**[Start of transcript]**

**Interviewer:** I want to make sure it works. Okay, we're recording. And I'll also be asking you about your perspective about your child's transition to adulthood in relation to his sensory sensitivities and interests.

**Interviewee:** Okay.

**Interviewer:** And I'll be doing something called a semi-structured interview where I have planned questions. But then I will be also following your lead and adapting the questions to make our conversation actually relevant to you and your family. Do have any questions before we begin?

**Interviewee:** No.

**Interviewer:** Okay. Awesome. And if there are any questions, you don't want to answer or don’t feel comfortable answering, that's totally okay. We don't want to make you uncomfortable in any way, so.

**Interviewee:** Okay. Sounds good.

**Interviewer:** Awesome. Shall we start?

**Interviewee:** Sure.

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

**Interviewee:** Sure. So since…so it's like, I would say there’s a mix of things that he is sensitive to and things that he's not, that don't bother him at all. And I would say for him the sensory piece doesn't really lead to a lot of special interests per se, but more just kind of like impacts a little bit, I don't know, how he experiences the world.

**Interviewer:** Okay.

**Interviewee:** So that's kind of vague.

**Interviewer:** No, it’s okay. It's a great start.

**Interviewee:** So, there aren't…he doesn't have visual sensitivities that lead him to, I don't know, spin objects or something like that. It's more like the hearing sensitivity, he's really bothered by loud sudden noises. And so…but the way that presents itself is like, you know, a fire drill at school is like that **[making gesture?]** the whole time.

**Interviewer:** Which he’ll cover his ears.

**Interviewee:** Yeah, which you might expect to see in a younger child, but for a senior in high school, that's like not really typical behavior. So that's the way that presents itself. What else?

**Interviewer:** I think in the form you indicated touch and taste?

**Interviewee:** Yeah. So for touch he seems to be very sensitive to like a light touch, he really does not like that **[03:00],** he *really* does not like a light touch, but does like a very like deep pressure. So we have…we got a weighted blanket and that is a *huge* hit. And he doesn't like to be hugged except if you hug him like *really* hard. And that he really likes. And that…it reminds me of Temple Grandin's squeezing machine. I don’t know if you're familiar with that, she built herself a machine because she really found that kind of deep pressure to be very soothing. It's also heartbreaking that she needed to build a machine to get that for herself rather than getting it from other human beings, but I guess you do what works. But anyway, so it kind of reminds me of that. That deep pressure is very…it seems to feel very good for him. And I don't know if this is related to that but like sort of intense movement also, it seems to...he really likes that and seeks that out. So like the most intense roller coaster at the theme park is…he wants to ride that like six times in a row, or the super-fast zip line that is…looks terrifying, he is in.

**Interviewer:** He likes that.

**Interviewee:** And it's interesting because personality-wise you wouldn't…he's not like a daredevil risk-taker kind of person at all. But those sensory *experiences* are so compelling to him that he does seek those out. So the rollercoasters and the zip lines, and the ropes courses and the like crazy spinning thing and…or something that goes really, really fast. That's all he really likes those and seeks those out.

**Interviewer:** Does he like spinning himself, kind of thing, kind of like vestibular wise?

**Interviewee:** When he was little, yes, not so much now. I think they're just fewer opportunities as an 18 year old to do that.

**Interviewer:** Yeah. No, absolutely.

**Interviewee:** But yeah, when he was little he loved that. And also we did a lot of OT when he was little, of the sensory integration variety. And one thing that they pointed out to me, that one of his OTs pointed out to me was I'm going to forget the word for it. But like when you spin and then you stop your eyes go back and forth.

**Interviewer:** Yeah, the saccades.

**Interviewee:** Yeah and his never did that. So you could spin…he could spin in, you know, one of those little discs wings and…**[06:26 inaudible]** spinning really fast and then if you stopped him and looked at him, his eyes, they would not be doing that.

**Interviewer:** So Interesting.

**Interviewee:** So yeah. So which the OT presented as evidence that, what might make sort of your typical person feel really dizzy, didn't make him feel…like he…anyway.

**Interviewer:** Yeah, that's super interesting.

**Interviewee:** So, that's…I guess that's all under the heading of touch. And then taste, again sort of a mix of like….he’ll pretty much try any food, but there are some foods that he completely detests and will physically make him gag. And it doesn't seem to be a texture thing, it seems to be of flavor thing.

**Interviewer:** What doesn’t he like?

**Interviewee:** Chocolate, just cannot stand it in any form. Asparagus, although that's not that uncommon **[chuckles]**. Those were the only two that come to mind. But all other flavors and textures you know, he likes crunchy things, he likes smooth things, you know whatever. And he doesn't seek out a particular texture or only eats a certain, you know, color of food.

**Interviewer:** You mentioned he really doesn't like light touch. What does that look like for him? Like what types of light touches does he dislike? And what does that dislike look like for him?

**Interviewee:** Yeah, **[08:15 audio glitch]** you know, if…say an aunt or an uncle is over and would go to put a hand on his shoulder, as one with you in like a friendly way like, “*hey, how's it going*?” He just…he’ll physically recoil. You know, like shrink away to try to be like, *“eww, don't touch me.”*

**Interviewer:** Got you. No, that makes total sense. Awesome, thank you. So helpful. You gave me so many excellent segues, **[chuckles]** to my questions.

**Interviewee:** Oh.

**Interviewer:** Yeah, you’re doing great. So you talked about for sounds, he will cover his ears when he dislikes them. What else does he do to like manage these on sensitivities?

**Interviewee: [09:09]** I'll be right back.

**Interviewer:** No worries. No worries.

**Interviewee:** Give me like 10 seconds, right?

**Interviewer:** Yeah, no worries. Take your time, take your time. No, it's super okay.

**[silence]**

**Interviewee:** Okay sorry. I just wanted to close the windows.

**Interviewer:** No worries.

**Interviewee:** **[09:39 inaudibly]** you probably heard me swear **[laughing]**

**Interviewer:** That's okay. You’re human, I'm a human, we both do it, it's okay **[laughing]**. Are you okay?

**Interviewee:** Yeah, I'm fine. I just pinched it a little bit.

**Interviewer:** That hurts, that really hurts.

**Interviewee:** Managing sensitivities to sound. So I would say that one, like really mostly covering his ears. And then the other management is more…it's more on my part or his teachers’ part, like sort of managing his environment.

**Interviewer:** Totally.

**Interviewee:** Meaning, like giving him a heads-up. If I'm going to make a smoothie and he is within earshot of the blender. I'll just be like, *“I'm turning the blender on.”* before I turn it on.

**Interviewer:** Totally

**Interviewee:** Or if they're having a fire drill at school, they'll try to give him a heads up to what’s coming.

**Interviewer:** Actually, that makes sense. So I guess…what about taste? How does he manage that? That might be bit of an obvious question, but.

**Interviewee:** Yeah, just total avoidance of tastes that he doesn't like.

**Interviewer:** Yeah, I'm assuming he also avoids light touches that he doesn't like?

**Interviewee:** Yes.

**Interviewer:** Awesome. And then you talked about OT when he was younger. Can you talk a little bit more about that?

**Interviewee:** Sure, so let's see. We did…I'm trying to think of when we started doing OT. That was probably when he was in early intervention, so before he was three. And that was more of a more traditional OT, like less on the sensory piece and more on the functionality piece of, you know, like feeding himself more effectively and you know, just kind of like activities of daily living,

**Interviewer:** Mm-hmm.

**Interviewee:** When he was little. And that but as it turns out the OT who we had through early intervention **[12:00]** was kind of interested in the sensory stuff. And so through *her*, I started learning more about that and then once early intervention ended, he started going for OT at a place in Watertown.

**Interviewer:** Great!

**Interviewee:** It's called OTA. I think it’s rebranded, I think it's called the Kumar Center now, anyway.

**Interviewer:** Sure.

**Interviewee:** And they did…so we went there for a while and looking back, I don't know how much it helped him, but it **[12:50 inaudible]** he really liked going, and it was really, I guess educational for family in terms of like, there are different ways that people kind of perceive sensory input. And that affects how they kind of move through the world, and how they interact with other people, and experiences they try to seek out, or avoid. And so through that we kind of learned that yeah, he has kind of this mix of stuff that he is less sensitive to and stuff that he is more sensitive to and yeah. But he’s…I’d say he stopped going to OT, maybe, I mean this is sort of a guess but maybe around third grade-ish.

**Interviewer:** Yeah. You mentioned you weren’t really sure if it helped him. Why aren’t you sure about that?

**Interviewee:** Well, so, just in terms of like thinking about it…so I'm a speech language pathologist. And so thinking about it in terms of here's a goal and we need to track the data, and determine if the goal has been met. And that would be determined if he's doing, you know, x behavior 80 per cent of the time, you know, however you set it up. And I felt like there wasn't a lot of that, you know, it was more kind of impression based or anecdotal like, *“oh it seems like this one was less…”*

**Interviewer:** Got you.

**Interviewee:** …rather than in 80% of opportunities he had these reactions.

**Interviewer:** Yeah. So like tracked a little…tracked less vigorously perhaps?

**Interviewee:** Yeah, yeah. And I mean, you know that might be **[15:00]** sort of intrinsic to…it's hard to measure sensory stuff.

**Interviewer:** It is, because it’s so internal.

**Interviewee:** Right and like…and how do you measure, I don't know, the absence of something right, like something to…I don't know. It's just…I can understand why some of it seemed a little bit loosey-goosey, sometimes I feel like that about speech language pathology stuff, dealing with kids on the spectrum, and if they’re social aspects, if we're dealing with aspects of social communication. And sometimes it's just like the very nature of it doesn't really lend itself to super strict data collection.

**Interviewer:** Yeah, absolutely.

**Interviewee:** So I get that. So…but I think that was part of the reason we stopped going and also it wasn't covered by insurance and it's really expensive. And so put those things together, it's like, *“I think it's working, but I'm not sure.”* And it's also really expensive and also my other child has to sit with me for an hour in the waiting room while the older one, you know…it's just like life gets in the way.

**Interviewer:** Absolutely.

**Interviewee:** You could sort of weigh all the different things that your family has to accomplish in a day. And so that one kind of fell by the wayside.

**Interviewer:** Well it’s understandable, it’s a lot do in one day. And it's also it's not covered by insurance, that's not trivial at all, you know.

**Interviewee:** Yeah.

**Interviewer:** Thinking back to when he was younger. How…were his sensitivities different over time? You know, either with regard to OT or irrespective of that? Like how they changed over time?

**Interviewee:** Yeah, I would say that his sensory sensitivities have lessened over time, or he has *better* learned how to show his sensitivities in a smaller way. He might still be feeling them just as much but has learned that, yeah, when you're 17, 18 years old, you don't do x the way you did when you were 5 because other kids think it's weird. So yeah, so it might just be like he's sort of learned to not show it as much.

**Interviewer:** Absolutely, kind of like a social awareness maybe?

**Interviewee:** Yeah, yeah. The taste sensitivities I think for sure have lessened. There used to be way more foods that he didn't eat.

**Interviewer:** Yeah. What marks that **[18:02 crosstalk].**

**Interviewee:** I don’t if **[18:04 crosstalk]** Oh, sorry, go ahead.

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

**Interviewee:** I was going to say, I don't know if that's necessarily a pathological thing or just a childhood development thing, I don't know.

**Interviewer:** Yeah, kids tend to be picky when they're younger, pretty across the board.

**Interviewee:** Yeah, so there used to be many things that he wouldn't even try that.

**Interviewer:** Yeah.

**Interviewee:** But now he eats, no problem.

**Interviewer:** Sorry. Go ahead, please.

**Interviewee:** I don't know if this is relevant or of interest at all, but I'll mention it. So he is allergic to peanuts like very allergic, like has an EpiPen on him at all times.

**Interviewer:** Got you.

**Interviewee:** And before we knew he was allergic to peanuts, he had peanut butter on a few occasions. And I don't know, as I'm saying this out loud, I don't even know that this would qualify as a sensitivity but whatever we're talking about taste.

**Interviewer:** Sure, whatever. I’m learning.

**Interviewee:** Even the first and second time he had peanut butter…so he was he was two.

**Interviewer:** Sure.

**Interviewee:** One and a half - two…he expressed that he did not like it. And so I don't know if that was the taste or if it was a physical…this is making my tongue…

**Interviewer:** Swell **[chuckles]**,

**Interviewee:** But yeah, that in retrospect should have been clear from the get-go. This is not a good idea for him, because he always had a very strong…like he didn't have the words to say…

**Interviewer:** Totally.

**Interviewee:** …necessarily, *“I don't like this, don't make me eat this.”* But, you know,would cry and make his displeasure known.

**Interviewer:** **[chuckles]** As kids do.

**Interviewee:** Yeah.

**Interviewer:** Thinking about his changes over time and this kind of social awareness you talked about, do you think these changes are related at all to any independence that he's gained over time?

**[silence]**

**Interviewee:** I don't know. I've never thought of it in those terms, *maybe*. I mean I guess yeah, I mean if independence is sort of a component of just maturation, you know becoming more adult like **[21:00]**.

**Interviewer:** Yeah, I think you froze.

**Interviewee:** Then he...did I freeze?

**Interviewer:** You froze slightly. Can I tell you what I heard?

**Interviewee:** I have?

**Interviewer:** I think so. So, I heard maybe in the sense that is like independence is a part of adult maturation, is that it?

**Interviewee:** Yes.

**Interviewer:** Cool, okay. I think we’re on the same page now. Awesome, thank you. And then thinking back to sensitivities, does that cause or increase anxiety for him?

**Interviewee:** Yes, I think the sound one, the sound sensitivity most of all, just because I mean something like a fire alarm or a fire truck going by on the highway or an ambulance…it's…they’re so unpredictable, you never know for the most part when those things are going to happen. And so I think that makes them more anxiety provoking.

**Interviewer:** And what does that anxiety look like or represent as for him?

**Interviewee:** Again, like covering his ears and just…like you can just tell, like you just see it…his facial expression is worried and he's not he's not particularly expressive, normally with his facial expressions, like he's normally pretty low affect or flat affect. But yeah, you can you can see it on his face.

**Interviewer:** How does he manage that anxiety, at all? Or does he?

**Interviewee:** He doesn’t really.

**Interviewer:** Yeah, no. That's super okay, awesome. And has its anxiety changed over time or has it been pretty constant?

**Interviewee:** Again, I would say what I said earlier, I think he's more able to show a smaller reaction in public. I think if it's just our family then he feels more comfortable to show exactly how he's feeling. But I think when he is kind of you know, if he was at school or out in the world, he would try to kind of tone it down.

**Interviewer:** For sure. I mean, I think we all kind of do that. We kind of let loose a little bit more around family and those we’re comfortable with, and then hide a little bit more.

**Interviewee:** Yeah.

**Interviewer:** And then what goals and hopes do you have for him in regards to his sensory sensitivities?

**Interviewee:** Can I pause us again for as second?

**Interviewer:** Absolutely!

**Interviewee:** I'm going to switch rooms **[24:00]**.

**Interviewer:** Okay, sure absolutely. Do you want me to pause the recording?

**Interviewee:** **[24:03 crosstalk]** likethe internet connection**.**

**Interviewer:** Yeah, absolutely.

**Interviewee:** Sorry, wait. What's the question I'm supposed to be thinking about?

**Interviewer:** What goals or hopes do you have for your child in regards to their sensory sensitivities?

**Interviewee:** Okay.

**Interviewer:** I can also repeat it when we're back.

**Interviewee:** Bear with me, I'm going to close it so I don't make you dizzy.

**Interviewee:** Oh whatever, no worries **[chuckles]**.

**[Silence]**

**Interviewee:** Hello.

**Interviewer:** Hi.

**Interviewee:** Let’s try this spot now.

**Interviewer:** Okay, sounds good.

**Interviewee:** **[25:48 inaudible]** in another room. Okay.

**Interviewer:** Whatever works, right? **[chuckles]** Have I been cutting out too?

**Interviewee:** Yeah, every once in a while. So I never know which person it’s coming from like, you know, you get that bar across the middle that says your internet connection is unstable.

**Interviewer:** Yeah.

**Interviewee:** And so yeah. So I've been getting that, but I think it’s probably from me just ‘cause the internet here is no bueno.

**Interviewer:** **[laughing]** It's okay. We're doing our best. This is what we're doing, right?

**Interviewee:** Exactly. Okay. So yeah. Can you repeat the question?

**Interviewer:** Absolutely. I can repeat as many as times as you need me to. What goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** Yeah, so I guess, I would hope that he…he's not…he doesn't feel limited by them and that he's able to find strategies that work for him **[27:00]** to make him feel comfortable in different…like a range of different contexts. So that any sensory sensitivities he has don't, you know…basically I want him to be able to figure out ways to be okay with the sensitivities.

**Interviewer:** Absolutely, that makes perfect sense, thank you. Shifting gears slightly, thinking about as he's grown up and aged a bit. How has your community reacted to his sensory sensitivities?

**Interviewee:** Oh. That's an interesting one. I don't really know how to answer that.

**Interviewer:** That's okay. I have a couple other prompting questions. So I can ask that and maybe that will kind of help and if you don't know, that's okay, too.

**Interviewee:** Okay.

**Interviewer:** Was the community more accepting and accommodating when he was younger?

**Interviewee:** Yes.

**Interviewer:** Yes? How so?

**Interviewee:** Because, well as we've kind of discussed earlier, there are some responses that he has to, say a very loud sound that areconsidered acceptable or typical in a five-year-old that are not seen as acceptable or typical in a teenager. So and it's…yeah.

**Interviewer:** Yeah, perfect! And then were there…when he was younger were there places that were more understanding, accommodating? And what about now? Or less.

**Interviewer:** Yeah, so I think every school environment has been quite accommodating. We have…so both our kids have always gone to private school, and so…and we chose very particular schools because they were very inclusive, and very progressive, and like really focused on the social-emotional piece, and had a lot of very quirky kids there. And so yeah, so I think in those environments and that's…this is what we wanted, that, you know, if you had a reaction to some kind of sensory input that was a little bit...that might seem pretty odd in another context. It wasn't really treated as odd in those school setting.

**Interviewer:** **[30:22]** Absolutely. What are other places that weren't school?

**Interviewee:** Yeah, so I would say, you know, out in public, like in the grocery store or the library or something like that, I would notice people noticing my child's behaviour, but he wouldn't notice it. He wouldn't notice their reaction.

**Interviewer:** Yeah

**Interviewee:** Right? I mean, I think it's part of his profile. And so in a way that’s better for him. He is not aware that people are, you know, giving him whatever, a look. And so he was not perceiving that and so was not hurt by that.

**Interviewer:** Absolutely.

**Interviewee:** So that's…in a way that's good.

**Interviewer:** It is, yeah, no one wants to be hurt. And then what hopes or worries do you have for how the community will react in the future?

**Interviewee:** Yeah, I am worried that peers will not react well to him and that will negatively impact his social life, relationships, etcetera.

**Interviewer:** Absolutely.

**Interviewee:** Like facing, you know…like that it'll be hard for him to find friends or maintain friendships because sometimes he has strange reactions to sensory things.

**Interviewer:** That makes sense. Thank you for sharing that. Shifting gears again, in the like transition to adulthood, where do you see your son?

**Interviewee:** Can you be more specific?

**Interviewer:** Yeah, so at what stage of independence is he? So I know he lives at home with you. Does he not want…does he want to live by himself? Does he…can cook for himself? Does he manage a social life? Finances, things like that?

**Interviewee:** Okay, sure. So yeah, he lives with us **[33:00]**. He wants to be – *wanted* before covid-19, *wanted* to start college and live in a dorm, and have roommates, and do all the typical college stuff, but that's not happening. He's doing a gap year and so he'll be living at home for another year. But after that, yeah, the plan is, you know, kind of typical whatever that will mean, college experience of living away from home, and even though it will just be in Boston, but it won't be in our home. And…

**Interviewer:** Is a gap year **[33:46 crosstalk].** Oh, sorry go ahead.

**Interviewee:** He's taking his road test to get his driver's license next month.

**Interviewer:** That's exciting!

**Interviewee:** So yeah, so that's good. And he's…he loves public transportation, like loves being able to just like take the T or take the express bus which runs right near our house.

**Interviewer:** Yeah, us too.

**Interviewee:** Yeah, yeah. So that’s…he's great with…very independent with that. Can he cook for himself? Yes, some things, I mean, I think it's much as like any 18-year-old boy can. Sorry that's really like ageist and sexist, but.

**Interviewer:** That's okay **[laughing].**

**Interviewee:** You know ramen, grilled cheese, soup, stuff like that.

**Interviewer:** He’ll survive. That's enough.

**Interviewee:** Yeah. What else?

**Interviewer:** I think you mentioned **[33:48 crosstalk]**

**Interviewee:** Go ahead.

**Interviewer:** I think you mentioned he has a part-time job on the form.

**Interviewee:** Yeah. So again, like that's been definitely negatively impacted by Covid.

**Interviewer:** Very understandable.

**Interviewee:** He had a job at a day camp for the summer, but then the camp isn't running so that went down the tubes.

**Interviewer:** Such a bummer.

**Interviewee:** But he's…he's teaching coding, computer coding once a week online.

**Interviewer:** That's great.

**Interviewee:** So that's good. And then he's doing an internship at a biotech start-up next month, again, online.

**Interviewer:** Great!

**Interviewee:** I know, yay!

**Interviewer:** That's really great **[chuckles].**

**Interviewee:** And then during…for his gap year he's going to be doing an internship at his old elementary slash middle school.

**Interviewer:** Awesome.

**Interviewee:** Though he'll be there probably 30 hours a week.

**Interviewer:** That’s fantastic.

**Interviewee:** Hopefully closer to 30. Yeah, just **[36:00]** doing whatever. Like helping them build their alumni database or you know, like helping in their after-school program. Anything they need, he's you know.

**Interviewer:** He's that guy. Is the gap year happening because of Covid.

**Interviewee:** Yes.

**Interviewer:** That makes sense. Sorry that’s such…Covid is really putting a kink in all the plans.

**Interviewee:** Yeah, yeah. I mean like we have a lot to be grateful for, it could be so much worse and we're all healthy thank goodness, and…but there's still a lot of sucky things about it.

**Interviewer:** Absolutely, absolutely. Well, I'm glad he's still able to make a lot of opportunities out of this situation. And then does he like take care of himself, clean up after himself, things like that?

**Interviewee:** Yes. Yeah, you know, he does his laundry and keeps his room clean, and personal hygiene and all the good things

**Interviewer:** **[chuckles]** Perfect. And then what do you think will…sorry do you think he’ll be able to have more independence as he continues to grow up?

**Interviewee:** Yes, I do.

**Interviewer:** Like, what type and how?

**Interviewee:** I would say he'll be able to take on more financial responsibility. Like, you know, he doesn't pay any bills right now, but he will be able to. Just in terms of knowing you know, this is how a credit card works and you know, you have to pay it every month, and…or like saving money…he's an awesome saver actually, and you know, putting money away for whatever, graduate school, or a house, or an apartment, or you know. So that yeah, I totally think that he'll be able to do all those things. I think he will be able to do scheduling of appointments and stuff, although I think that will not come easily to him, time management is a little bit of a challenge. What else, what are other parts of being a grown-up? **[Rachel laughs]** Yeah, I don't know.

**Interviewer:** And then talking about achieving financial responsibilities and achieving the ability to schedule oneself. What do you think will help move him into those other stages of adulthood and independence?

**Interviewee:** I guess *opportunity* and practice.

**Interviewer:** Yeah, for sure.

**Interviewee:** I think he…he's very motivated to be independent. He wants to be able to do everything and go anywhere and you know, so I think that, yeah, I think that spurs him on to achieve these things. Like when he started going to high school, his high school was in the Back Bay – as you know, we live in Newton and like he'd never taken like a T-bus before or the T or like, you know, navigated like walking around the Back Bay or whatever but he was like, “*no, no*. *I got this, I want to do this*.”

**Interviewer:** Yeah.

**Interviewee:** So yeah, so I think that those kinds of situations will continue to present themselves and he'll be like, *“Yeah, I'm in.”*

**Interviewer:** Awesome, it sounds perfect. And I'm putting these two things together, sensory sensitivities and transitioning to adulthood, how do these two things intersect for your child? Or are they parallel? **[chuckles]** They might not intersect.

**Interviewee:** I think they do intersect, but I think he's not totally aware of that intersection. So I think he tries to just kind of like power through. Okay, so I’m imagining him on the express bus, right, by himself.

**Interviewer:** Yes.

**Interviewee:** And in before times, when people…like when buses were crowded.

**Interviewer:** Pre-Covid.

**Interviewee:** Yeah. And I'm imagining someone kind of brushing up against him.

**Interviewer:** Totally.

**Interviewee:** Right? Which he’ll not like, but I think he would just kind of power through. You know, be like, *“no, I don't like this but it's a crowded bus what am I going to do?”* And you know, maybe try to move away if he can and if he can't then just deal with it.

**Interviewer:** Yeah, so just kind of like coping with it, it seems like?

**Interviewee:** Yeah. Yes.

**Interviewer:** And then, kind of in that vein, would you consider his sensitivities like an obstacle, a vehicle, or a bit of both towards his independence?

**Interviewee:** *Not* a vehicle.

**Interviewer:** Not the vehicle. Okay **[42:00].**

**Interviewee:** I get…an obstacle but not like a big one.

**Interviewer:** Sure.

**Interviewee:** I mean, yeah, it's interesting, because so like I think he does have sensory sensitivities as we've discussed, but they're not they don't have a huge effect on his day-to-day life, which is both good and in a way also bad. Like it's good because of course I don't want him to have big obstacles that he has to overcome every single day, but he presents as pretty typical, and so then when he does have a reaction that's a little bit of an outlier, I think to other people that's even more off-putting because it's like, *“wait, what. what are you doing? What's going on?”* Whereas if he were more kind of profoundly affected by these things, he would show all the time that he's profoundly affected. And so people would give him some slack because it's like, *“well, you know that's the way he is and that's fine.”* Does that make sense?

**Interviewer:** Yeah, so kind of his like sensitivities are a low amplitude in a way and so people's expectations…it kind of seems like they didn’t expect it.

**Interviewee:** Are higher. Yes, yes.

**Interviewer:** Absolutely. That's really interesting, thank you for sharing that. And then similarly in that vein, what do you anticipate as being challenging for him as he does gains more independence in regards to those sensitivities?

**Interviewee:** I think it may be challenging for him to advocate for himself effectively, and to recognize when he needs to advocate for himself and when it would be appropriate for him to do so, and how to do that appropriately. So, meaning you could say to someone, “*Stop making that noise!*” or you could say to someone, “*hey, I'm sorry to bother you. Do you think you could like turn it down a little?*” and you know, I mean, obviously those are like kind of extremes, but…

**Interviewer:** Yeah.

**Interviewee:** …you know, the way you present your case to someone matters a lot in how they receive it, and whether they're able to modify their behaviour, you know, according to **[45:00]** what you requested, right?

**Interviewer:** Absolutely.

**Interviewee:** And that piece is difficult now for him and I think may continue to be difficult.

**Interviewer:** I think you said you were also working on to knowing when to advocate. What do you mean by that?

**Interviewee:** Well, like judging the situation, judging your audience, is this person your boss or is this your buddy? Or are you in a really crowded situation or is it more like one-on-one? Or are you in public or…just like the different aspects, like the…like reading the cues of the context?

**Interviewer:** Absolutely.

**Interviewee:** And also figuring out the importance of it or the magnitude. Like how much is it bothering you? Can you not bear to exist for another minute with this sensory thing going on? Or is it like, *“eh, it’s kind of bugging me, but like I'm okay.”*

**Interviewer:** Got you. No that makes total sense, thank you. And then what do you think will help him, either learn how to advocate more appropriately quote-unquote for himself or help him with this, not vehicle but also not real obstacle of his sensory sensitivities?

**Interviewee:** What do I think will help him?

**Interviewer:** Yeah.

**Interviewee:** **[Sigh]** Maybe one thing that might help would be just greater self-awareness **[47:00]** slash self-acceptance.

**Interviewer:** How so with the self-acceptance?

**Interviewee:** Just sort of being okay with, *“yeah I don't…loud sudden noises really freaked me out and that's okay, that's part of me.”*

**Interviewer:** Yeah, absolutely.

**Interviewee:** Rather than, *“loud sudden noises freak me out, therefore there is something like wrong with me.”*

**Interviewer:** No, for sure that makes complete sense. And what do you think could...what do you think would help him get to the point of self-awareness or self-acceptance? Like interventions, therapies?

**Interviewee:** That is…that's the big question.

**Interviewer:** It is the big question.

**Interviewee:** I am…I'm hoping that just like time and maturity, frontal lobe development.

**Interviewer:** Got some ways to go.

**Interviewee:** I…yeah, I hope that all of those things will help. I'm all for therapy, whether it's talk therapy or CBT or you know, something. Like using the services of a mental health professional, I’m all for it. And I hope that he will seek out that help in the future. We've tried that in the past, but it just…it didn't go anywhere. I think because the self-awareness piece was so lacking. And this was a few years ago, a couple of years ago. The therapist was like, “*we can't really get anywhere because we have nothing to talk about, yet.*” you know. He's like, “*everything's great! It's awesome! Let's play a game.*” So yeah, but I'm hoping that down the road that will be a helpful support.

**Interviewer:** Absolutely, hope so too. And do you feel like there are any gaps in the available services that he could be utilizing?

**Interviewee:** From a sensory perspective? **[chuckles]** Or just in general?

**Interviewer:** From both, and then thinking kind of about how his sensory experiences intersect with his ability to transition to adulthood successfully. Do you wish there were a service that…or a type of therapy, or a type of intervention that could help him?

**Interviewee:** That's a tough one. Yes. I wish that existed, but along with that wish, is I wish that he would want him to avail himself of that therapy. Meaning, when…it's been my experience with him and with other teenagers on the spectrum, I have known that they get to, you know, basically when they…sometime during their teenage years they’re like, “*I'm done with…I'm not doing this any…I'm not going to this social group. I'm not going to this therapist. I'm not…I don't want to do it, you can't make me do it*.” And you know, they're not going to make progress if they're not invested in it, there's no point, right?

**Interviewer:** Mm-hmm **[51:00]**.

**Interviewee:** So, I don't know how you saw…I mean that is it back **[51:06 inaudible]** problem. Like how do you help someone who doesn't want to be helped, because their teenager. And that's kind of part of their normal teenage development, is being like, “*No*.”

**Interviewer:** *Yeah*, absolutely.

**Interviewee:** So I don't know. I don't know what the solution is there. But in the abstract do I wish those interventions for kids on the spectrum from age 12 to 18? Yes. I wish that existed.

**Interviewer:** **[laughing]** Many people do, awesome. Thank you. And then kind of thinking a bit more broadly again, how does his or how do his sensory sensitivities impact your goals, hopes and expectations for him as he navigates adulthood?

**Interviewee:** I don't. I don't give them a ton of thought as he transitions to adulthood. I…my concerns are more in the social realm. This is so my **[52:27 inaudible].** So yeah, so maybe that's where I'm like expanding the bulk of my energy is thinking about, whoa! The social piece and how that affects so many things.

**Interviewer:** Absolutely.

**Interviewee:** Yeah, more so than the sensory piece.

**Interviewer:** Perfect, thank you. And then, kind of our last set of questions. As a caregiver, as a mom, as a parent of a kid with ASD, but also some sensory sensitivities what does transitioning to adulthood mean to you?

**Interviewee:** It's…I would say it's…it means **[silence].** It’s like an exciting opportunity but also like a frightening challenge.

**Interviewer:** Can you talk a bit more about that?

**Interviewee:** Yeah, so, transitioning to adulthood is like you're kind of like, “*okay. w've done most of what we wanted to do and it's you now*.”

**Interviewer:** Yeah.

**Interviewee:** Like, “*It’s all up to you*.” **[54:00]** and you get to make many, many more decisions and be solely responsible for eventually everything about you, about your life, right? And that's pretty big and also frightening, because it's like *whoa*! Does he have all the tools that we hope he has, and will he know how to figure stuff out if he doesn't have the tools? And so there's a lot of uncertainty.

**Interviewer:** Totally, absolutely. And has this perspective changed over time?

**Interviewee:** Yeah, yeah.

**Interviewer:** How so?

**Interviewee:** I mean when he was first diagnosed, when he was two. I might cry.

**Interviewer:** Aww.

**Interviewee:** So, sorry.

**Interviewer:** No, it's okay. Are you okay? I'm so sorry.

**Interviewee:** No, it's fine [**sniffling].** Sorry, but…

**Interviewer:** No, please don’t apologize.

**Interviewee:** …when he was first diagnosed, we didn't know what the future would look like and would he be able to go to you know, a typical school, or go to college, or you know, would any of that happen, ever? And it is happening, so that's great.

**Interviewer:** It is great. Well, thank you for sharing that. Thank you for the whole vulnerability. I'm sorry I upset you by my question. We're almost done. I have two more questions **[laughing]**, but we cannot…do you want to stop?

**Interviewee:** No, I'm fine.

**Interviewer:** Okay, what do you see happening in his future?

**Interviewee:** So, I think he'll go to college. I think I'll probably go to graduate school, he loved…I don't know in what.

**Interviewer:** Sure.

**Interviewee:** But he's big into education, just loves learning and you know, he'll get a job. He'll probably work too much **[laughing]**. I think he'll probably stay in New England **[57:00]**, if not, right in the Boston area. Yeah.

**Interviewer:** Do you think he'll do Masters or PhD, you mentioned graduate school.

**Interviewee:** Yeah. I don't know. I think it depends…yeah, I'm not sure.

**Interviewer:** That's fine.

**Interviewee:** I’d love to see law school happening.

**Interviewer:** Oh really? Awesome.

**Interviewee:** Yeah.

**Interviewer:** There are a lot of good ones around here.

**Interviewee:** Yeah. I mean I used to be a lawyer. My husband's a lawyer, so it could happen.

**Interviewer:** Yeah, absolutely. And then, so you mentioned you don't really pay a lot of…you put a lot of your thought more thinking about his the social aspects of his life as opposed to like the sensory aspects, but…this is my final question for everyone. So did his sensory sensitivities impact your current perspective about transitioning to adulthood and what that means?

**Interviewee:** No, I don't think so. I mean, I think the sensory piece is something that we’re aware of but it's…it has never…it doesn't really rise to the level of, I don't know, *“arrgh, what are we going to do about this? Or how are we going to you know, try to remediate this?”* Or you know, it's more like kind of in the on the list of things that sort of require our attention and support. It's like, it's a lower priority.

**Interviewer:** Absolutely. Well, that's actually it for all of my formal interview questions. Is there anything else that you'd like to add?

**Interviewee:** No, no, nothing is coming to mind.

**Interviewer:** Okay, perfect. Well, thank you so much for your time and your thoughts, and just like sharing your life and your experience with us. We so appreciate it. We learn so much by talking to everyone.

**Interviewee:** Yeah, I'm happy to do it.

**Interviewer:** Yeah. Well, thank you so much. I know you mentioned that you are part of that Asperger's autism network.

**Interviewee:** Yeah.

**Interviewer:** Do you know anyone else who might be interested in participating, maybe more like on an individual basis? It's okay, if you don't.

**Interviewee:** Yeah, I *do*. I'm thinking of one friend who I would be happy to reach out to. Her son is…he's19. Is that?

**Interviewer:** That's perfect. Yeah, we're looking for 16 to just under 26.

**Interviewee:** Okay.

**Interviewer:** He’s smack in the middle.

**Interviewee:** Yeah. That’s…she's the only one who's kind of popping into my mind right now.

**Interviewer:** Yeah. If you…I mean **[1:0:27 crosstalk].**

**Interviewee:** I’m happy to forward the study info along to her.

**Interviewer:** Yeah, if you don't mind that’d be fantastic, we'd love to learn from her too. But yeah, thank you so much. I will send you a full thank you email. It will have a gift card in it for you as well, an electronic one, just because we do so appreciate your time, sure.

**Interviewee:** And, how long is the study going on for?

**Interviewer:** Until we hit our ‘n’. We are looking for 45 people and this is my seventh interview. I have six to eight more scheduled in the next two weeks. So we're chugging along…but our funding technically ends in like 13 months from now, but we will very likely be able to get like a no-cost extension. So we're probably looking at like another two years realistically.

**Interviewee:** Okay, all right. Yeah, that's…sounds like kind of slow going trying to turn to find people to participate.

**Interviewer:** So this is actually been pretty fast. Originally we were going to do it in person study, which obviously we cannot do safely right now.

**Interviewee:** Right.

**Interviewer:** And that was going to take a lot longer but I mean, I started recruitment like a month ago and I already have 15 people who want to be part of it, so.

**Interviewee:** Oh good.

**Interviewer:** It’s actually going much faster than anticipated which has been awesome.

**Interviewee:** That's great! And so what part of BU are you doing this through, what school?

**Interviewer:** So, I'm in the depart…so I'm in the College of Arts and Sciences, but I'm in the department of Psychological and Brain Sciences.

**Interviewee:** Okay.

**Interviewer:** Are you familiar at all with BU, like location-ally?

**Interviewee:** Yeah, yeah. So I got my Master's there.

**Interviewer:** *Ohh*, awesome.

**Interviewee:** At Sargent.

**Interviewer:** Oh, okay. We're right across the street from Sargent. We're on Cummington Mall, do you know where that is?

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

**Interviewer:** Yeah? And actually one of the other studies our lab is doing is in collaboration with Sargent.

**Interviewee:** Oh cool.

**Interviewer:** Yeah.

**Interviewee:** That's great.

**Interviewer:** And we actually have a speech language pathologist who's also partially at Sargent as well, so.

**Interviewee:** Oh cool, who?

**Interviewer:** Her name is Lindsay Butler?

**Interviewee:** Hm, don't her.

**Interviewer:** We also have another SLP named Karen Joanski. I can’t even pronounce her last name.

**Interviewee:** Okay. Don't know her either.

**Interviewer:** Yeah, but we have a lot of…our lab is mostly language-based actually. This is kind of the side project, so.

**Interviewee:** Yeah, cool okay.

**Interviewer:** Thank you so much. We really do appreciate your time.

**Interviewee:** You're so welcome. I'm happy to do it. And if I think of anybody else who I can like, you know forward the…

**Interviewer:** Yeah.

**Interviewee:** …info to.

**Interviewer:** That'd be awesome. Thank you. I hope you have a nice weekend. Hope you enjoying your time outside since we’re done with quarantine.

**Interviewee:** Yeah, I know, yay!

**Interviewer:** Awesome.

**Interviewee:** All right.

**Interviewer:** Thank you so much.

**Interviewee:** Sure. Take care.

**Interviewer:** Have a nice day. Bye.

**[End of transcript].**