**[Start of transcript]**

**Interviewee:** …Bigger screen.

**Interviewer:** Yes, absolutely.

**Interviewee:** So, OK.

**Interviewer:** And so, during the interview, I will be asking you questions about your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities.

**Interviewee:** OK.

**Interviewer:** And we’ll be doing something called a ‘semi-structured interview’ and that means I have my planned questions and my script, but I’ll be adapting them to fit our conversation so they actually make sense for you and for your family.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** Nope.

**Interviewer:** OK. And if there are any questions you don’t want to answer for whatever reason, that’s perfectly OK. “*I don’t know*” is also a perfectly okay answer. And if there are things that come up from earlier later on, feel free to jump in. It doesn’t have to be a perfectly linear conversation.

**Interviewee:** OK.

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

**Interviewee:** Sure. Do you want me to start from when … now, how he’s doing now or from where we started at?

**Interviewer:** I will be asking you about the past. So whatever makes sense for you to answer, whatever is easiest for you.

**Interviewee:** OK. So maybe we’ll just do a quick summary. So he’s always been wickedly intelligent. Very, very smart, but not common sense smart. And then there were things we missed, like, at two, he would love to line up all of his cars and he had memorized the preamble of the Constitution from a song that we had and so he would sing the preamble of the Constitution at weird places, you know, in the car. He was two. And then once we hit kindergarten, we started noticing some … he’d have to walk the room in class. The teacher would say, he’d constantly walk the room, checking to see if anything had been moved. He would do the other kids’ work on their whiteboards so he could get outside faster to get to what he wanted. He would … the most sensory one, when we got the diagnosis for sensory processing disorder. He would … the kids would … they’d line them up and he would turn around and whack the kid behind him and then turn around and hit the kid in front of him so he was ready for … so they’d just touch him and get it over with. And so he can’t handle when something unexpected … unexpected touch is a big thing for him. He’s improved immensely on that, but it’s not wise to come up behind that boy without him hearing you. And so … well, their solution to that was just to put him at the end of the line, right. Nobody behind you, you can manage the distance in front of you, so. And then we started … that’s when we started occupational therapy. At 21 months—it was overnight—the sensory eating issues started **[3:00]** and he wouldn’t … he really could only handle two textures. And so we started OT again in kindergarten, so, and got him up to five textures and he still works on that today. And *Binging with Babish* is, like, the best thing ever. I don’t know if you’ve heard of him.

**Interviewer:** Yeah. It’s so much fun.

**Interviewee:** And that has helped us move him … and I say ‘us’ … that has helped him. He found it … he **[inaudible at 3:32]** made the cocoa last night. Probably going to make that again today because we have extra whipping cream. But so … he’s aware of where his shortfalls are and he’s trying to actively work on himself.

**Interviewer:** That’s wonderful.

**Interviewee:** So he still struggles with the oral sensory stuff, though, the texture stuff. He doesn’t like scratchy clothes. Light—if it’s too bright outside and here in Colorado … We moved from Seattle to Colorado, you know, kind of darkish to really brightish. So we got glasses, his glasses automatically tint now to help with that. So those are the … and he stomps … he still stomps a lot. We do a sensory diet since I’m an exercise physiologist, I’ve always managed his sensory issues, a good deal of them more through fitness than through medication, but we do use … medication is needed. And he knows … he’s an advocate for himself and hopefully for others with a JFK Center here in Colorado. And so, he’s working on himself. I think things that he doesn’t realize he’s doing is … he has a regular pacing routine. And that helps organize him that organizing and it kind of helps with his tactile too because as he paces he grabs something and he’s tactically going through it as he walks, and then he’ll pick stuff up and carry it around the house and you have to go find it. So we’re working on launchpads in each room so that he knows where he can set stuff down. Because, like, we lost … already lost the potato masher, I’ve got to go find that, and the paddle to the mixer and the little tongs. You know, he likes things that can be active. It’s kind of funny. So I’m thinking … other sensory … I did light and bright … loud noises, he doesn’t … it’s not as severe of a reaction as it used to be, the stomping up and down stairs, or, you know, I know when he needs deep pressure by how much he’s stomping. I’m trying to think. He … **[6:00]** Yeah, see, I did tactile, I think that’s it. If I think of anything else … I think that’s really what we’re managing now. He is still growing, that’s what I was going to say, and he’s 6’4. And when the growth spurts start, everything’s out of whack: all the sensory stuff is intense and you don’t know which one’s going to pop out, right. Impatience or wild laughter, you never know. So, yeah, he’s 19. Hopefully … he comes from a … my dad’s side’s really tall. So, yeah, hopefully he’ll stop before his feet get really big like my brother, anyway.

**Interviewer:** Hopefully. I think on the form you indicated smell as well.

**Interviewee:** Oh yes. Pickles—he absolutely cannot stand the smell of pickles. And vinegar—he’s not big on vinegar. That could be conditioned, though. When they were little, if they said … were disrespectful or said bad things, they got a squirt of vinegar in their mouth, so. And then my middle kid decided he liked it, so I had to switch. Anyway, so I’m not sure if that’s, you know, operant conditioning, if that even is what that is. But vinegar. Pickles is the most aversive and then, of course, we’re in Colorado and we were in Washington, so weed, the smell of weed. All of us hate it. But, I mean, it kind of … and as long as he can get away from the smell, he’s OK, so, but if … the longer he’s exposed to it, the more irritable he becomes. So it’s kind of, like, he can’t manage the … it’s, you know. Oh, that’s the tactile thing—he still has that—so, when you touch him, like, what feels like a pat to you or I sometimes feels like a slap to Carter.

**Interviewer:** Oh, OK. **[crosstalk at 8:17]** So, like, extra sensitive.

**Interviewee:** He really over-processes … his body really over-processes messages. And I think that’s part of the unexpected touch thing is when they come up behind him and pat him on the back, that’s like somebody pounding him, right and so … yeah, I forgot about that, so. And smell, I can’t think of … pickles is, like, probably the worst thing and it’s … we hear it a lot because Brianna the youngest loves pickles. So, you know, it’s a balance. We have fans everywhere, so we can get rid of smells and so.

**Interviewer:** For the texture—in terms of food, what are the textures that are challenging for him **[9:00]** and what are **[9:00]** textures that are OK for him now or before?

**Interviewee:** Slick is challenging. I wouldn’t say necessarily … he can handle … slick he can’t handle hardly ever—not even if it’s candy.

**Interviewer:** And by ‘slick,’ could you give me an example of what you mean by that?

**Interviewee:** Peaches are slick. Peaches, canned peaches.

**Interviewer:** Yeah,OK.

**Interviewee:** But fresh peaches … sorry he thinks he needs extra of these.

**Interviewer:** You’re fine.

**Interviewee:** So, let’s see, what’s a good one? So, like, a fresh peach—you have the rough and bumpy and the fuzzy at the same time on the outside. Then you have crunchy depending on how ripe it is, kind of crunchy on the inside and then as the closer you get to the pit, the slicker it gets. So all three of those at once, that’s really hard on him, and it’s not that he doesn’t … he loves the taste of peach. He … I think it’s the three textures at once are overwhelming to that sensory. But slick is the hardest. Let’s see … what are the ones that he worked on? Crunchy’s OK, crunchy and salty at once we can handle and sometimes the flavor at the same time. He’d, like, he’d sprinkle bacon on everything. I mean when he was little, it was mostly dairy, it was mostly … he could handle noodles, but you had to really rinse them and drain them really well almost kind of a dry texture not kind of that … And then the creamy came from the milk. He can taste the dehydrated onion after it’s been cooked in a packet of taco seasoning. So we have to take out all of the … you know, I try to find taco seasonings without dehydrated onion or dehydrated pieces. I’m hoping he gets better at that. So what else … taste, I think slick’s the worse. He’s doing so much better. I mean, when he was little, I had a list. I mean, everything but macaroni and cheese and hot dog, I felt like that’s all he would eat, so.

**Interviewer:** Yeah, awesome. And then, for brightness, you said it was, like, sunlight. Does, like, internal, like, household lights, do those also bother him?

**Interviewee:** Not as much.

**Interviewer:** So it’s, like, sunlight.

**Interviewee:** Except for the natural light … he’s not as sensitive to it as he was, you know, or I shouldn’t say … maybe, aware. I think some of the things … like, I asked him about the blinds the other … last night when we were talking about the blind or that question came up. And he’s like, “*You know, really, Mom, I just don’t care about that anymore, so I use … I just don’t notice because I’m busy with other things*.” So I said, “*But if you had*,” you know, “*a choice,* **[12:00]** *would you want light, or …?*” he’s like, “*I just* … *I don’t know*.” But when we go outside, Carter makes sure that he has his hat to help shield the light. So I think it’s the sudden bright. If he has a slow accommodation time to it, I think he’s good. But in the house, he doesn’t seem to care anymore. This is what he told me.

**Interviewer:** And then kind of overall, how would you say his sensitivities have changed over time: have they gotten better, have they gotten worse?

**Interviewee:** They’ve improved and I’m so glad. Yeah, sometimes it’s hard on other family members, right. So and, like, Braden, our middle, he has a hearing loss and so he’s kind of loud. And Carter would get mad at him growing up, “*You’re too loud*.” I mean, like, “*I can’t hear*.” So **[13:00]** it was, you know, kind of a balance, you know. So, anyway …

**Interviewer:** Well, I’m glad he’s improved. Do you think any of these changes are related to any independence that he’s gained over time?

**Interviewee:** I think the eating is … I think the textures … he’s really taken that over from us, you know, saying, “*OK, we’re going to … if you try something new, you’ll get a Lego or something for* …” you know, the bargaining. And I would say he’s … can be unusually stubborn on certain things, especially growing up. He’s kind of growing out of that. I think that has to do with self-protection. You know, “*I’m protecting myself from changes you want me to make*.” So yeah, I think he’s improved.

**Interviewer:** Wonderful. And then how does … So I know you talked about, like, for texture, like, he watches *Binging with Babish*: how else does he cope with and manage his sensitivities or how do you help him cope and manage his sensitivities?

**Interviewee:** So we use *‘How Does Your Engine Run?’* I don’t know if you’re familiar with that program.

**Interviewer:** No.

**Interviewee:** It’s an occupational therapy. I don’t even remember who the OTs are. I actually use it with my students. And so it talks about having enough activity to know where your engine is on the scale. So we have, like, a, you know, a half-circle and you want your engine to be in neutral, right, not too drowsy but not too revving either. And so we use car because all the kids can relate to cars or trains. Carter started with the train because he liked trains. So knowing what kind of physical activity or what kind of sensory thing you needed to do to get your engine to neutral. And I love this program. So, like, at school, he would tell the teacher “*Hey, I think I’m feeling a little sluggish*.” Or she would notice that he’s getting a little squirrely. So she’d give him a crate of books and he would carry it up the stairs and drop it off at the other teacher, come back down and be able to focus. So we’d have him work that input. He knows … and I’ll say, “*Hey, it looks like you’re revving up to manias*.” “*Yeah, I need to do some rowing*.” Because he’d be … like, we used to have a rower we moved in and anyway, “*So I think you need to walk or I think you need to do stairs*.” So and he kind of, you know, manages that on his own. He knows where he’s at. He has, you know, exercises for heavy work that we use, but there’s some times when you can’t do exercise. And so we do have medicine, he’s on Adderall, and we have increments of 5 mg so we have a 5 mg, 10mg, 15 and 20. And based on what the activity is … like, if he knows he **[16:00]** needs to focus, like, for college he had to take … he’s taking calculus-based physics and that takes a lot of focus and concentration and now with the pandemic we can’t … well, we have a gym membership. We can’t go to our gym because of the pandemic. And so we’re relying a little more heavily on some of the medications for the longer term stuff. And so he would take probably 15–20 mg, but he decides, he knows how much he needs. We worked really hard for him to be able to be independent to understand what he needs. That doesn’t necessarily mean that he always does it. And you have to kind of “*Hey!*” I don’t know if that’s just teenager …

**Interviewer:** It could be developmental.

**Interviewee:** So, yeah, so sometimes, but most of the time, he’s really good about managing it. So … but you can tell, when the stomping is … if the stomping goes on for longer than an hour, you know, up and down the stairs and pacing, I’ll say “*Hey, it might be time for some squats*.” So, yeah, so that’s that. And then other sensitivities … you know, there’s a smell, he knows to get away from it. I taught him to self-advocate with teachers using that engine talk because the teacher can understand the engine talk. I think our biggest issue with him being able to self-advocate is the teachers think they know better than he does about him. And that would be … I think, you know, talking with other moms, that’s global. So I think that’s the challenge we’re working on next.

**Interviewer:** Then, has he received specific therapies or interventions to help him with his sensory sensitivities?

**Interviewee:** Oh, yes. Years of occupational therapy, years of providing him with bacon. “*Carter, you get to play this game.*” In … it was a game called *‘Rush Hour’* and he loved that game. It’s organizing. You know, you’re probably familiar with some of these games.

**Interviewer:** With the cards, right?

**Interviewee:** Yes, and the card … and you put the card up and then they’d have to solve it. And then there’s an app called *‘The Room.’* It’s a game, but it was originally started off as a therapy technique for kids. So I almost got my OT degree, but … that’s why I know a lot. But I use it every day, so. He had speech therapy. He is super, super kind, super nice, super polite. Carter’s my boy scout. Braden’s my Harley boy. Carter … to a fault … you know, the speech therapist even commented on that, **[19:00]** he will try to change the situation to save the person. You know, they give examples and he’s still super kind of … still worried or concerned about, like, a boss taking advantage of him as he moves into the work world. So I think those are things that are concerning that … I don’t know if he’ll ever get there.

**Interviewer:** For the, like, OT and the speech, so, like, we’re helping … **[crosstalk at 19:33]**

**Interviewee:** Speech therapy, that’s what she’s helping him with and social pragmatic language skills is what he is working on so … Oooh! **[crosstalk at 19:40]**

**Interviewer:** No, you’re fine.

**Interviewee:** So it’s not like … **[to her dog]** Oooh, you’re drooly. Sorry.

**Interviewer:** It’s OK. No worries.

**Interviewee:** Ughhh…He’s old **[her dog]** so he doesn’t have two of his front teeth. So he drools … poor guy…so it smells like … fine, so they’re drinking out of the tree. The … so, let’s see, let me go through, I had physical therapy for low motor tone in his back, because, you know, your mom can’t do everything for you. And sometimes, you know, you can’t be a prophet in your own land. So we did physical therapy for low tone, motor coordination. He kind of … you know, he’s really good with fine … He loves Legos. And so that really helps him. But he had writing issues, so we did a lot of clay therapy. We did that with the OT as well. He had speech language in school and privately, the physical therapies, we’ve had counselling once we hit middle school we had and then anything outside that I could find, you know, social groups and stuff. And in Spokane, it just didn’t have them and that’s why I took my physiology research, *‘How Does Your Engine Run’* and stuff and that’s kind of what I started there. So that’s kind of what I do … trying to fill that gap. But let’s see … so, the fitness, OT, PT, speech therapy … We’re working on finding a new counsellor now because the Covid and we had some other things. We’ve lost some people another one this week to Covid. And so we need to … and he asks, he says, you know, “*I need someone I know*.*”* Joe —that was his favorite therapist, his name was Katy Joe. “*I need another Katy Joe*.” So we’re working on finding him another Katy Joe. But …

**Interviewer:** Well, it’s wonderful that he knows how to ask for that. That’s a really hard thing for a lot of people to do.

**Interviewee:** Right. But it’s … you know, it’ll take a lot of work. So it would be nice if they had, **[22:00]** like, best practices for parents and kids with autism. I mean, I feel like I spend a lot of time talking to other parents about “*OK, try this, try that*,” you know … Oh and a professional organizer, we tried a professional organizer and it helped for a while and at puberty it all went out the window. So, but we’re working on that. He’s actually starting to move into to being a little better organized. This just started in the last two weeks, so.

**Interviewer:** Wonderful. **[crosstalk at 22:33]** That’s great. And for all of these, like, therapies, interventions, that we’re focusing on, his sensory things, do you think that helped him?

**Interviewee:** Yes, I think Carter knows what his executive functioning strengths and weaknesses are, too. And I think altogether that he’s being able to leverage those better for sensory stuff for advocating. So I think … He’s just back on my knee, so … **[referring to her dog]**

**Interviewer:** No, no. You’re good. And then, when Carter is faced with a sensory scenario that’s aversive to him, does that cause or increase anxiety?

**Interviewee:** Yes.

**Interviewer:** How so?

**Interviewee:** He … the feeling inside … he … that just jacks his anxiety up. You’ll know, you’ll see the pacing. I know the pacing comes out a bit when he’s working on something or something’s making him feel bad. Or you start doing the tics, you’ll start doing, you know, like this **[tapping at 23:35]** or needing a fidget tool, a squeezy ball, or … that’s when we’ll say, “*Hey*,” you know, “*do you need … where’s your engine at?*” And anxiety, it’s usually over … and that, for him, his anxiety comes out as twitchy and … although sometimes he … there are … so, during middle school, when he was bullied … middle school and high school he was bullied really bad, such that we are about to take them to court. And, based on … the state ombudsman was involved, and she said, “*You know what, this school has been sued before for this and they didn’t learn. And I … you know, I can’t tell you to sue them, but I can say, I think you’re at a point you might should consider it*.” So anyway, when he was depressed, he would be at the lower end and the anxiety would come with the depression. So it was like a sluggish twitchy. Does that make sense? And so we haven’t revisited that, thank goodness. But it would come out really for the anxiety and he would say … get snappish and irritable. “*OK. What’s going on? Tell me about what’s going on.*” Yeah. **[25:00]** I think with that … with … when high school … with the bullying came the suicidal ideation and I really think that it came from students telling him things about him, you know, “*You’d be better off dead*,” that kind of thing, which was said to him. And part of the problem for us was the bullying started with a teacher and so respected adult and he is a boy scout. So he will do whatever that adult says and yeah so. So that anxiety and he’ll start to rock a little bit. It’s more of a pacing, he’ll pace back and forth, he’ll avoid … he does have visual defensiveness quite severely. That’s what else we did for him: we put him in theater, a special theater class for helping people do public speaking, so that helped him with the visual defensiveness, but he still has it. And when he’s anxious, it’s really high.

**Interviewer:** And what would you say ‘visual defensiveness,’ do you mean avoiding eye contact? What do you mean by that?

**Interviewee:** So, he’ll look at you and it’s like and he’ll go like that. And he’ll look at your lips, he won’t look at you right in the eye. Because it’s almost like too much. He said it’s almost like too much information. He’s very empathetic. And he says that … that’s how he described it. He’s like, “*It’s like too much information, Mom* *there, I can feel*”—he’s so very empathetic—“*feel what they feel and it hurts sometimes*.” So to the point of pain, so he doesn’t … he’ll do this, you know, he’ll look everywhere but your eyes so … you train them to look above the eyebrows so it still looks like they’re looking, you know, but … I think sometimes that interferes with being able to read facial cues because you can’t, you know … he’s not focusing on the rest of their face. He’s like, “*Gosh, that hurts inside.*” So, but he’s a lot better at it. But I forgot that we had done that.

**Interviewer:** And when he does have this kind of, like, sensory-related anxiety, does he use exercise in those similar techniques to kind of help bring his engine back to neutral?

**Interviewee:** Yes. If … you know, and sometimes that doesn’t work and that’s when we get to the counsellor. And I think that’s kind of where we’re at right now with Covid and the pressure of school coming up again. And he had an apprenticeship at Lockheed Martin. And so he … so how it works is you … they train you … each week, you learn, like, three or four new tasks and then at the end of the week, they train you or they test you and if you’re at 90%, or above you move on and if you’re at 89 or below, you wash out. And he washed out in the fourth round. And he’s … they asked him to come back, to sign up again and come back and so he’s got a little **[28:00]** soldering iron because he … It’s fine motor work under a microscope. He’s working on computer chips. And I can’t … the … I don’t know anything else because it’s Department of Defense stuff, right. So he’s been practicing and he’s struggling with the decision. “*I think I can only do school or work. I don’t think I’m strong enough, organized enough to do both*.” So he’s having to make a decision. And so I’m pushing school. So, yeah.

**Interviewer:** Got you. And then thinking back to his anxiety related to …

**Interviewee: [crosstalk at 28:38]** I’m sorry …

**Interviewer:** No, no, you’re fine. Don’t **[crosstalk at 28:40]** … It’s all good information. This is qualitative data. It’s OK. Don’t worry. I’ll just ask my questions and we’ll go back. Thinking about his sensory related anxiety: has that changed over time as well or is that pretty constant?

**Interviewee:** I think it’s changed. I think he has a better handle on what it is. He can name it. Whereas, when he was younger, he could not name it, right. He didn’t have the words or … the words for emotion or just the words to say, “*I’m not feeling right inside*” and being able to say what it was coming from, and I think now he does, he can say, “*No, I don’t like that*.” And I think that’s where he’s going with Lockheed Martin. He can’t use all of his strategies in an environment like that because it’s closed. And so chewing gum, you would … we would load him up with chewing gum and hard candy. You know, getting that sensory in through the mouth. So anyway, OK.

**Interviewer:** Thank you. Don’t worry about tangents. They’re totally OK. I can **[crosstalk at 29:49]** I can move us back. Don’t worry about … That’s my job, not your job. So then thinking a little bit more broadly and globally, what goals or host you have for your son in terms of his sensory sensitivities. towards the future?

**Interviewee:** In terms of sensory, I’m really proud of him with the eating, because that’s been a big challenge our whole life, right, our whole life with Carter eating’s been a challenge. And so I think … and being able to fit into a workplace as quirky, having people accept him as quirky. Like, Lockheed because they have an autism program … he wasn’t in it, but they have an environment that is supportive. And so I am afraid, when he moves on … because he wants to go work for NASA, that’s his dream. And I want him to have his dream. But I also see some things about his dream that might be a little impossible, like, the Jet Propulsion Lab is in Pasadena, California. And he doesn’t like crowds. Like, oh, **[31:00]** that’s, like, a really crowded compact place, you know, but, you know, you have control, I think, having to let go. I think it’s … I think I’m … it’s easier for me than for his dad. His dad sometimes sees him as that younger kid and is trying to protect him from other people, right. “*Oh, I can’t do that. Other people* …” like, you know, it’s other people that need to start to change. So, but I think for that, I think sensory wise, that he can manage his own … that he knows … he can recognize a situation that he’s going to go into, where he may need to make sure he has a hat, sunglasses, and I think this is the one we’re still kind of working on … The glasses he gets, but, like, noise, like, if he mows the lawn, he’ll come in and out a hundred times, right. I got my water up, ope, I forgot the earplugs, ope I forgot the hat, oops … You know, getting him so that he’s all … thinking ahead towards what he needs. Or about what situation he could face, I think that’s the work that we’re working on now, to be prepared, but not like a prepper or anything. You know, just, you know, we have the bag that we pack for when we go hiking. And, you know, it has water … refilling the bag, so we don’t, you know, that kind of thing. Just being prepared.

**Interviewer:** Yeah, like, planning for his needs, that kind of thing.

**Interviewee:** Right. And I think … concerned about when we’re not here, right. And as he ages, are these sensories going to come back? You know, can they? You hear about that … people regressing, right. And does the regression include sensitivities, is it …? I don’t know. I haven’t even had time to look at that, but it’s in the back of my mind. So, because I really want them to be able to live independently and manage. I know that he wants to so and I think he has the chops to do it. So, it’s going to be training him to recognize when people are taking advantage of him so he’s not constantly taken advantage of.

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

**Interviewee:** You’re welcome.

**Interviewer:** We’re going to go on to our next chunk of questions, if that’s OK with you. As Carter has grown up and aged a bit, how has his and your community reacted to his sensory needs?

**Interviewee:** I think … we had to change communities. I think, **[34:00]** when we started that, we got him into a special program called APPLE (alternative parent participatory learning experience). And I love that mostly—because there’s never anything perfect, right, not for any kid, neurotypical or not. And so we’re … we had to do 90 hours of volunteering and we were allowed into the classroom, we could inform the curriculum. And so, you know, we all called the teachers by their first names and you had the same teachers, so we had some … we made sure there were places that were supportive for him. And it was a lottery system. So, you know, it’s not … I think, just in general, the neurotypical kids did better too, that that’s a better model than the traditional model. But it, you know, takes a lot more energy that parents are required to donate 90 hours, right, and be in the classroom. So … and then we found a similar middle school, they didn’t have a program like that. There was one starting, we tried it, it had the horrible teacher in it, the first horrible teacher. Then we switched to a school called Tech, which is K through 12. And again, we have more hands on … so that kind of environment works better. I think in terms of family, everybody’s been really, for the most part supportive. They don’t always understand about the engine talk really. I think that’s more of a … they’re disinterested, it seems too easy. Sometimes it feels like people want it to be complex so they can say, “*Look, what I did*,” you know. Like, really, it’s just a matter of, “*Hey*,” you know, “*you’re stomping a little bit, go take some extra stairs or something*.” But, for the most part, everyone’s been really supportive. I think the neighborhood kids growing up were not and so that was hard, finding playmates and kids who could work around the quirkiness. So that was harder. And so he was lonely, especially in high school, he was lonely. And I think that that isolation, that’s one of the things that I’m working on with him. So I’m peer certified, I just picked up that certification this year. I don’t know if you’re familiar with peers. And I work with … I collaborate with the Bully Recovery Resource Center in Colorado, which is excellent, and running some bullying boot camps, that’s what we’re working on now. So, but yeah, those are kind of … Yeah, **[37:00]** I don’t even remember the question, but honestly **[inaudible crosstalk at 37:05]**

**Interviewer:** You did great. You answered another question, actually. Well, in your … so great, thank you. Would you say that his and your community was more accepting when he was younger or less accepting?

**Interviewee:** I would say less accepting.

**Interviewer:** Yeah? How so?

**Interviewee:** I think it took a lot of the … well, parents were just like, “*He’s acting like that because he’s spoiled*” or “*he’s acting like that* …” They didn’t understand what autism … they have a preconceived idea of what autism looks like and expect you to … and even as a parent there, it was very cliquish. And I know the other moms feel this way too—if your kid isn’t just right you’re not in the cool moms’ club. Or you’re kind of an outsider. And I even had one mom … we had something happen in the classroom with Carter. And, but it was unexpected touch and he bit her. It was first grade, they took away his field trip for it. And even though I said, “*Hey, she shouldn’t have been next to him or touching him anyway*,” they put it on the kid, not the adult. And I have … you know, that’s a soapbox of mine, you know, you don’t deflect from what the staff should be doing. Anyway, see, I get my hackles up. I still think about that and I get mad about it. And she, on the phone, told me, “*Well, for kids and parents like you*.” So … and in the autism community and in the sensory community, we get a lot of that, the parents do. And so, you know, it’s hard to be seen as something we don’t feel we are and then not seen at all for the things we want to be seen for, so, I think that that sucks.

**Interviewer: [crosstalk at 38:58]** Thank you for sharing that. Sorry?

**Interviewee:** We still remember her name. I’m like, “*Ugh*.”

**Interviewer:** Got you. Thank you. And were specific aspects of the community, like, certain spaces or places, were certain ones more or less accepting of him and his needs?

**Interviewee:** Outdoor stuff. So we … because I’ve worked in extension, like we were in 4H and, you know, and they’re so blind there, though, I don’t know, necessarily … I was the director, so the director’s kids, do you know what I mean? So, I think there might have been a little bit of that. But for the most part, they … we did lots of outdoor stuff.

**Interviewer:** And they were accepting?

**Interviewee:** And those kids who liked outdoor stuff, they were like, “*Oh, yeah, I’ll climb the rock that way*,” you know, not recognizing that **[40:00]** it was a quirky thing, you know, like, “*Can I climb up this rock backwards?*” That was a big thing for our kids for a while they were going up things backwards. Carter started it and everybody kind of followed, so. And I think that was the place where he could be a leader, where it was outdoor stuff, which was … in indoor, there’s more prescribed, right. Usually they’re playing board games and it’s prescribed. So there wasn’t a lot of that. And once he starts a board game with the other kids, you know, it’s more … he’s more rigid about the rules. So but in outdoor activities, so we did a lot. We were part of the rocket club, we … you know, 4H, survival club, military kids. And anything that they were just interested in—we tried to follow their strengths. So, like, Carter, he’s a stargazer, he loves astronomy and so we’ve always had telescopes around. And Legos, lots of Legos, that will be the indoor thing. But again, the Lego … he has to follow the manual. He’s not a … he considers himself a Lego doc, but not a Lego master. So, but I’m trying to think … what other places with, you know, with family, it felt more comfortable because with the kids in the other family, you know, the other kids were kind of mean to him. He’s like “***[throat clearing******noise]***,” you know, nobody’s butt’s sacred in family. And … but … and just regular, like, birthday parties and things, he started getting not invited at about second and third grade and had a really bad experience with his best friend at the end of second grade, who told him, “*People only like you because the teacher makes them*.” And I hate that kid and his mom was a teacher. I shouldn’t say, that’s not fair. I don’t guess I hate that kid. I really dislike that kid.

**Interviewer:** You can hate where he’s at.

**Interviewee:** Carter still has the picture he drew him. He still has it from first grade. That was his best friend, right. So things like that. And then so … and then having the teacher say, “*Oh, he has lots of friends. The kids are concerned about him*.” And I said, “*No, there’s a difference between* …” and—having to teach the teacher—“*there’s a difference between friendly and friends*.” And so yep, they’re friendly towards him, they all want him to do good … that the kids don’t … I wouldn’t say … there’s a couple that were malicious, that … they would get him to do things, trick him into doing things, like touching a girl’s breast in sixth grade. That was horrible. Anyway, but the principal, you know, you have to have a good relationship with your **[43:00]** teachers and principals. And the principal, she was … knew right away what was going on and she’s like, “*Oh no*,” she was, “*I’ve got this*.” And then … but then it still made Carter feel really bad because that’s that knowing what’s right and what’s wrong, right, and being tricked into it and laughing, thinking they’re laughing with him, but they were laughing at him. And that left some real, you know, not so good feelings for those kids. And there was nothing I could do really, other than complain to the principal. But, like, if that was in a family environment, you bet I could get after those kids. You know, “*I’m going to talk to your parents*.” Yeah. So anyway.

**Interviewer:** Yeah. I’m sorry that happened. Thinking again a little bit towards the future and a little bit more broadly again—what hopes or worries do you have for your son in terms of his sensory sensitivities, but also about the community that he’ll be involved with?

**Interviewee:** I’m afraid of reactions, like, he’ll be judged based on an aversive reaction he has. Like, you know, they talk about first impressions and everyone’s trying to say first impressions aren’t important. They shouldn’t be important. Now, I taught my kids they shouldn’t be important, what’s important is the content of someone’s character, but however that is not how it works when you hit the ground. And when you hit the ground, when you’re there, if you give someone and, like … and I … we go through examples of things they’ve seen, how they’ve judged someone else and then turned around later and found out “*Hey, I was wrong*,” right, or use movies to teach that. But I think that’s what I’m worried about, like, especially in a work setting, because that’ll prevent him from progressing towards what his dreams are, his goals are, I think or, you know, in a dating setting. I mean Carter has a girlfriend, but it’s very platonic and it’s more because … in high school, she’s also has ASD and reached … they were in a group together and they just filled that hole of loneliness for one another. They don’t really have anything in common. Like, he’ll … I laugh because I’ll say, “*So, Carter, what classes is she taking in school?*” “*Oh, I don’t know*.” “*What … did she decide on a major?*” “*Oh, I don’t know*.” “*Well what do you do?*” “*Well, what do you do?*” “*We play games*.” They play games. So it’s very … I think Jazz wants to do all the hand holding and stuff, but Carter’s more aversive to that, you know, but it’s fun to say “*I have a girlfriend*,” right? And she is … she’s a girlfriend and she’s a very sweet girl. She has a lot more physiological autism issues, **[46:00]** as well as she has celiac. She can’t do … she has gluten pills she has to take with her, in case she is accidentally exposed. So but and so he’s … you know, so he has that but as that becomes more serious, I’m wondering how that’s going to work developmentally. And what if it all starts to happen when he’s somewhere else? Like, if he makes it to NASA and … I shouldn’t say if—when he … because yes, he can … when he makes it to NASA, this is a concern that I have that. And maybe driving. I think right now the one that provides me with anxiety is the driving, especially … I don’t know if you know Matthew Russian’s story? That terrifies me. And Matthew Russian, he just got a pardon, but he is a young, black, autistic man was in a car accident. His anxiety was high. The guy was swearing. He picked up what the guy was saying and did the echolalia thing and the police used that as an excuse to imprison him. It was horrible. It’s been terrible. And I think, oh my gosh, what if he’s in a situation that he can’t handle and that involves police, especially here in Colorado. And where we’re at the police are a little scary, a little aggressive—little … they’re scary. And trying to educate them hasn’t gone the road that I would like it to. So they’re not very open to science here where we’re at in Colorado or anything that’s not … it does have definitely the feel of might is right here where we’re at.

**Interviewer:** That’s hard.

**Interviewee:** Yeah, we’re on our way out of here. But I think those are the things that I’m most scared of. And not that I don’t think he can’t drive. I think he’ll be a really good driver. I’m afraid that when he does do something wrong, he’ll do a “***[startled noise]***,” you know, “*I did something. How do I manage it?*” That’s when the anxiety comes. And then the problem solving maybe isn’t the best when that happens. But yeah, so driving, girls and work relationships, I think.

**Interviewer:** Yeah, fair. Thank you. And now, thinking about his transition to adulthood—where do you see him in that?

**Interviewee:** I think I see him wanting more independence. He wants to drive. He wants the job, but not necessarily willing to do all of the **[49:00]** work it takes to get one on your own. He has a … we use the workforce center here. He has a workforce counsellor who checks in with him every other week on jobs. And he’s had two interviews.

**Interviewer:** That’s good, though.

**Interviewee:** Yes. And it’s funny because he’s already had the professional job with Lockheed, right, but he didn’t have to go through a job interview for that, per se. He went through a performance-based interview for that because they’re … they want people who are good with their hands, which he is, right. And the interviewer asked him a question and he didn’t know the answer. So he says, “*Yeah, I got nothing*.” That’s the best. And so and then they … he had an interview. He wants to do stockroom because he doesn’t necessarily want to be with people and they didn’t call back. Neither … the one gave him the thanks, but no thanks, but Lowe’s hasn’t called back and Lowe’s supposed to do … be … have an inclusive kind of a thing, but … so I don’t know. And I don’t know, because the second wave of Covid shutdowns came, so I don’t know. You’d think they would at least have called or communicated and they haven’t. So he’s feeling a little … So, one of the things we were doing is we were looking for things that he could do on the internet. And so that’s one of the things that … like, I told him, “*I’m doing this research thing and some of them have incentives, so you should be looking*.” So that’s what he’s been looking for right now.

**Interviewer:** A lot … I mean, I did a lot of studies in college because it paid enough money to suit my college needs … incentive, so people do it.

**Interviewee:** Yeah. So that’s where we started directing him. That’s happening this week. And because he did the questionnaire with me last night. I said, “*OK, you can have my gift card that comes with this*.” I think you said that or …

**Interviewer:** Yeah, there is a gift card.

**Interviewee:** OK, so then I told him, he could have that. If I did it, I said, I … “*You know, it depends on my performance report for you, Carter*.” So, you know, so, anyway.

**Interviewer:** I promise you’ll get it.

**Interviewee:** OK. That’ll be happy. That’ll keep him out of my hair. “*Can I have this? Can I have this?*”

**Interviewer:** Yeah. So thinking about his skills, where are some things where he’s able to do things independently and what are some things where he needs some more support from you and your family?

**Interviewee:** I think he can do a lot of things independently. It’s a confidence issue. I think it’s also … “*If something goes wrong, I don’t know if I’ll do the right thing*,” even though we’ve told him what that right thing is, you know. So, it’s repetition. Like, in the kitchen, he’s finally starting to get more comfortable in the kitchen. He really wants to learn to cook and that … I **[52:00]** asked him actually, night before last, “*Would you like to take a cooking class?*” And he said, “*Oh, I would love that, Mom*.” Whereas, even three months ago, it would be, “*Are you kidding?*” “*Hey*,” you know, “*I’ll let you try out the recipes I want*” is kind of how it is—which that, you know, he does. He made steak with assistance, steak *au poivre* which he got from *Binging with Babish*, right. That was, like, a really fancy meal. We did that. As you know, that’s a … that took resources. Man, that was expensive. And so things like that, I think. I think it’s more about confidence than it is skills. He’s … that’s how he avoided the autism diagnosis until he was 17. I think we didn’t have … I don’t know, the right practitioner. They would say, “*Oh, he’s too smart. Oh, he’s too smart*.” And we kind of got that from the school. “*Yes, yes and no*.” “*You know, he presents classic*,” was what the speech therapist has said, “*I don’t understand*.” And I said, “*Well, we’ve been through this three times now*.” And then we went to the University of Washington, we drove and had it done there. And she was like, “*Oh, he made it through all the batteries and we didn’t think so, but then we did the face to face and it was like, that’s it*.” So because he’s … you know, so it was interesting, but … yeah, I think, skill wise … fear getting past the fear of sharp things. Like, I think that was … for the kitchen, the fear of sharp things. You know, “*I could cut myself. I could hurt myself. I don’t like going to the doctor*.” Or “*I’m not going to injure myself*.” It’s just in a … self- kind of prevention, but not the way you want it. So I think … yeah and, for the future, my fear would be that if I’m not around who would take … who would be patient enough to go through it with him? Even if he’s paying, like, you know … I think there’s definitely … there’s opportunities for businesses with our kids, but I don’t see anybody taking those steps. So I feel like I’m trying to fill that hole through parent support. And I can’t … when he moves on, I mean, I can’t fill that hole, right. So it’s letting go, it’s letting go.

**Interviewer:** Yeah. When he is able to get enough confidence or kind of get past some of his fear, is he able to prepare simple things for himself, like, in the kitchen kind of?

**Interviewee:** Yes. Oh, he cooks already. So, all the kids have to do at least one meal a week. And Brianna’s about to do her first meal **[55:00]** here. But he does macaroni and cheese. Let’s see … what else can Carter do? We’re working on enchiladas. We’ve … he doesn’t like chopping chicken. That texture thing. He doesn’t like the feel of cold wet meat.

**Interviewer:** It’s slimy.

**Interviewee:** Yep. It’s that slimy slick. But he’s learning to cut chicken. He’s learning to cut onion. So, he did the steak.

**Interviewer:** That’s advanced.

**Interviewee:** Yeah, so he … Oh and, you know, anything that can just go in the oven. He knows how to turn on the oven and shut the oven and that’s not … you know, if it takes less than three steps, it’s not really cooking. So, yeah, but no, he does a mac and cheese most often, but a stroganoff, hamburger stroganoff, he’ll do hamburger stroganoff, you know, things like that.

**Interviewer:** Is he able to … I mean, pre-Covid, is able to go shopping with you and, like, help buy the food that you need to prepare?

**Interviewee:** Oh, yes. He’ll make me lists. For hot chocolate. And he’ll make the hot chocolates on the stove. He’ll take the whipped cream and … “*Ghirardelli, Mom, you have to get Ghirardelli. Whole milk, Mom, it can’t be skim*.” Yeah, he knows his list. He knows the grocery store. Sometimes when he gets in the grocery store he gets a little overwhelmed. If there’s lots of people, he’ll kind of … but he knows what to do. He’ll divert himself to an area that’s quiet, look at his list, decide, make his plan. “*Where am I going to go?*” You know, kind of, you know … and I think we do it so routinely now we don’t realize we’re doing it. Does that make sense? Before it felt more intentional. Like, “*OK, we’re going to go through this. This is what you’re going to see*.” You know, with the social story, “*Here’s the pictures of what you’re going to see*.” And now we kind of … I almost feel like we skip that step. We go right to “*Uh, it’s crazy. What do I do?* Go over here to the pop section where there aren’t a lot of people and we take a couple deep breaths and we go, “*OK, we’re going to go tackle dairy first*.” And, you know, kind of like that.

**Interviewer:** That’s great. How is he with, like, taking care of himself and, like, the home and, like, laundry chores, physical hygiene?

**Interviewee:** Physical hygiene, I feel like that’s … with Covid it’s gotten kind of out of hand with all kids. So I can go to pre-Covid. He actually … I shouldn’t say that … he’s actually more aware of his body odor now. Whereas before, it felt like no and we were like, “*Please, please take a shower*.” And now it’s like, “*Can I take a shower, Mom? Can I take a shower?*” I think, for Carter … he’s always asking for permission to do things, like “*Just go do* **[58:00]** *it*.” But I’m not sure that’ll ever come while he’s living with me. And chores … most of the time we have to have the … we have a chore board. And I’ll … and I have an alarm on my phone. And so at four o’clock, I’ll say “*Hey, everybody*,” you know “*it’s time. Chore up*.” But he has things that he’s supposed to do without a reminder that sometimes he misses, like unloading the dishwasher. So—which just reminds me, I don’t think he unloaded it last night, so. But he wants to make hot cocoa, so that’s not going to happen unless he does that. So … Excuse me **[clears throat]**. So chores … that’s kind of how that goes and Covid’s kind of … with the personal care, you know, he’s making sure he’s taking a shower, but then he’s putting his pajamas back on. So, you know, things like that.

**Interviewer:** It’s hard for everyone right now, though, I think.

**Interviewee:** Yeah. Yeah, it is and, like, my daughter, you know, dressed just from the waist up. Really, you know, she wears her pajama bottoms or … “*Because I just have to look good from … you know, for Zoom, right? Can be comfortable*.” I’m guilty, too. Although today I’m … I’ve got to train an intern on physical stuff for **[inaudible at 59:28]** And it’s cold this morning. I think we’re going to get snow.

**Interviewer:** We got like a foot plus yesterday.

**Interviewee:** We got some two days ago and then it’s just been cold and … but it feels colder this morning and the storm glass had the crystals in it. So I think we’re going to get some stuff, some snow.

**Interviewer:** Totally. How is your son with, like, money management? I know you mentioned, like, on the form you said he has a small job. I know it’s not paid. But has he had jobs that paid him?

**Interviewee:** Well, Lockheed paid him, and they paid him well. So, he would like that again. And he does … for the most part, I think he understands that money has value. I don’t think he understands budgeting necessarily, because I feel like … or it might be that “*I want this so much, I’m going to ask for it. And I’m willing to hear, you know, ‘Money doesn’t grow on trees*.’” So, but he’s very … he wants his own money. And that’s … I think that’s the struggle between “*Do I go to work or do I go back to school? Because I know I’m not good at both. I can do one or the other, but not really both.*” And … although I see that changing. I think he could go full time work and maybe one class a **[1:01:00]** quarter or semester I think getting used to that idea first is what we have to prep him for. But, money wise, I sometimes feel like he understands that money … you know, that things cost money. I don’t think he always gets the budgeting thing, how much money, when you have all these other things. And then you have this much money left, you can’t just go get that thing. So I think that’s where we’re at with that. But we do, you know … and he was just talking about it the other day and there … he said it here, I can show you. I don’t know—are you guys familiar with cash flow, this game?

**Interviewer:** No.

**Interviewee:** It’s fabulous. In fact, I’m building a curriculum around it to help, but it’s called ‘cash flow.’ And it’s by Rich Dad. And with teaching him about investing, what passive income is, what cash flow is and so and he was wanting to play it the other day, that’s where he came up and said, “*Where is it?*” so … But I don’t necessarily … again, that whole budgeting piece, that with your daily budgeting, you know, this is really how much you get … because that’s kind of futuristic. You know, you have an opportunity to buy a home or do this, you know, what … these are your investment opportunities. And he gets investment, hey, I just don’t think he gets daily money management. And during Covid it’s kind of hard, so …

**Interviewer:** It is hard. And does he express interest in wanting to live on his own one day outside of your family home?

**Interviewee:** Yes, in his own spot, maybe a little bit unrealistically, you know. He’s going to have a plot of land somewhere by the Jet Propulsion library. I don’t know how **[01:03:00]** that’s going to happen. And he’s going to have his own lab, right, his own science lab. So, we’ll see how that goes. But yes, he … and I think he’ll get there. I just think that it’s not going to be on what society says is the right timeline. We don’t necessarily go with all of that stuff. So we’re more, like, you know what, you can stay home as long as you want because I enjoy having you home. As long as you’re taking out the trash, you don’t have a problem. You know, so.

**Interviewer:** Absolutely. And you mentioned he has a girlfriend How is he with managing his social life to some extent?

**Interviewee:** Oh, he’s doing really good with that. And actually we have a … we call it ‘the boys club,’ a group of kiddos we’ve been collecting and we just added a new kid last week. We saw the Nextdoor app, it was a mom, you know, my child has ASD and he was just bullied at school and so we reached out and grabbed him and pulled him in and they have a Discord. They communicate to each other on Discord and we the moms kind of set things up too. I think the moms are having … some of the moms are having a more challenge of it now that it’s moved to Discord. The kids moved it away for the moms, which, that’s good. Not all the moms feel that way, but that’s my job is to get them where they’re going, right. And they kids they do a Dungeons and Dragons.

**Interviewer:** That’s what my boyfriend does on Discord.

**Interviewee:** Yeah, they’re doing Dungeons and Dragons and Mark. So we have three of the kids who are in high school, are seniors. And two of the kids are first year to college and then there’s Carter, who’s second year to college, right? And so … and so far, it’s fabulous. I’m so excited. So, yeah, so they’re doing pretty good socially. So, girlfriend wise, Jess doesn’t do any of that Dungeons and Dragons. Carter’s hardcore into *Star Trek* and science right and astronomy, like, you know, there’s Jupiter and Saturn. The … I don’t know if you know this, but we’re going to be taking pictures and I’m to make cards, Jupiter and Saturn … the Star of Bethlehem the first time in 800 years, the alignment of Jupiter and Saturn in the night sky is on the 21st. And you have to … you’re in New York, aren’t you?

**Interviewer:** I’m in Boston.

**Interviewee:** Boston. So yeah, I don’t know … you’ll have to look and it might be cloudy. But it’s … you know, it hasn’t happened in 100 years. So it’s a big celestial thing. And so she could care less. “*Oh, that’s nice. Carter. Let’s play this game*.” So that’s kind of **[1:06:00]** that relationship. So I don’t think it’s going to stay. I think there’ll be … so, I think the other thing I asked him, “*Do you feel … you know, is it more romantic?*” And he says, “*Well, not really. It’s more* …” He’s really kind and polite, doesn’t want to hurt anybody’s feelings and doesn’t want to lose a friend. So like, “*Well, you know what? It’s working for you. Let’s cross that bridge when we come to it*.” So yeah. So that’s kind of how it works with girls right now. Although … we were in the car the other day, and some girls pulled up alongside us and they were trying to flirt with him. He was like **[makes a gesture?]** and then he laughed, you know, he was … Yeah, he didn’t know what to think of that and it was really funny. So that’s where we’re at.

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

**Interviewee:** Oh, yeah. I think so. I think he’s just slow to develop socially, you know. The good thing about Carter is that he does not succumb to peer pressure. He will stand his ground I feel like. He had this one uncle—he has—I’d say ‘have’ we haven’t seen Uncle Scott for a while because he’s in Spokane—would tease him, “*No, that bike’s orange*,” and it’s a blue bike. You know, just kind of things like that, you know, if Carter says it’s black, Uncle Scott’ll say it’s white, because he likes to see if he can. And he does it to all the kids, not just Carter. He’s like, “*No, it’s not, uncle Scott. What are you, blind?*” You know, that kind of a thing and so … whereas my middle kiddo, he would say, “*OK, sure. That bike’s blue*,” or “*that bike’s orange*,” and he would kind of … to fit in. Braden will change to fit in. Carter will not. So and still, maybe a little bit now to a degree, but he won’t. So he’ll stand his ground. So it’s pretty funny. They’re good to have them, you know, they’re polar opposites.

**Interviewer:** And what do you think will help your son move into adulthood more?

**Interviewee:** I think we need more services in the community like that. Like, again, you can’t be a prophet in your own land, we have all of these parents having to do everything for their kids. We need them helping us build the confidence or finding those gaps where “*I’m afraid of this*,” because maybe some unrealistic expectation that they have because they’ve seen on some game or, like, the knives thing, like, Carter has this whole knives thing. Like, “*Well, you know, if you’re not holding the sharp end, you’re good*.” You know, so I think we **[1:09:00]** need to do a lot more advocacy on neurotypical people. I don’t think that the burden should be on the autistic child to be something they’re not to fit in. And that’s so much more work. When … you can see it when you really work with all the kids at once. They’re accepting. And it’s not, you know … they’re following the example of their parents. And so I think that I … like, I don’t necessarily believe in autism awareness, I believe in autism acceptance. I think awareness is good, but I want acceptance. So I’m, like … I need more than, I want more than just opening the door. I want people to go through it. So and I think that resources that help us and the autistic kids get through that door. I also think that the neurotypical people need, you know, more education on that. I think … so and that takes a lot of work. I mean, that’s a culture change. And we’ll be doing that forever. But I think that’s … services like that, I think, you know, we don’t necessarily need a cure for autism. But I think … and I have this debate with one of my other friends who has autistic kids, but who is also autistic himself. And he’s hardcore against, you know—what is the bad one? Autism Speaks, I say ‘the bad one’: Autism Speaks. At some point, though, his experience with autism is different than another parent’s autistic … someone who has really severe autism. They need different resources than you do. It has to be a balance between needs, but that still allows dignity and respect for each one. And I think that there’s a lot of people in the autism community polarizing that, trying to polarize. And, like, we’re not going to get …. so here’s someone that works in policy, so I do a lot of health care policy and research … we’re never going to get where we need to go if we’re polarizing things. So we’re never going to get everyone through that door and through the door together if we aren’t working on that. So I think that, you know, we have to work with them, we can’t be against them. And we have to respect every view along that treatment spectrum. I myself don’t believe … I shouldn’t say ‘I don’t believe in ABA.’ I believe there are inappropriate uses and appropriate uses of ABA. So, I don’t want my kid running into the street. **[1:12:00]** If you think of it from … OK, he’ll get a squat on the butt for that when he was little right. That’s kind of ABA-ish. You know, go on street, get slapped. So, you know, get a spanking, I shouldn’t say ‘slap,’ but, you know … and I just had to threaten it, with my kids, I just have to threaten things. And they’re really pretty good—except for him, you know, he’s a little harder. But I think that that’s important, making it balanced. And maybe it’s spoken like a true extension specialist, you have to have both sides and then they have to be … they have to make their own decision. So, but … and for me, personally, you know, I didn’t use ABA on my kids. You know, I do everything I can through the physical and mental realm, you know, a nutrition realm. And then just advocate, advocate, advocate. I think something that would be helpful is how do you prepare people to be receptive to a message? I think that … and that’s on both sides, I think we do that naturally, as parents for our kids like, “*OK, we got to get him to understand this. How are we going to prep him?*” We need to do that for researchers and for neurotypicals and for doctors. Doctors—that’s something we need. Doctors need to be better educated, especially psychologists, in treating kids that have co-occurring conditions. Really ADHD and anxiety and ASD together, like, that’s what we can have with Carter and depression. It took forever to get a doc. You know, I had to vet quite a few before I found someone comfortable. Now I kind of feel like we’re in that boat again, here in Colorado, though Dr. Nelson, so far she’s pretty open to everything. So that’s not common right off the get-go. So … but anyway, so there you have it. I’ll leave it on that one. I could go on forever.

**Interviewer:** That’s OK. No worries. Are there specific interventions that you think would help your son navigate adulthood though? That was a lot of, like, system things that you would want to be better.

**Interviewee:** So things … resources for Carter that he can find?

**Interviewer:** Yeah. Or just like, what do you think will help him move into adulthood, move into the place where he wants to be, like, with his dream job and NASA living independently, like, what will get him to his goals in your mind?

**Interviewee:** I think part of what’s preventing him from those goals right now is it’s the money to pay for those resources that you can … Like, right now, some of those transitional programs, they’re **[1:15:00]** $45,000 and they want you to send your kid away. He should be able to learn that stuff and still live wherever he wants to live, right? There should be … I think there aren’t affordable services for those constructs aren’t in the community. I think insurance … for kids with ASD, they go after age seven and then again at age 12, they cut them off. It doesn’t heal itself, the autism, the need for resources is still there. So I think the insurance world needs to understand that better, particularly around mental health. They need those … I think a lot of it is conditioned. The kids, the teachers, the professionals, even parents, we treat them a different way than we treat our neurotypical kids. Like, they can’t do it without help. So they grow up believing they can’t without help. And we’ve got to change that. And I’m not sure what resources … if that’s giving them an independent, like, a big brother, big sister, you know how they had troubled kids and they have a big brother, big sister, like a mentor. I think a peer mentor program would be really good for kids with ASD. And it would be a successful ASD kid, it would be an ASD to ASD, not … And then it could be whatever resource that peer … the mentor needs from if they need a neurotypical person. But I think a peer-to-peer mentoring program could say, “*Hey, here’s how you handle the doctor, did you want me to go with you?*” Or, “*Here’s a list of four things to ask your doctor when you go. This was my experience*.” And because that peer to peer is so powerful. So I think a peer-to-peer mentor program would be awesome. But, you know, I think of great ideas all the time. But again, it comes down to who’s willing to put the investment into those resources. Yeah. So I think the money thing, I actually am working with ENT credit union to build a ASD “*How do we use the bank?*” that kind of a thing, because I noticed when he got his first bank account, he didn’t know how to access it. He didn’t know how to use the machine. He didn’t know how to talk to the teller. It’s more than adding and subtracting. So, working on that, hopefully, that’ll launch in Jan. Not January, July.

**Interviewer:** That’s exciting, though.

**Interviewee:** Yeah. So anyway, things like that. They’re practical, the practical things, so, that we take for granted.

**Interviewer:** Absolutely. **[1:18:00]** And now putting these two things together—his transition to adulthood, and his sensory sensitivities—how do they intersect for Carter?

**Interviewee:** I think some of the sensory stuff prevents him from transitioning because he’s afraid of it. Does that make sense? He’s afraid of having that sensory experience. Therefore, “*I’m going to ask mom and dad to do that or I’m just going to avoid doing it. But I need that eventually, but I’m not sure how I’m going to get it*” and then that kind of delays things. So I think that’s how they intersect, for Carter anyway. “*I think I’m going avoid this because I don’t like the way it feels*.” Either it’s sensory … you know, I don’t know if that’s inside sensory or outside **[inaudible at 1:19:00]**. “*I just don’t like the way it feels*.” So, yeah, I think …. that one’s more … I need to process that one a little longer. I need to think about that one a little longer.

**Interviewer:** OK, I have a couple of follow up questions. So hopefully, they’ll kind of jog some thoughts and it’s OK if they don’t. Would you say his sensory sensitivities are an obstacle, a vehicle, neither or a bit of both towards his independence?

**Interviewee:** I think a bit of both. Yeah. And then ... I’m going to … just one sec, I’ve got to wake Brianna up for school.

**Interviewer:** Sure. Do you want me to pause? I’ll pause so you can come back whenever you want.

**Interviewee:** Just one sec.

**Interviewer:** No worries. this is going a little bit longer than we had planned. I have a few more questions. **[crosstalk at 1:19:45]** No, no, it’s, it’s wonderful. Just I was going to say if you need to go, we can find another time to finish up. We can continue now. Whatever is good for you. I don’t want to mess up your very busy day. So you tell me and we’ll just …

**Interviewee:** Let’s keep going. Check one thing on the **[inaudible at 1:20:07]** computer and just make sure—deliveries, we’re all doing deliveries today. No, I’ve been calling everybody. OK, no, we’re good. OK. We don’t have to call everybody, we can just drop it off their porch. I’m not going to do that. I’ll call them. It’s a chance to give them a little bit of socialization because they’re all closed off.

**Interviewer:** Yeah, indeed. Well, thank you. We should hopefully … we’re almost … we got through the big questions, hopefully it won’t be too much longer. You just said that you think Carter’s sensitivities are an obstacle and a vehicle towards his independence? Why do you think they’re both?

**Interviewee:** I think that the obstacle’s that intersectionality, the avoidance, but I also think when Carter gets … like, with cooking, when he decides, **[1:21:00]** “*OK, I want to do this and I can’t because this is in my way, so I need to figure out how to navigate it*,” so it’s kind of a motivational thing for him. And I’m seeing that with the texture and the taste. I’m starting to get pressure from him for the driving. It’s a little it’s more of “*I think I want that. I think I want that*.” So I think it’s the recognition that it is in his way. And then when he recognizes that, then he uses it as a lever to get moving on it. Does that make sense?

**Interviewer:** Yes, that makes perfect sense. Thank you.

**Interviewee:** I think that’s how it’s both.

**Interviewer:** Yeah, absolutely. Thank you. And then, very similarly, but what do you anticipate as being challenging for him, as he does gain more independence in relation to his sensory sensitivities?

**Interviewee:** I think … say that one more time for me.

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

**Interviewee:** I think … this is going to sound kind of funny, helping other people let go of him. His family has been supporting him to say, “*No, I’ve got this*.”

**Interviewer:** Yeah, no, that makes total sense.

**Interviewee:** Carter is so polite, and he won’t want to make waves. So—and I’ve already seen him do this—he will let the person help him, then they’ll go away, then he’ll do it the way he wants it done, rather than making them feel bad about helping him. So I think that that might be about to get in his way. I think I can see that in the future getting in his way in a work setting, right, like, you know, “*No, you need to show them the right way to do it*,” right, “*because you’re in a work setting*.” So I think that … I anticipate that because he is very, very kind and very, very sweet. And so helping other people let go … he’s not, you know, he’s very sentimental. And—let’s see, how else, what else do I anticipate? I think sometimes … I think what **[inaudible at 1:23:53]** that he may need help with … sometimes he generates too many options. **[1:24:00]** Helping prioritize the options, helping him prioritize … which one’s going to work the best for him. Does that make sense? I think that … I just … thinking ahead to him gaining his own independence that instead of … because he would list all of the options and then he would try to do every single one. And I think recognizing, picking out the ones that are most likely, I think that that would be, that would be in that box. Probably those.

**Interviewer:** And then, what do you think could help your son in this intersection?

**Interviewee:** Oh gosh … tips on how to do that, right. The how to, like, you know, you always see problem solving tips. You know, here, you know, ‘the top three things to solving a problem.’ But those aren’t always helpful. He needs examples and models. So, like, “*When you get this big list of things, you’ve created your list. Which ones on your list do you look like you want to try, which ones on your list?*” So … and sometimes the most unrealistic thing is on there for want to try. OK, “*So what resources do you have to try any of those, right?*” Because a lot of times he’ll go to that, “*Oh, yeah*,” the pie in the sky one. And so I think the model of it, that they need that conceptual framework. They need … he needs I say ‘they’ because I’m thinking of the boys’ group. That … and it seems to be … I do more work with boys than girls, but I do work with girls too. And I see that … but I see it more in the boys. The girls kind of seem … some of that seems to flow a little easier for them. Not that it’s not challenging, just that they seem to get easier. Oh, “*I have*,” you know, “*I have scissors and a hairbrush so I can cut my hair*.” Versus, the boys are like, “*Well, I have to have a razor and I have to have dum dum dum, but I don’t have all that stuff*.” Instead of “*Hey, it’s just scissors*.” You know, so that kind of a thing. But they need the models, I think.

**Interviewer:** Absolutely. Other than models, do you think there are any specific services or interventions that could continue to help him in terms of, like, sensory in his transition?

**Interviewee:** Yeah, well, I think … you know, this is going to sound funny. Maybe it doesn’t. Well, we’ve used fitness for so long and there isn’t anything specific in the community. I mean, Dave Jeslack and me and another couple of other guys in Seattle. I mean, we’re rare. **[1:27:00]** And building specific programs designed for them as adults that they like and I’m thinking in the higher functioning—I hate that term—low support needs side of the house, because it’s not likely that someone with high support needs that … they’re still going to be with their OT and their PT, right, and these kiddos they can access insurance for that or these adults. But what they’re getting at the gym isn’t, you know, it doesn’t feel good, it doesn’t feel right. So I think programs around that. And the practical things that we take for granted, those are the things that they get hung up on. “*Well, how do I use the bank?*” You know, “*I don’t know. How do I talk to a teller? How do I interact at the grocery store? How do I use that touchpad?*” And although they’re through that, they’re digital natives most of them now. For other adults, no, I think … what other? Career readiness stuff. You know, everybody is focusing on the job application blah, blah, blah, blah, blah, how to … but they’re not doing: “*How do you look for a job? How do I do a Google search for a job? How do I know what I’m really interested in?*” I don’t know if you’re familiar with Barb Bissonnette’s work. She’s got some really good stuff out and I built my career readiness curriculum off of her stuff. But, like, with Carter, I didn’t even realize that the application process, you know, it’s not about your resume and your cover letter. It’s, “*When they asked me this question on this electronic form. I don’t know how to answer that*.” So what those mean, like, ‘preferred time,’ “*Well, preferred time for what?*” Well, for the interview. They … he didn’t. And so I think we have to go back to the whole process, not just the pieces of the process we neurotypicals get hung up on. Yeah, they’re going to get hung up on those two, but they’re already, you know, he’s hung up on, “*How do I find the job? How do I get a soccer job? How … you know, and I Google it and 50 people come up. How do I know which person is credible?*” We ran into some of those for at home jobs, where you have to fill out a survey first before they’ll give you … and it’s all this personal information. It’s a scam, you know. And so that’s, “*How do we avoid scams when we’re looking for a job?*” Like, and actually one of the other moms … the knife people. What are those … **[1:30:00]** it’s a pyramid scheme.

**Interviewer:** Like Pampered Chef?

**Interviewee:** It’s not Pampered Chef. It’s, like, Jin Su. I’m ageing myself. Do you …

**Interviewer:** I don’t know that particular company, but I can admit I know pyramid schemes …

**Interviewee:** You go door to door selling knives, but you have to buy all of your knives from them first. And then you have to go door to door. And then, like, you know, “*Let’s think about this: door to door in a digital world right now and Covid world right now? That’s a scam*.” And they don’t, but they don’t have the history or the experience to recognize those. So giving them the questions, the critical thinking questions to ask, you know, “*Is this* ...,” you know, “*Do I have a person, an adult, I can show this to or a person I can vet this through?*” I think … and sources for vetting. If we had, like, an organization where, like … you know, like, a Consumer Reports for autistic kids.

**Interviewer:** Yeah, for sure.

**Interviewee:** A Yelp for autistics, or, you know … that’s in one spot, because Yelp is kind of intimidating to be on there. They navigate it. I’ve seen lots of my kiddos and my parents use it, but having, you know, they’re on, they have created Facebook groups and specific … to get, capture that information. So wouldn’t it be nice if we had it somewhere, like a grading system too, like, you know … or even a something that businesses could earn, like, an endorsement from, you know, Boston Mental Health, “*We endorse*,” you know, “*the Advocacy Network, because they offer these three things and so we know it’s a trusted place to go*.” So, I think things like that would be more practical, more beneficial. Those are the things you’re seeing in the chats, that I’m seeing in Facebook groups, you know, that we’re having to kill ourselves over to find. So it’d be nice not to have to … you know, to find that. Like, so I just saw one the other day “*Who has …?*” you know, for bowling, “*Who has … is there a sensory bowling league somewhere, where they are not so pressured to be fast?*” And, you know, so activities like that. So. Sorry, I get … more come as I think about it.

**Interviewer:** That’s OK. No, that’s great. So, given everything you just said, I think I know the answer to my next question. Do you feel like there are gaps in the available services and interventions for individuals like your son? Yes. OK.

**Interviewee:** Career readiness, **[inaudible at 1:32:54]** space and they’re all evidence based. I think for me and other parents. I like evidence-based stuff. I like … **[1:33:00]** I mean, I like to know and so I think we need evidence-based stuff. For autistics, like, the peers. And I know PEERS is doing a research on career readiness right now. But … and I’m watching that close because they’re missing that practical piece. The piece that they can’t do is getting on the computer and filling out the electronic form. It’s the application, not the cover letter or the resume. Anyway, so practical things that are evidence based. Yeah. Yeah, yeah, yeah, yeah.

**Interviewer:** Perfect. Thank you. And then again, thinking more broadly, more globally, how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him, as he has navigated adulthood or is beginning to navigate adulthood?

**Interviewee:** I think I’m hopeful because he’s aware of his own challenges. That we can have the conversations, that he can come to me and say, “*I’m frustrated about this*.” I think what I have anxiety about is I can’t always fix it, I can’t … I don’t have the resources. Or I don’t know … or I have to be the one to create the resource. I feel like we’re all creating an awful lot. It’d be nice to not have to create it. I do believe nothing about us **[sic at 1:34:35]** without us. And so that’s why the evidence based, I would really make sure that we’re involved in the creation of it. So, the anxiety is that we have to wait longer than we should for him to get where he’s going because the resource isn’t there for him to use. Does that make sense?

**Interviewer:** It does. And are these feelings related specifically to his sensory sensitivities or more just to, like, who he is?

**Interviewee:** Yes. This is going back to sensory. So, well … because I think if he had those resources, he’d be able to better manage his sensory issue or to better explain them and educate others about what they are. So that’s kind of how I connect it to this in a way. I think in general, the initial averse reaction that’s going to get in his way and he’s just going to have to troubleshoot that when it happens. But I think everybody has that every once in a while, even neurotypical people, you know, we always have … everybody does something that’s humiliation. There’s always a chapter that you don’t tell everybody about, right? So, but I think for Carter, he’s just going to have more of those because he’s so sensory averse. Like, the first time somebody at work comes up and pats him on the back, that’s going to be not such a **[1:36:00]** good thing. I don’t know how he’s going to manage that other than just grin and bear it or to go, “*Ugh, get away from me*.” You know, those are the things that … and I really … I don’t know how that’s going to go. I just know that if I’ve given him enough tools in his toolkit, he will be able to troubleshoot it once it happens. And so I think maybe that’s part of it, giving them evidence-based tools for their toolkit. So.

**Interviewer:** Thank you. We’re now down to our last chunk of questions. It’s the shortest one, we’re almost done.

**Interviewee:** Yay!

**Interviewer:** You’ve been wonderful.

**Interviewee:** Sorry.

**Interviewer:** No, no, please don’t be sorry. This is wonderful. I’m learning so much. I just hope your schedule isn’t too messed up now.

**Interviewee:** I just have to make sure she’s on at nine.

**Interviewer:** OK, perfect. We’re almost done, I promise. So finally, as a caregiver, as a parent, as a mom of someone with ASD and some sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** That he can live on his own independently if he chooses to. And that means being able to enter into contracts, like a rental agreement, and understand what they are, and to be able to advocate for himself when something’s wrong, to know who to go to when something’s wrong. Like, “*Is that … do I need to contact, like, an ACLU? Do I need to contact a police officer?*” Maybe that he’s handling school that he can go to school, that he could go and live in a dorm and manage the school environment, which I think we’ve got that. I think we’re at that. I think the problem’s that he wouldn’t know if he had a problem maybe not who to go to in that environment. But that means … that’s independence to me that if he chose to, he could be able to handle all of those things. Handling medical benefits, navigating a medical environment, I think that’s really important. Especially being able to advocate for yourself as someone with autism, because their health issues present themselves differently and doctors aren’t always familiar with that. So being informed about what your own needs are, I think that’s part of the independence piece. The car piece, transportation just in general. As long as he … you know, he uses the bus system, the train system now and he does it very well, he loves that kind of stuff, which is good. But, you know, if he’s at … were into a car accident, how does he handle the insurance company? How does he handle the other person, you know. Being able to have all of those skills to living truly independently. **[1:39:00]** And then the last part of independence for Carter is that he knows how to network and he knows how to use his network. And it’s more than just knowing people. It’s understanding that, in your network, you need some key people: like, you need someone for legal advice, you need someone to vent to, you need someone to hang out with and have fun with, someone who can be your confidant, right. So I think teaching him that that’s part of that independence, is that network. So, that’s what independence means for me.

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

**Interviewee:** Oh, yes. I think I add to it all the time. I’m thinking am I missing any pieces, you know? Because you want him to be able to go and soar, right. But then you’ll go, “*Someone else is doing that. Oh, I need to add that to the list*.” And then you come back and you look at the list and you’re like, “*Oh my gosh, nobody can do all this*.” And so, being realistic, I think, for me, from that realism side … Yeah, I think when he was little, there’s times when, like, when he couldn’t eat anything but one thing and nobody could touch him because he was so… And those growth spurts, those are awful. You were there to hug him or to ask, “*Can I hug you?*” But I had my doubts, right. And I think there’s still moments where I go, “*You are going to be at home forever*,” right, which I’m OK with, but I don’t think he is, right. So, you know, I think his dad’s afraid to let him out there because people will take advantage of him. I think dad’s got some work to do. But I think that is much better now. Like, when he was in grade school, I was really scared. And then the moms I talked to that are in grade school, they’re really scared. But, for Carter, things have improved. I know that’s not the case for everybody. So, but I have high hopes that he’s going to get there. I just don’t think he’s going to be there by 25. I think, you know, maybe more in his 30s. I could bewrong because, you know … because he wanted to take cooking lessons last night or the other night. That took me completely by surprise. So, which is “*I want to be independent. I don’t want to rely on you for my food anymore, Mom*.” That’s great. So.

**Interviewer:** Absolutely, it is **[1:42:00]** great. Great. So what do you see happening in your son’s future?

**Interviewee:** I think he’ll get there. I think … again, I think it’s not going to be by 25. I think maybe by 30. I think he’ll probably live with us through his college career. Although he talks about going to University of Arizona and getting an astronomy degree. He’s definitely thinking about being away from us. It’s because we’re noisy. Brandon and I, we’re noisy. The rest of them are quiet. I think … yeah, I think the sky’s the limit. He just … he needs to be able to recognize when someone’s taking advantage of him, you know, he needs to … So I think probably by 30. And I would be comfortable sending him to … you know, if he wants to go to Arizona, as long as I’ve gone and helped him connect to that network.

**Interviewer:** Yep. Absolutely.

**Interviewee:** Or he’s back with me with all my answers to all my questions. And that’s just how this works. And so I guess there’s a little bit of letting go in there for me too. But yeah, I think, no, I think in his 30s that he will be on his own but still connected, so perhaps it will be weekly or daily. It won’t be daily. It’ll be weekly. I can’t get him to talk to me daily now, sometimes, you know, other than, “*Hey, there’s no milk in the fridge*. *We’re out of this, we’re out of that.*” So, I think that’s what it’s going to look like in his thirties.

**Interviewer:** Do you see him having a family of sorts later on when he’s in his thirties or so?

**Interviewee:** I know he would like one, but I don’t think I see that for him. I think that there’s so much unexpected stuff with kids that that would be overwhelming to him. And … but as far as maturity goes, he’s making, gaining leaps and bounds so maybe it’ll come.

**Interviewer:** Yep. Do you see him having the dream job that he wants, like, having a full-time job?

**Interviewee:** I do see him getting to his dream job because he is very focused on that and it’s part of that intense interest, right, that specific interest that he has. I see that he can be pulled away by kindness. So that concerns me a little bit, you know. So, but, you know, it’s his life. It’s not my life. So he … **[1:45:00]** again, he has to make the decisions, I can only give him the tools to get to his decisions and advice if he asks me for it, because, you know, if I’m just spouting all the time, they don’t listen. They don’t. And so I think that that would concern me, if he got into a relationship and if … got a girl pregnant or something like that, I would be really, really concerned because I’m not so sure he has the maturity to be a parent. He has the maturity to be in a relationship, but I don’t think, you know … parenting, I think that’s not something I would recommend or want for him yet. I think that would be a reassessment in his thirties after he’s found someone. He’s very platonic in how he looks at girls, so I’m not thinking that’s going to be a worry for me. Now the other one, he’s going to be girl crazy, but yeah. And Brianna, who knows? As long as they meet, you know, bring her stuff that she wants, she’ll be OK. She’s pretty specific. Anyway, yeah. So I think that’s what I see him having: his own place, a job. I see him gaming forever and astronomy forever. But I don’t know, that romantic piece, I think that might elude him for a little while. But I don’t think he cares. I mean, right, so.

**Interviewer:** And then, last final formal question: how have your child’s, how has Carter’s sensory sensitivities impacted this perspective that you just articulated in terms of, like, what does it mean to transition?

**Interviewee:** I think it’ll feel like success, right. So “*Yay, we got him there*,” you know, “*Yay, he got*”—I shouldn’t say ‘we got’ when I say ‘we,’ it’s the family ‘we.’ We’re our own little community, right?

**Interviewer:** Yeah, of course.

**Interviewee:** Sorry. Gosh, I don’t know what that … it’s just from I’m talking so much these last few days. Yeah, I was on the phone collecting data till 10 last night, so they could not get them off. They’re so lonely. Anyway, I think success, yeah, I think that and continued success. I don’t think that you just achieve it and it goes away. I think it’s, you know, it’s incremental. And we’re seeing incremental success this whole time, right. So and, as I said, I don’t believe in failure, I believe in a different approach, so and that’s kind of how we all move, we’re all kind of that way. **[1:48:00]** But—I’m trying to think—yeah, that’s the best word I have for it, that he can do what he wants, and that, I don’t want to say that he’s an insanely happy because I don’t think … I think happiness is part of it. I would say that he has a good quality of life. Carter would rate his quality of life high, that he has a purpose. And he gives back and knows how to advocate for himself to get his needs met. That’s transitioning to adulthood. That’s it. And then he can take care of me when I’m old and feeble, right.

**Interviewer:** And so how does a sensory piece mean success? Is it just because it’s one extra thing he has to integrate?

**Interviewee:** Yeah, I think that it is. It’s just a piece of him as a whole. So I don’t necessarily think it’s a bad thing. I think that he understands how to do his, you know … he understands what he needs to do to manage those sensory issues, what he needs to do well. You know, “*If I’m at a restaurant, I need to ask if the sauce on that pizza is chunky or smooth. And if it’s chunky, I don’t order it*.” And so and he’s doing that already. So, “*If I’m in an environment that’s loud, I get noise-cancelling headphones through HR or school IEP, whatever*.” I think that that’s integrating the sensory piece and knowing how to manage it and recognizing it when it is a sensory piece.

**Interviewer:** Absolutely. Thank you.

**Interviewee:** You’re welcome.

**Interviewer:** That’s all of my formal questions. Thank you so much. Do you want to add anything else?

**Interviewee:** No, I don’t. I don’t think … I haven’t been I think I’ve already talked to an extra hour longer than you anticipated, so.

**Interviewer:** That’s OK. It’s not a problem for me. I don’t have anything until one o’clock.

**Interviewee:** Lucky. I’m not so lucky. I don’t have that. It’s OK, it’s all good. The injury is kind of … I hope it’s not a torn meniscus, that’s like ahhhh. I think it’s a bucket handle tear, though. So, but it’s all good, right. I’ve got my ice pack. I’m warm now, so, no, I don’t think … I have just that. I think they’re … ASD kids, they’re wonderful. They think in so many different ways. And—oh I guess I do have something to add for Carter. It just jumped into my head. So when he was in middle school, he was part of a research study on really smart kids. And the researcher pulled us aside and said about Carter, that he thinks among smart kids … he’s a smart kid amongst smart kids, because he thinks differently. And I **[1:51:00]** think that … and she had all these things to do. And at that time, I was like, “*What am I supposed to do with that? I can’t do any of those things*.” But what I think is, other people look at him as quirky even smart people as quirky because of that. But he needs to know how to manage that. And they finally … they kind of put a label to it. It’s ‘fluid reasoning.’ He has fluid when it—or is that what it was?—some kind of difference in his fluid reasoning. Anyway that … something in that piece of interpreting things and success figuring out what to do with that, that would be mine … yeah, so I don’t think I have anything else.

**Interviewer:** Well, thank you so much, especially for giving so much extra time. This has been so wonderful to hear from you and it’s been invaluable. I’ve learnt a lot. So, thank you.

**Interviewee:** Oh, good. I hope so. I hope you’re not like, “*Gosh will she ever stop talking?*”

**Interviewer:** No, no, it’s wonderful. It’s … so every parent has a different perspective on every question. It’s exciting to hear everyone, so not at all. It was a pleasure.

**Interviewee:** OK. Oh good. All right. Is that your cat or your dog over there bothering you or a person? Oh you were looking over to the side.

**Interviewer:** My boyfriend sneezed, and I was hoping you didn’t hear it. There’s another human here. I wish it were a cat or a dog. We don’t have time … I wish we did. Do you know anyone else who might want to participate in the study? We’re still looking for a few … **[inaudible at 1:52:35]**

**Interviewee:** We’ll be sending that out today.

**Interviewer:** Oh, thank you. I appreciate that.

**Interviewee:** I can do … so the boys club, the boys group, so, it’s very skewed towards boys because …

**Interviewer:** That’s kind of the nature of ASD in general.

**Interviewee:** How about if we have Jess participate, his girlfriend?

**Interviewer:** If her parent wants to join, we would love to have them. It would probably be her grandparents, so.

**Interviewee:** That’s OK. We collect … we … are we still recording?

**Interviewer:** Do you want me to stop recording?

**Interviewee:** Yes.

**Interviewer:** OK.

**Interviewee:** Yes, please because that’s HIPAA protected information.

**[End of interview]**