. He likes to have hard cash in his wallet. So, you know, he … I used to take him downtown, drop him off at school and then he would take the train to meet his dad. He sometimes would take the bus and the train to get to somewhere else and I’d pick him up somewhere else. So, that … yeah, that’s all good. And practice does help, you know?

**Interviewer:** Has he ever expressed interest in wanting to live on his own one day?

**Interviewee:** No. He’s like, “*I don’t think that’s a good idea*.” And so we keep on saying, “*Your siblings are out on their own. You’ll want to be out on your own, especially, like, you know*,” back to “*I don’t want to do that*.” I’m like, “*Well, you live here. If you didn’t live here* …” you know. So, I think my thing is, is I think if we can get him a taste of it, he’d be fine. And he has … his sister’s an OT. And she said, “*It doesn’t have to be somewhere for seven nights in a row. If he went for two nights and you did it for three weeks, he probably would soon say the fourth week, ‘I think I’m going to stay another night*.’” And she’s right. But I always think of it all or not. So I thought that was a great example. I was like, “*Yeah, you’re right. It* …” you know. Because, you know, so yeah. And again, I think he **[1:12:00]** thinks of living alone as being isolated. And I think that becomes that worry, and the fear that’s in the back of it and not realizing what living alone could look like.

**Interviewer:** Absolutely. So does he have any sort of social life that he manages to some extent?

**Interviewee:** So we’re working on that, because all transportation relies on us. So we’ve got a script of: you get an invite, you’ve got to check with us. Now everything’s gone on Zoom. So he does Best Buddies, he does do this Pittsburgh harmony, which is a musical singing group with college students. And so he’s, like, very excited this year, because he can do both on the same Sunday. Whereas before we had to say, “*You have to pick one*,” because they usually conflicted. And there was a conflict with one or the other. And it was, like, and we refuse, because they’re not that close, to try and do half and half. We’re like, “*Pick one*.” So but yeah, see, you know, he would probably be out every night. He could be out or out, you know, and he would love to go to movies and, you know, we’ve done some walks at the park with friends and stuff like that. But yes, he’s very social. And I don’t think he’s the planner. But he’s always quick to say like, “*Yes, I’ll do that*.”

**Interviewer:** That makes sense. And do you think your son will be able to achieve more independence in the future?

**Interviewee:** Yes.

**Interviewer:** In what way?

**Interviewee:** So we’re looking at some colleges that might have … they have a supported living environment for next year and they have built-in supports for some recreation and some other activities, like even flick and fold, like a movie and laundry. And they’re embracing this living and learning community that’s diverse. And I think David would take advantage of that. Mercyhurst College has got a autism program and he went a couple years ago for three weeks. And he thinks he failed because he didn’t do well in the class. It was an academic class, as well as a variety of other things. And he took advantage of every social opportunity there. So he didn’t and they didn’t get graded on that. But he went to all of them. It was like the Amazing Race. There were all these activities. He and his roommate planned a trip to the amusement park. That was all him and his roommate. And so I think that would be the piece. But since David did so poorly in the class, David thinks he failed. Back to that perfectionist piece that’s like, I’m like, “*You managed meds, you managed diet, you managed laundry, you managed, you know, you lost no clothes, you came home with everything you went with, you know, you stayed up too late. You were texting your siblings and your cousins at two in the morning. You did everything you were supposed to do*.” But yeah, he didn’t get an A.

**Interviewer:** Gotcha. What do you think will help your son move into adulthood a little bit more, besides maybe the supportive environment you just described?

**Interviewee:** From … I think his dad and I have to become less help helpful. **[1:16:00]** And I think we consciously have to work ourselves out of this job. And I think that’s the hard thing because he’s a good person. And to say no more and have him figure … push him outside of his comfort zone. You know, that’s the hard part. The other thing is, when you were talking about welcoming environments, a lot of parents on the autism piece have gotten the phone calls for so many different times that we don’t fit in, and we have to come and pick them up and you get tired of trying. I have a friend and I actually told her about your survey. I don’t know if she’ll ever do it or not. But, I mean, she and I used to have the running joke, “*Who’s going to get the call from the school this week—not this week, this day?*” So I think that’s the hard part is trying to tell ourselves to push because he can do it. Because he does have, I think he does have the underlying skills.

**Interviewer:** Yeah. Besides this, like, lack of parental involvement you just described, do you think there are other services or interventions that could be helpful for your son?

**Interviewee:** Yes. So, there are services available in Pennsylvania, but they don’t really … again, it’s they don’t really fit the autism mold. So when I asked for things, it was like, “*Oh no, I’m sorry. They’re not approved. Oh no, I’m sorry, they’re not approved*.” And when you look at … you know, everything I want to do, it’s not approved. So there’s an academic disability they’re at Philly … they’re trying to sell only to school districts, but it talks about, like, computer awareness and savviness. And all of … a lot of the kids on the spectrum need direct lessons. They just don’t naturally learn that and I can’t get that service. And yet, I don’t know too many kids on the autism spectrum who aren’t on the computer. And, you know, for example, David signed himself up for this free service at college for his paper. And they said, “*Do you want it expedited?*”And he said, “*Absolutely.*”At the tune of $50. And they turned it around in an hour. And he loved that. And so he asked for it again. And there’s that fine, you know, and, you know, he’s never going to do that again, but it’s those kind of computer stuff that, you know … that was just a big $100 mistake. But there are, you know, so, like, there’s stuff like that, that you just can’t get the right services, and I do feel like they need it. So … and then to try and build it on your own … you know, we’ve—I don’t know—**[1:20:00]** we’ve done … I’ve done a lot of homeschooling for David. I’ve done … David’s done school school, and we’ve done a lot of homeschooling. I think a lot of parents with autism do both. And you just kind of go, this is the stuff that, you know, again, everybody and their mother has gotten the phone call for auto technology, or, you know, “*Your auto warranty*,” you know, “*it is expiring tomorrow, you need to talk to us today*.” It’s just some of that stuff that, you know, I think there’s a lot of transition services that need to get … we don’t look like we did in 1950 or 1970. And we really need to … and same thing with healthy relationships and sexuality and all of that. So there’s just not a lot of good programs out there. And the state of Pennsylvania has some things but it … just you can’t get them. And so if you find something they’re … it’s expensive.

**Interviewer:** Yeah, that makes sense. Thank you. Now, putting these two things together—his sensory sensitivities and his transition to adulthood—how do they intersect for your son?

**Interviewee:** So I just … It’s a good question. I’m having a hard time giving you a good answer—or any answer, besides the fact of the needs are great and the existing programs just probably aren’t there. And, you know, like, for example, the feeding therapy, I don’t even know where I’d go and find that right now. We still don’t know what’s the issue and he has choked. But it’s, you know, right now, it’s, you know, he’s not learning the lesson—and something about our form of autism: everything needs to be constructively taught. But I don’t even, I wouldn’t even know who to turn to and I don’t look at myself as unknowing, or, you know, like, I wouldn’t know where to get a resource for that.

**Interviewer:** Yeah, totally.

**Interviewee:** So, I just kind of go, like, it’s probably a bigger issue than I realize. But I … you know, and I can’t get … I think your questionnaire in the beginning and probably why jumped on it. I was like, “*Whoa, this is bigger than I thought*.” And it’s a conversation that I think needs to be addressed because I also think that sensory sensitivities really address a lot of behavior issues, too.

**Interviewer:** How else do his sensory sensitivities impact, like, his behavior that’s relevant to him transitioning?

**Interviewee:** So I just see him … silly things like the, you know … we didn’t realize how much, like, the mask piece became an issue, the washing the hands, the … He touches his **[1:24:00]** face all the time, which we didn’t know. And a lot of it is … I don’t think he’s aware of where his body is in space. His need for heavy input is much larger than a normal person. So I just … I definitely think, like, this is, you know, and how do I more shape that behavior? So that is it … finding a cross country running partner to do trails four times a week with him, has that become a much better shaping behavior?

**Interviewer:** Absolutely. And do you see his sensory sensitivities as an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** I could definitely say, “*Hey, I see his, some of his* …” Like, we were talking about him travelling through an airport and how he’s ... that becomes an obstacle when you’re a 35-year-old man and somebody’s going to just slug you. Those are my concerns, and I can’t put a sign on him that says, “*Oh, by the way, excuse me, I have autism*.” And he’s … you know, he’s no longer looking like a kid either. And so I do feel like it’s an obstacle in some respects. And the sensory, because we don’t … And in the same breath is that at some point a boss is going to yell at him for not listening or not hearing—‘listening’ is not the right word, well listening is … I don’t know, but not hearing because he tunes out so much. And how does he advocate and who do we get to advocate? Because when he’s 35 I can’t be that role anymore even if they do know he has autism. Like, I have a friend who’s got a 50-year-old brother with him. And he kept on telling work, “*I can’t work because I’m a … I have Covid*.” And they finally contacted the sister. And the sister says, “*No, he doesn’t have Covid. He’s done 10 tests. He doesn’t have Covid, but he, you know, he’s worried about Covid and he’s worried that you might have Covid. It’s like, I had to get involved as his 25-year-old sister*.” So and that’s more of a worry thing, but it’s the germs, you know, that’s how his autism presents.

**Interviewer:** Yeah, for sure. 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:** Say that on again for me.

**Interviewer:** What do you anticipate as being challenging for your son, as he does gain more independence in relation to his sensory sensitivities?

**Interviewee:** Him understanding how his … it’s that self-perspective, as his sensory system is not like everybody else’s and I don’t think he has that. You know, I don’t think … like, when we answered your forms, there was a lot of areas that it was fine, but, **[1:28:00]** like, I don’t think he understands those questions on the auditory piece that nobody else is doing that. And I do think some people on the spectrum do have that introspection, but he does not and I don’t know he’s going to get that. You know, like, that’s one of those emerging developmental pieces: will he get it or not?

**Interviewer:** That makes sense. And what do you think could help your son at this intersection of sensory and transitioning?

**Interviewee:** I think, you know … to be honest, I think some experts that aren’t Mom telling him and even—I don’t know—did you watch that show Love on the Spectrum?

**Interviewer:** I did not, but I heard a lot about it.

**Interviewee:** So they went through some sensory profiles, and even just being aware of, you know, ways you want to be touched or not touched or what environments are too loud. And, like, and it was … they actually had people coming in and working with clients. They taught that. And I think that going back to … in the autism world, a lot of that does have to be concretely taught. And I don’t think it’s that way with other learning disabilities, at least, so because that kind of comes with that maturity.

**Interviewer:** Absolutely. Besides these experts who are not parents, do you think there are other interventions or services that would be beneficial at this junction?

**Interviewee:** You know, I don’t even … and maybe it could come out of a social skills group where it’s actual other peers, that you talk more about the sensory system in general, you know, where, you know, the girl next to you is saying, “*My hearing doesn’t bother me at all, but I can’t stand*,” whatever you know, or, you know. I just think they know what they know and they don’t know what they don’t. They definitely know what they don’t like, but I don’t know if they can do that comparison, unless they have it in that quieter environment. You know, and that, you know, that’s kind of, like, so we did watch Love on the Spectrum. And he looked at me, and he’s like, “*It’s not funny. It’s more educational. The* **[inaudible at 1:31:01]** *feels more like work*.” And I was just like, “*I just found it extremely enjoyable, the show, because it showed us that we’re not alone*.”

**Interviewer:** Yeah, that’s important.

**Interviewee:** Yeah. So you know, but it was just a very … but he just looked at me and he’s like, “*This is educational*.” But yeah, so that’s kind of … so I, you know, I don’t even know if it has to be a sensory person expert, but, like, part of a curriculum on the social emotional piece. That, you know, and, again, where does that fall? I don’t know.

**Interviewer:** Yeah. And then, relatedly, do you feel like there are gaps in the available services and interventions?

**Interviewee:** Yeah, because, you know, I mean, **[1:32:00]** I do. Because, you know, if there weren’t, you wouldn’t have anything to investigate. And, back to kind of what I said earlier, it’s … we’re starting to notice that these don’t go away, they can be large drivers and how people’s lives are affected. And it does matter about quality of life. So yes, I mean, I definitely think there’s gaps. And, you know what, I mentioned this to a couple other parents that I knew. They were like, “*Yes*,” you know, and I think we got stuck on that, you know, when they’re little, some of it looks so categorized. They walk around with headphones on their heads or they spin or they do some visual stimming before their eyes. And so we just think, “*Oh that’s autism*.” But when they get older, it looks very differently. **[crosstalk at 1:33:18]** But it’s still there.

**Interviewer:** How does that relate to gaps for you? What do you …?

**Interviewee:** So the gaps, you know, because, like, right now, I feel like it’s either his dad or I that fill those gaps. And the ownership from David just isn’t there. So if we don’t fill it, or if we don’t set the guidelines, it’s not going to … and if it’s not addressed, then it only gets bigger and it becomes more interfering.

**Interviewer:** Yeah. Absolutely. And now—thinking largely and a little bit more broadly again—how have your son’s sensory sensitivities impacted your goals, hopes or expectations for him, as he does navigate adulthood?

**Interviewee:** Some of it would just disappear, I thought, as he gains certain skills, that some of it would disappear, like I … you know … like, I just thought he would learn and some of it’s just him. Yeah, so yeah.

**Interviewer:** Awesome. We’re almost done. We’re going to move on to our last chunk of questions, but they’re the shortest.

**Interviewee:** Just have to move to a different room just to get my power cord. Sorry.

**Interviewer:** No worries, no worries. I’ll wait. I understand the need for electricity in this context. It’s very important.

**Interviewee:** All right. We’re set.

**Interviewer:** Awesome. So finally, as a caregiver, as a mom and a parent of someone with autism, but also these sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** A little bit, like I said earlier, I’m out of a job. I’m not … I mean, he has been my full-time job. And it’s a 24/7 job. Autism doesn’t take a day off. And so we haven’t either. And a lot of it has been his needs over everybody else’s. So it his over **[1:36:00]** mine, his over my husband’s but also of his siblings. And so, as he’s transitioned into adulthood, there have been more opportunities, but his needs still are the family’s biggest driver. So when we go visit my other son in Chicago, it has been the driver to make sure that … for, like, that constant activity level has to be addressed. When we go, we just don’t sit at his apartment and hang out, you know, there are activities and things to do. Same thing with food to be ... You know, like, it shapes a lot. How do we get there? I think I told you he doesn’t need a lot of sleep. So if you take a flight and you leave at 5 am, there is no nap. He will not go to bed—doesn’t matter where we travel—until 10 o’clock. And then he doesn’t necessarily sleep, but, you know … So till that kind of … so and it is gradually happening. And so we’re getting there, but you know, his, you know, if his routine is set and his needs are met, then it allows for us to have a lot more freedom.

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

**Interviewee:** Yeah, I mean, I … like, a lot of parents at my time period stupidly **[inaudible at 1:38:00]** let me hear that, your voice and, you know, if you work a 40 hour a week, ABA program and autism will be gone in, you know, three to four years. It just isn’t. You know, I said to several people, I’m going to write a book. It’s the hardest thing I’ve ever done. Raising three other kids under four was much easier. And it’s an ultra, ultra marathon. So I thought it would be done faster and especially when you do a little bit of that ABA, because that’s very rewarding in the fact that you teach a skill and you’re done and you move on and you generalize it. But now you’ve got all those pots that have to come together and a lot of our pots are still in very much isolation. They do integrate, but not in the traditional way.

**Interviewer:** Yeah, totally. Thank you. And then what do you see happening in your son’s future?

**Interviewee:** Like I said, I mean, the home run is him living independently, him … you know, that would be our home run, him living independently and him getting most of his needs met, by, you know, 75% not us and 25% us. And, you know, my three other kids … I mean, most days they like their job. Their job may be hard, their job may be … it’s still work, but they like **[1:40:00]** what they’re doing. And if David is liking what he’s doing nine out of, or eight out of ten days, that will be great. You know, I think that would be a home run for us.

**Interviewer:** Yeah. So you see him having a job?

**Interviewee:** Oh yeah. I mean, he’ll have a job, he might have two. You know, it’s finding the people that are willing to have … you know, I think he has the stamina for a 40 hour a week job, I think he’s got the drive to do a 40 hour a week job, and he would probably do above and beyond. The reality of finding an employer that works with us … he may end up with two part-time jobs. You know, and that may be it, or it may be a part-time job and a part-time volunteer or something. But … you know, like, the reality for adult employment is dim for people on the spectrum, so I’m very aware of that. But that’s our goal. And again, a livable wage. You know, not $7.25 an hour because you can’t live on that.

**Interviewer:** Nope. You mentioned he’s going to finish his associates after this semester—do you think he’ll do more schooling after that?

**Interviewee:** Yes, we’re actually talking about it. So … and I don’t know if it will be computer science. I don’t know if it will be … He talks about doing a math major, I don’t know. He’s definitely a math and science person. So I, you know, long strings of information he holds very well. So he loves the calculus, he’s done several accounting classes, math. And that piece has … like, that activity level, has been good to show that extra … there has been some developmental growth there, as he’s gone through the classes. So again, like, we all know development doesn’t stop at 18, but it really has been great for him.

**Interviewer:** Yeah, that’s great. Do you see him having a family or a partner of sorts?

**Interviewee:** Yes, I can see him having a partner. He would love to have a girlfriend. That is his goal. We’re fine with that. He’s got a couple nephews and nieces. And he enjoys babies, but he really doesn’t like when they cry. There’s a good example—like, again, wouldn’t ride with his nephew because he cried and didn’t want to see him and so had a really difficult time being in the car with him, so I think he’s realized that that’s probably not in the cards. And that’s OK. I mean, better to know than not know.

**Interviewer:** That’s true. Absolutely. Last, final question: how have your son’s sensory sensitivities impacted this perspective you’ve described, in terms of what it means to transition to adulthood?

**Interviewee:** Sometimes I think he **[1:44:00]** … I think we all know what we know about it. But I don’t know. I think the hard part with adulthood is we don’t realize how not traditional it is, because you were out of the school environment. We conform, you know, pick something you don’t like to eat. You just don’t eat it anymore or whatever, you know. Ask me to put on a wool sweater, I’m just not going to do it for you … nope, they’re not my favorite. And if you buy me one, it might sit in my closet, but I still won’t wear it. But I don’t think we realize how it’s such a part that, you know, so you start to look around and go like, “*Oh, yeah*,” you know.

**Interviewer:** Absolutely. So that’s actually all I have. Would you like to add anything else?

**Interviewee:** I’ve talked way too much.

**Interviewer:** That’s OK. That’s all right. That’s why I’m hear. Happy to hear all of it.

**Interviewee:** Thanks for the opportunity. Good luck with your research.

**Interviewer:** Thank you. This has been a pleasure. Thank you for making time. It’s been great. Do you know anyone else who might want to participate?

**Interviewee:** Yeah, I’ve got a couple friends and I sent out something to them.

**Interviewer:** Oh, thank you.

**Interviewee:** Yeah. So I actually … because again, we’re all kind of, you know, a couple of them are just like us, where they just have left … you know, they’re 21, they’re out of school, but yeah, I do. And then, when we were talking, I mean, I did think … because there’s another family we know that have twins and her daughter and my son both tie their shoes so extremely tight that it’s uncomfortable for us to look at their feet, but it’s that tight feeling that they really … So I hadn’t mentioned that to her. So I thought I’d might reach out because she has twins and be like two for one.

**Interviewer:** That’s great. We’re looking for just a couple more people, so we’d love to have them.

**Interviewee:** OK. All right.

**Interviewer:** Would it be helpful if I resent you our flyer? Would that be helpful?

**Interviewee:** Sure. That’d be great. Yeah,

**Interviewer:** I can do that. And then, in the very beginning, you mentioned that you took photos of that last survey you did with your son. If you want a copy of the report, I can just send it to you.

**Interviewee:** Yes. That’d be great.

**Interviewer:** Yeah. Do you want to see the other reports too—or just that one? It’s up to you.

**Interviewee:** You know, why don’t you … because he works with a therapist who does a lot of adult autism clients.

**Interviewer:** Yeah. I’ll send them along.

**Interviewee:** I might send a flyer to her because, until you just said, that I hadn’t thought about … she might know some others.

**Interviewer:** Yeah, I can do that. Absolutely. So yeah, thank you. This has been great. As soon as this audio file renders, probably around tomorrow, I will send you the follow-up email, and we’ll have a gift card as a thank you for all of your time.

**Interviewee:** All right. Thanks very much.

**Interviewer:** All right. Have a wonderful evening.

**Interviewee:** You too. Bye.

**Interviewer:** Bye.

**[End of interview]**