**[Start of Transcript]**

**Interviewer:** Great, we are recording. And I will be asking you questions about your perspective regarding your child’s transition to adulthood in relation to his sensory sensitivities. And I’ll be doing something called a semi-structured interview, which means I have my planned questions and my script, but I will also be adapting them to follow our conversation so it fits for us.

**Interviewee:** What did you call it again?

**Interviewer:** It’s called a semi-structured interview.

**Interviewee:** Semi-structured. Got it.

**Interviewer:** Yeah, so I have my questions which you can see, but then I’ll be asking follow ups, so it actually makes sense for us. And if there are any questions that you don’t wanna answer for whatever reason, that is perfectly okay. And if you think of something later on in the interview from the beginning, feel free to jump in, it doesn’t have to be perfectly linear at all. Any questions?

**Interviewee:** No, we’re good to go. That did not sound scripted at all.

**Interviewer:** Thank you! I try to make my scripts sound very natural **[chuckles]**. Could you please start off by telling me about your son’s sensory sensitivities and sensory interests?

**Interviewee:** Current ones?

**Interviewer:** Yeah, we’ll talk about the past as well, so whatever feels natural for you to start with.

**Interviewee:** Okay, oh wow. And that’s interesting too because I feel like when you talk about sensory sensitivities, it’s so embedded with his autism and OCD, it’s like okay…so. Anyway, where do I start…so the first I would mention is Jack really craves *big time* proprioceptive input, I mean he jumps everywhere, and it’s not just a little skip, it's like jump *really* high and then he'll go *way* down, you know, bending his knees and coming back up. And if you look at him, he is…there's not an ounce of fat on him at all, and it’s because he’s always doing this really intense jumping, and it’s extremely loud, I mean it sounds like there’s the giant coming down from the beanstalk or whatever, you know, like *super* loud. So, that is the number one thing that has been around forever. And he, even as a baby, he broke his crib jumping up and down in the crib, and that was before we knew he had autism. I remember one time I was having a play group at my house – I have an older daughter, so there were older kids, they were all upstairs playing and Jack was in his crib, like supposedly taking a nap and like I heard a racket going on. So I went upstairs, and all the kids were in his room with the crib, and he was, I don’t know, a year old or something, maybe…maybe more like 15 or 16 months old, because he was able to jump up and down. But he was jumping up and down in his crib and then it collapsed, so it was like sideways and he’s like sliding down, jumping up and down, kids are running around the room screaming. So anyway, that *huge, huge, huge* need for proprioceptive input is the number one.

And then just deep pressure. So, whenever Jack is around someone he knows and trusts, he’ll ask you, *“squish please, squish please.”* And he really wants his hands squeezed, and he doesn’t want just some little, *“aww, let me squeeze…”* like he wants you to break his hand, like *squeeze* it super hard. So, just that super deep pressure. It’s been interesting over the years, like we’ve had weighted blankets and weighted objects for him, and he’s never gotten into them, and I think it’s because they’re just not heavy enough, like I think he wants more. So I have right now like a 25-pound weighted blanket, which it’s hard to carry around because it’s big enough for him, he’s like 6 feet tall, but he's not interested in it. So, it doesn’t do the trick for him, it has to be really intensive jumping. So, one of the things I did to kind of meet that need for him, is I got him into running. So, he runs for exercise and that helps, but that’s the biggest one.

**Interviewer: [00:04:38]** Does he seek out that deep pressure in places other than his hands, like really deep hugs maybe?

**Interviewee:** No, he wants it on his hands and then he jumps up and down…

**Interviewer:** Yeah, and then…oh sorry, go ahead.

**Interviewee:** That’s it. It’s interesting, coz I would think like, *“oh let me give you a deep squeeze,”* or whatever, he’s not really into that. So, he has a weird thing too though, which I don’t know if this contributes. He has a rare form of hereditary neuropathy, so I don’t know if that affects the way his hands are feeling sometimes. But I non-scientifically don’t think it does, because he wants deep squishes on his hands every day, like all the time, not when he’s having an episode, which he does have episodes, and it’s apparent because he loses use of his hand, or he’ll have foot drop. So, anyway. Oh, I was gonna say, just that brings another thought into my head. As he was getting older, kind of heading into transition age, he did start to get underneath his mattress – and I’ve seen other kids with autism do this too, and he would get in between his mattress and his box-springs, which is very…I can’t even imagine sleeping on your box-springs, but he would do that with the mattress on top of him, and then that would trigger damage and cause him to have an episode of neuropathy, usually. So, we had to take the box-springs out of his room because he was injuring himself and doing nerve damage. Anyway...**[crosstalk]** no, ask me, go ahead.

**Interviewer:** Was he trying to go in between the mattress and the box-spring for pressure, you know?

**Interviewee:** I don’t know, he would just get under there and that's how he would sleep, and you know, if you’re doing that for hours and you have…he has a thing called HNPP – hereditary neuropathy, with liability to pressure pulses. So the pressure pulses they’re on like the different nerves, you know, in the foot or in the wrist or the elbow or the arm. So anyway…we had to remove the furniture from his room because of that.

**Interviewer:** Yeah, I’m sure. And then on the form you filled out I think last month, you indicated that he’s also sensitive to sounds.

**Interviewee:** Yeah, so, in a positive way. He’s never been one…so it’s interesting, so he’s never been one like, *“oh, I can’t go in there because it’s too loud,”* he’s not that kind of kid. He wears headphones, like noise- cancelling headphones, not at night when he’s sleeping, but during the day he wears those. And then he’ll do this thing where he takes them on and off to make the noise cancellation come and go, you know, on and off, on and off. Like he’ll do it, and kind of go like this and then he’ll put it back on. So, there’s something about that that’s interesting for him, that’s kind of his self-stimulatory behavior. **[Jack screaming in background]** I don’t know if you can hear him right now?

**Interviewer:** I can **[chuckles]**

**Interviewee:** He’s screaming! Like he screams for fun. And then he listens to music as much as we let him. And so, he has an iPad and he listens to…he’s never ever listened to like Barney or Sesame Street, he’s always been into like Rihanna or Maroon 5, Justin Timberlake, Katy Perry. And so he kind of does the same thing too with the music, he has it on really loud unless we’re like, *“oh, what are you doing to your hearing?”* But he’ll listen to it and he will take kind of one of the headphones…oh Junior wants to say hi.

**Interviewer:** Hi! Beautiful dog.

**Interviewee:** Aww, he so sweet too, he’s very sweet. **[Talking to dog, then back to Rachel]** He will take one and have it kind of halfway off of his ear **[00:09:14 inaudible]** which is some sort of something with the way he’s manipulating how the music sounds. And then sometimes he’ll do the on and off thing with the music too, yeah.

**Interviewer:** And then what about other sensory sensitivities or sensory interests? I think you indicated smell on your form as well.

**Interviewee:** He has gone through periods where he will smell…we actually used to have a Golden Retriever, she just passed away.

**Interviewer:** Ooh, I’m sorry.

**Interviewee:** I know, here she is, hold on **[gets up and presents picture]**. Here’s Sunny. Jack loved to smell her, he loved the way she smelled, and so yeah. And then he sometimes will smell people’s hair, so it’s only certain smells, but we have to monitor him to make sure like if we’re walking in public, he doesn’t go up and just smell someone’s – it’s their hair usually. So, there’s that. And with sunny, like he would just bury his face in her hair and just take it all in and it's like the fur and the smell, he really liked it. So, yeah.

**Interviewer:** What about tastes, any like seeking behavior or any sensitivities to taste?

**Interviewee:** I don’t know. I know that he seems to like things that are spicy, like he eats chicken wings every weekend that are kind of spicy, he likes spicy buffalo pretzels, you know, but other than that, I don’t know.

**Interviewer:** Yeah, and then anything with vision, any sensory seeking or preferences or avoidances?

**Interviewee:** So when he was younger – this isn’t transition, but when he was first diagnosed with autism, he would do like things out of the corner of his eye, he’d walk along the fence line, like those kinds of things, and just peer out of the corner of his eye. He’d do the same thing with blinds, he would walk along the blinds and just cut his eyes as far to that direction as possible and then just walk and look. And then he used to shake his head too, and then kind of, you know, you could tell he was experiencing something with his eyes, but it’s really like a self-stimulatory behavior, is kind of what I thought about that. Other than that, I don’t…let me think about that for a minute, I’m trying to think if he looks at things like in a sensory seeking kind of way. Not that I can think of.

**Interviewer:** Sure, that’s perfectly fine. And you’ve alluded to this, but how have his sensory habits or preferences changed overtime?

**Interviewee:** So, the vision thing seems to have just dissipated, like the proprioceptive input thing seems to have just increased with size, like he just continues, that has been with him. The sound thing definitely is…I don’t know that it’s increased, but it’s definitely been there, you know, from probably…I think that I started seeing [it] when he was like 9 or 10, you know, and it’s just continued now, it’s definitely part of what he does. And of course, like so many kids with autism, he wasn’t like this when he was younger, some kids are, but he definitely is that kid now where if he doesn’t have headphones or something, he’s like this, his fingers in his ears, just…

**Interviewer:** In what contexts?

**Interviewee:** He just holds them on there constantly.

**Interviewer: [00:12:02]** Oh, okay, even if there’s no noise?

**Interviewee:** Walking on the street, sitting in the chair, riding in the car, anything. If he doesn’t have headphones, he’s like this, holding his ears closed. And I know that he likes loud sounds, like he’s been to loud concerts. Like when he turned 13 – he doesn’t do birthday parties, he doesn’t recognize holidays or anything, but we took him to see Lady Gaga because like, you can just let your freak flag fly at the Lady Gaga show and no one cares, right? So, I mean like loud lights, he loves that stuff. His favorite place – I think I might have told you this before is, I don’t know if it’s his favorite place, but based on observation, the happiest I’ve seen him is Time Square.

**Interviewer:** Oh, really? Because of all the noise?

**Interviewee:** Loves it! And all the visuals, like he really craves that. But he still will…I feel like with this, and I could be wrong, I don’t know that it’s to block out the noise, but it’s more to apply some sort of pressure in his head, do you know what I mean?

**Interviewer:** Yeah, definitely. It’s like a muscly kind of thing when you do that.

**Interviewee:** Yeah. But it’s a problem, and that’s part of the reason…they were talking about, like at school, they were like, *“we really wanna work to try to get away from his headphones”* or whatever, because they’re stigmatizing, and I’m like, *“I don’t care, the noise- cancelling headphones, I don’t care.”* Because if he’s like this, do you know how hard it is to get him to eat? Like he doesn’t wanna…like it gets in the way of just the functions of everyday life, you know, *“Jack, you have to wash your hands, you have to wash both your hands, you’ve gotta put it down.”* So his headphones are just…he’s super handsome, they look great on him, I don’t care. Plus stigmatizing, who cares? You can be around him for one second, he’s autistic, that doesn’t make him less of a person. They’re well intended but I’m like, *“no, we’re not worried about that, it’s all good.”*

**Interviewer: [00:15:14]** Absolutely. You mentioned that he doesn’t have like those visual behaviors anymore. When did those dissipate?

**Interviewee:** I wanna say like probably around age 5 or 6. They were there like in the toddler years, the pre-school years, and then they did go away.

**Interviewer:** Yeah. What about smelling, is that still a thing he does?

**Interviewee:** Oh yeah. It’s gotta be something, you know…since Sunny passed away at the end of April, so it’s been a few months. So, I’ve not seen him do it since Sunny passed away…and he doesn’t smell Junior, Junior doesn’t smell right. Plus Sunny was like a big teddy bear that he could smell, she’s like, ‘you can smell me all day long,’ and Junior’s more likely just to run away, like ‘you’re going to squash me.’ Anyway, I believe it’s still there, I’ve not seen it since she died though.

**Interviewer:** Has it changed though at all, did it crop up a little bit later or has it increased?

**Interviewee:** I think when he hit puberty, definitely it increased. I think there’s something that’s...I don’t know what the right word is, like an aphrodisiac or something for him, I think he likes it.

**Interviewer:** For sure. And these changes that you just described, do you think they’re related at all to any independence that he’s gained over time?

**Interviewee:** Definitely, yeah. I think like being able to smell Sunny when he wants to, like I think…that sounds so funny to say that in a sentence **[laughing]**…

**Interviewer:** No, not at all.

…smell his dog whenever he wants to. Like if he was younger, like 7 or 8, he didn’t have leisure skills, he didn’t spend as much time alone, but now, like I will…like right now he’s upstairs, I’m not with him, so that’s developed as he’s gotten into his teens, as long as I can hear him. So with that, that would give him more opportunity to interact with Sunny and I’m not there to be like, *“leave sunny alone.”*

**Interviewer: [00:17:25]** Absolutely. And how in general does he manage his sensory preferences and sensory habits, or how do you help him manage them?

**Interviewee:** I was gonna say he does not manage them, left unmanaged he’s gonna just have a good time. Jack and I do have a relationship where I can look at him with the mom stink eye and he knows, *“I need to stop.”* So there’s that. I think some of it I attribute to OCD, and he does take medication for OCD, so I think that helps too. But usually, it’s just a verbal, like we’ll say, *“stop.”* Like if he’s jumping, he can jump so much that the dishes will rattle out of the cabinets and break on the floor, like that’s literally happened. So, when he’s really doing stuff like that or I’m worried he’s gonna hurt himself, it’s harder to make him stop because he’s so into it. So sometimes with that we have to do a de-escalation, he has an area, he’s got a yoga mat down in the basement and he goes down and we just tell him, *“go lay down.”* And then he lays down, he usually is screaming, not happy about it at first, but if you sit on the stairs and he’s just there on the yoga mat and you don’t interact with him or anything, he’ll de-escalate usually within like 3 to 5 minutes. So, it took years to get that into something that consistently worked, like through an ABA program we started this de-escalation thing. So anyway, but it works, it helps. He will start back too though, you know, like if you’ve kind of said, *“no jumping, you need to calm down,”* he’ll calm down for a while, but then an hour later it might start back up again.

**Interviewer:** So you just talked a lot about his proprioceptive input, do you manage his other sensory needs or sensory habits, or do you help him manage them?

**Interviewee:** So, with the hearing, like I provide him with the headphones, and he wears them. It’s interesting though, as I said, he doesn’t wear them when he sleeps, by choice. He takes them off when he goes to bed and goes to sleep. And he doesn’t sleep like this either, like he just goes to sleep, so that’s kind of interesting. But yeah, I mean I feel like with the hearing thing is we provide the music, so that’s how we manage that and then… And I would say, my husband used to say, *“that’s too loud, you need to turn it down,”* but we’ve kind of given up on that because it seems to make him happy and it’s a leisure activity for him. And I guess on the other side, it’s weird that I think of this as a sensory thing, but it seems to be like he…you heard him screaming earlier, sometimes he’ll do that, he would do it for hours if we didn't intervene. So, my recent management of that has been if he’s screaming and screaming and screaming and screaming and all our ears are bleeding, I’ll go into wherever he is, he’s usually in another room, I will hug him tightly, like this, and just like love on him to the point where it gets annoying to him, and then he’s like, *“go away,”* and then I say, *“be quiet,”* and then he looks at me and he says, *“be quiet,”* and then he’ll stop screaming because he wants me to stop hugging him.

**Interviewer:** That works **[chuckles].**

**Interviewee:** I know **[chuckles]**. So, that’s what I’ve been doing lately, and it works. He’s like, *“mum, go away,”* and I’m like, *“be quiet.”* So that will last for a little while, and it’s better than yelling at him.

**Interviewer: [00:21:47]** Oh yeah, absolutely. Has he always enjoyed yelling? Has that changed overtime?

**Interviewee:** It’s gotten worse, I think. I really feel like once the hormones started, probably around 8 or 9, like prepuberty, like into it, it definitely became a thing, yeah. It’s a big issue, I’d say over the last two or three years – at home especially, it’s very hard to deal with. And he doesn’t scream like when we’re out and about, he doesn’t scream in the car, he doesn’t scream at school, it’s something he does at home. And a little bit of it is fine, I feel like if you’re a person carrying the burden, I mean I’ll say it, the burden that he carries every day of his life, you know, not able to express everything you’re feeling, I’d probably wanna have a scream fest too sometimes. So I feel like he needs that, but only to a you know, after a while you’re like oh! And I know our neighbors can hear it, but they’re always like, *“oh no, we don’t hear anything,”* and I’m like, *“you’re just nice.”* We can never move.

**Interviewer:** And do you help him manage his smelling behaviors and like interests as well?

**Interviewee:** Yeah, I just…I’ll intervene if you know, he’s getting too aggressive about it or if we’re in a public place and he’s trying to do it in an inappropriate way. Otherwise, I don’t care.

**Interviewer:** You talked about ABA briefly, has he received other therapies or interventions to help him with his sensory habits and sensory needs?

**Interviewee:** He’s received occupational therapy and physical therapy right along with ABA therapy. He really started those in a meaningful way like around age 4. He had a little bit early on, but it was not anything that really was of any kind of quality. But starting at age 4, ABA, speech, which isn’t really sensory, OT, PT, it’s definitely been part of trying to address that sensory stuff.

**Interviewer: [00:24:07]** Have they helped at all?

**Interviewee:** Yeah, I think it helps. And it’s great because that team all works together, so yeah. So you know, the OT’s always like, *“let’s try this weighted thing,”* or you know. He goes to Nashoba, they had a squeeze machine there, like the one Temple Grandin had, they acknowledge the sensory things. Before I forget, the other huge sensory behavior that he has is swinging, I don’t remember if I put that on the survey or not, but I don’t want to forget about that because it’s a *huge, huge* one.

**Interviewer:** Does he…tell me a little bit about it.

**Interviewee:** So, he loves to swing, and he has loved to swing on the swing set since he was in the toddler bucket, but once he was able to learn to swing on his own, which was probably around age 9 or 10, he just really took off and he swings really aggressively and he goes as high as is possible to go, like it looked like he’s gonna go all the way around. People get really scared, because also when he gets to the top, like he kind of lifts himself out of the swing a little bit and then comes down and it’s definitely seeking some sensory thing, but he loves it. So for his 16th birthday – again, it’s one of those things where we were like, well we don’t know what to get him because he doesn’t really care that it’s his birthday. We had a swing set that was more just a typical wooden swing set, but we got one of the types that they have on the school playgrounds, it’s like cemented into the ground and it’s heavy duty, like adults can swing on it, so he loves it. The other thing about that experience is often it’s combined with a visual sensory actually, now that I think about it. He likes to watch the leaves and the wind blowing in as he’s doing it, you'll see him watching the leaves. And sometimes he’ll just stand on a rock in our yard and just watch the leaves blowing. And when the leaves go away like they are right now, he definitely goes into a funk, every year, because they’re gone.

**Interviewer:** Ohh, that’s a bummer.

**Interviewee:** Yeah, I know.

**Interviewer: [00:24:44]** You mentioned that you thought his therapies like OT, PT have helped him. In what ways do you think they’ve helped him, or how?

**Interviewee:** So, I think with PT it sort of helps with the proprioceptive. So the PT, they do a lot of stretching, they do a lot of coordination around the neuropathy too, and then they help with yoga, with running, and I think that just feeds the need, you know, for that sensory input that he so craves. And then with OT, as I said, it’s more…they do things that are more OT like you know, holding utensils or whatever. But then they also try to figure out like the input he needs, like the squeeze machine or like a weighted thing, lap thing that he would use at school, a vest, they’re always just trying different things like that, yeah.

**Interviewer:** And then in circumstances where he’s not able to get that input he needs, does that cause or increase anxiety for him?

**Interviewee:** Yeah, yeah, he’s definitely anxious, definitely hard to manage, yeah. Not able to be calm.

**Interviewer:** Is he able to manage that anxiety at all or do you have to help him with that?

**Interviewee:** He’s gotten a little better over the years as we’ve worked on the de-escalation stuff. But sometimes no, like it will induce a big meltdown, and that’s loud, scary, not good.

**Interviewer:** Totally. Has the lack, has it always caused anxiety if he’s not able to get that sensory input?

**Interviewee:** Yeah **[crosstalk]** No I was just going to say definitely, he’s a sensory seeking human being.

**Interviewer:** And when he wasn’t able to get that in the past, was the presentation of the anxiety the same or is that different now?

**Interviewee:** I think it’s always been the same. I feel like it’s just louder and bigger now because he’s 17 and he’s 6 feet tall.

**Interviewer: [00:29:10]** It’s proportional **[chuckles]**. And then thinking a bit broadly, what goals or hopes do you have for your son in terms of his sensory needs in the future?

**Interviewee:** I think, sensory needs, I want him to be able to feel comfortable in his skin, so you know, in his personal space when it’s appropriate, I want him to be able to meet his sensory needs. I also want him to be able to judge when it's not appropriate, because you can’t jump on top of grandma at the Roche Brothers and knock her over, right? You can’t. So, I want him to be safe and I want him to be able to be participating in society where there are basic rules of safety, you know. I don’t want him to act non-autistic or anything, I don’t care about that, but it’s really more about not scaring people or just being safe. You’ll scare someone if you walk up to a stranger and smell their hair, you know, they could call the police on you. But then I also want him to…I don’t want him to ever be in an environment…and this I feel like is a misunderstanding of applied behavior analysis, because they haven’t tried to eliminate his sensory seeking behaviors at all, you know. They use them to reinforce other things that he’s learning, you know. So swinging, things he likes to do, squishes, they work with that to encourage him to learn how to do math, you know, the things that **[00:30:55 inaudible]**. So they incorporated…I’m fine with it too here at home as long as it doesn't interrupt things he needs to do like eating, sleeping, bathing and then chores or whatever, he does have those. But in his spare time, I want him to be able to feel better, feel good, because it’s all about that balance.

**Interviewer:** Yeah. Do you not think ABA should use it as a reinforcer?

**Interviewee:** No, I do. Yeah, I feel like a lot of people say oh ABA tells them they shouldn’t stim or they shouldn’t have sensory needs, and that’s just not true, it’s a misunderstanding of applied behavior analysis. And I’m like, *“no, that’s actually not true. Use it, it’s a reinforcing thing.”* So you can use it to like say*, “Jack, say your name,”* and then *“let’s go swing.”*

**Interviewer:** Absolutely. We’re gonna move into our next chunk of questions, but that was a wonderful segue, so thank you. Thinking about community, as your son has grown up a bit, how has yours and your community reacted to his sensory needs?

**Interviewee:** I think it’s scary sometimes, especially the jumping and screaming part, that *huge* jumping is *really* scary. So, sometimes people generally are…they don’t say anything but they definitely are like, *“what is going on?”* So, there’s that piece of it. Then I also feel like for him I’ve worked really hard to build off of it, like the proprioceptive stuff, so like with the running, you know, he runs with the cross-country team, and they accept him. Some of the kids are like, *“hey Jack!”* you know, holding hands with him, hanging out. Others are more like, you could see they’re a little intimidated because it's just such a different kind of behavior. No one ever really says anything about the headphones or the music. From a community perspective, I don’t really see any kind of issue there at all, it’s really more about just that proprioceptive seeking and screaming, you know, those kinds of things. And smelling.

**Interviewer: [00:33:38]** That makes sense too. And was the community more or less understanding or accommodating of him when he was younger?

**Interviewee:** I’d say probably a little more accommodating because he was cute and little. But I did…even then too, sometimes people would definitely give you looks, you know. Like I remember when he was going through diagnosis, he was around the age of 2 and we were in a gymnastics class, and they had a big window that ran across the front of the studio and it was just a floor to ceiling window and he just wanted to go up and down and look up the window, that was like a very cool sensory input. And at that point it was very hard to control, and I was still kind of learning, I didn’t know he had autism or anything yet. But none of the mums in that group would ever even speak to me, like they treated us like we had the plague or something, it was bad.

**Interviewer:** Ohh, I’m so sorry to hear that.

**Interviewee:** Argh! It was terrible!

**Interviewer:** I’m sure. I’m sorry.

**Interviewee:** We’re good.

**Interviewer:** You touched on a lot of different places in your community, like you talked about your neighbors being really accepting. Are there other spaces or places that are more or less accommodating or accepting of him and his needs?

**Interviewee:** So, he has another behavior, which you’ll have to decide if it’s sensory. He likes to gag himself and make himself throw up, which is not a good thing to do, really anywhere. But every Saturday we go to Outback Steakhouse for wings, because he asks for it on his iPad. And I can’t remember if I told you this when we talked last time, but he has been making himself threw up at the table, and he does it very stealthily, in a very stealthy way, where he looks fine, he looks fine and he just looks around and goes **[making puking sound]** and just throws up all over the table. So that’s *awful*, like we’re in a *pandemic* on top of that. But they're so great, like very…because they know him, like they’ve watched him grow up through the years, and they've seen him go through different things. And so, I feel like that is the ultimate kindness, you know, not just saying hey…because he did it for like 2 weeks in a row. And after that it seemed like they’d be like, *“hey guys, take a break, maybe don’t come back for a little while or just do take out, we don't need him throwing up on the table during COVID.”* But we were back this past Saturday, he did not throw up and they were like, *“good! Way to go Jack! No throwing up.”* And I’m like wow, they’re just people, they’re not the autism community, but they were like cheering him on. So, in that sense it’s good. I think if he’s at a cross-country meet and he goes up and smells somebody’s hair, that’s like…especially with opposite sex, they get scared.

**Interviewer: [00:37:24]** Yeah, absolutely. You’ve alluded to this a little bit, but what hopes or worries do you have regarding how his community will react to him in the future as he continues to transition to adulthood?

**Interviewee:** Definitely just people seeing him as a threat to their safety, you know, if he grabs them in a way that’s inappropriate, you know. Like he doesn't really grab people in inappropriate ways, but what they might think is inappropriate, like he grabs your arm or sniffs your hair – I guess that is inappropriate. Or if he just is doing the jumping thing, like I said if he barrels into someone who’s 80 years old and he knocks them down, you know. Bad things can happen, I mean, law enforcement can be called and it’s very frightening to think about those things.

**Interviewer:** Yeah, absolutely. Thank you for sharing that.

**Interviewee:** Yeah, very scary for him.

**Interviewer:** For sure. And you too.

**Interviewee:** Argh, yeah, I feel like we’re constantly in the fight or flight, you know.

**Interviewer:** For sure. We’re gonna move on to our next chunk of questions if that’s okay?

**Interviewee:** Ok. Someone texted me, I need to respond.

**Interviewer:** Yeah, no problem.

**Interviewee:** Ok. They’re texting me something that I sent them earlier. And I’m like why are you sending it to me? Do you read?

**Interviewer: [chuckles]** Sometimes people don’t read, truly.

**Interviewee:** Yeah, they’re like, *“did you see this?”* and I’m like, *“yeah, I sent this to you an hour ago.”*

**Interviewer:** That’s why you see it.

**Interviewee:** Okay, alright, emergency solved, yes.

**Interviewer:** Okay. In the transition to adulthood, where do you see your son?

**Interviewee:** Right now? Or in the future?

**Interviewer:** Currently.

**Interviewee:** Currently, OK. So, I see him as actually doing very well based on his diagnosis, because he’s diagnosed with autism, he’s diagnosed with a severe intellectual disability, so he doesn’t read, he doesn’t write, he speaks very little, he’s got super challenges, like he has severe autism. But, he can unload the dishwasher from top to bottom, and he's learning how to tie a trash bag, and his hands don’t work totally right, he’s learning how to wipe tables, you know. And these are things – predictably, people would look down and be like, *“oh you’re underestimating him,”* or whatever, but for him to be able to do those things is incredible. Those kinds of things surprise me that he’s able to get all the dishes, all the utensils out of the dishwasher and put them in the right places, it’s huge. So yeah, so I don’t know that he will ever…I’d say the goal is employment, that’s a lofty goal for him when you’re balancing the sensory, the behaviors, the intellectual disability, all of it. You know, that goal is employment, but if he doesn’t get there because things are too overwhelming, I definitely can see him what support doing things in the community [throughout] adulthood, so yeah. He’s learning how to do things, you know.

**Interviewer: [00:41:26]** That’s wonderful. You mentioned that he has trouble tying things, is that because of the neuropathy?

**Interviewee:** I’ve never known. So, his fine motor’s never been good, but then the neuropathy plays a part too, so he just...I don’t know, yeah.

**Interviewer:** You mentioned that he’s learning things right now, what are things he’s able to do and what are things he’s still in the process of learning?

**Interviewee:** So, he can do things like, he can get dressed, but his clothes are on backwards – *every time*, so stuff like [that]. But if you tell him to get dressed, he will put on bottoms, top, it might just be askew. He is still learning how to shower himself, he can brush his teeth, but when he’s done I usually go back in and do a little more just to make sure they’re clean. But you can say, *“Jack, go take a shower, go brush your teeth, put on your deodorant, get dressed,”* and he can go through those steps, it’s just gonna not be a great job. So, I’m trying to think…as I said, he can unload the dishwasher, he can put his socks and shoes on – not well, but he can do it. He can zip things, he’s not very good at buttoning things, that’s a challenge and I think some of that too might be the neuropathy at play. Who knows? He can bring in bags from the car like when we go to the grocery store, he can push the grocery cart if you’re with him, so he doesn’t like slam into grandma, he can take the things out of the grocery cart and put them on the belt if you tell him. I’m trying to think…he’s learning at school how to put gloves on just so he can wear them outside when he’s running and it’s cold or gloves to wear like when he's wiping down the tables. Yeah, so things like that. He’s not typing his name or anything like that.

**Interviewer: [00:44:15]** Sure. Is he able to prepare a simple snack or something?

**Interviewee:** Not really. Although I think he might be close, like if I said, *“Jack go make some chicken nuggets,”* he probably could get them on the plate, he could, and put them in the microwave, but that’s where it would stop because he doesn’t know how to read, like he wouldn’t know what button to push. So, I think if we worked really hard to teach him that, that’s something he could do. He can go into the kitchen, get a carton of ice cream, open it up, eat, you know. He *can* go in and pour himself a glass of juice, so he’s able to do those sorts of things, but like preparing something that needs to be heated up, not yet.

**Interviewer:** For sure. You mentioned that he does cross country, does he have friends through that?

**Interviewee:** He had one friend, he graduated last show, Oliver. And Oliver went to the Naval Academy, so he hasn’t seen Oliver since. But this year he’s not running because of COVID, you have to wear a mask the whole time you’re running, and for him, he does wear a mask at school but not when running, like it's just a little bridge too far. So, we took just the year off, but we’re gonna go back next year and hopefully he’ll make a friend, but it’s hard, you know, it’s hard. It’s interesting because I have a friend who lives on the corner of my street, you know, I can be in her house in 30 seconds. And then we have next door neighbor friends who’ve been there since we moved in, and they have boys that are Jack’s age, both of them, and they never have ever tried to do anything with Jack or be his friend. And they’re nice, they’ll be like, *“hey Jack!”* or *“hey guys, how are you doing?”* but he's just not on their radar, and I’m like I might need to try to do more to connect them, but anyway, the friendship thing is super hard.

**Interviewer:** I’m sure it is, I’m sure it is. You mentioned that the goal is employment for him, has he had any type of simple job like through school or not through school?

**Interviewee:** So not a paid job, but before COVID he was at, I wanna say it was 24 Hour Fitness or it might have been Fitness Together, one of those. And he was working the towel crew. So, it’s a group from Nashoba, and they would go over and get the towels and put them in the basket around the club.

**Interviewer: [00:47:20]** That’s great. And through that, was he learning more of the actions of the job or did they also get into money management and money?

**Interviewee:** He’s just starting on the money stuff, like identifying currency. So I could say no, not yet, it was more the actions of the job. And you know, not going to run on the treadmill while you’re supposed to be putting the towels in the container **[chuckles]**.

**Interviewer:** Absolutely. And then this may not be super applicable to your son, but does he ever express interest in his own way of wanting to live on his own?

**Interviewee:** I mean, I don’t know, he probably would love to, but I don’t know. That’s not something he can express. And I would say back to the friend thing, he does have a best friend and that’s his sister, like they’re very close. Although I’d say she is more of the giver, he doesn’t care about her as much as she cares about him, but she's been a constant friend to him and always wanted to include him throughout life. And if I ask, who is Jack’s best friend? It’s Amy.

**Interviewer:** That’s beautiful, that’s really good.

**Interviewee:** She is, she always will be.

**Interviewer:** I’m glad he has her, that’s wonderful.

**Interviewee:** Yeah, I don’t know if he appreciates it. But it’s nice because she’s like his age, she’s 3 years older but they’re the same age. So, the reason he listens to the music that he does is because he’s just listening to the stuff from Amy’s iTunes account. And the reason he ran cross country, or we felt comfortable doing that is because Amy had been in cross country for years, so we knew what to expect, and she could provide insight and help him train. But their fun, they like to just hang out together and just be in the same room, there doesn’t have to be anything major going on. She’s his best friend.

**Interviewer:** That’s great, that’s wonderful. And then thinking back to his independent skills, do you think you’ll be able to achieve more and gain more skills overtime?

**Interviewee:** I do, because I really…like the things that he's able to do now are not things I necessarily would have anticipated, so I think there’s always going to be challenges but I think there’ll be clamors of surprise of things that he’s able to do. So, I expect challenging awfulness and then a sprinkling of goodness too.

**Interviewer: [00:49:55]** For sure. And what do you think will help him move into more independence, like what will give you those little sprinkles?

**Interviewee:** I think continuing with the program he has educationally is huge, because they make achievable goals for him and just keep him moving forward, they have a plan, they really see him as a whole person. So yeah, I think that’s key, it’s just the services he receives via his IEP and the services he receives through DDS too.

**Interviewer:** Are there other services or interventions that you think would help him gain independence or continue to gain independence?

**Interviewee:** I think he’s getting everything possible. Well, I will say the other thing too that sometimes gets left off the list, it’s not just the activities, I also think the medication that he takes really helps him to just function in the world and learn and you know.

**Interviewer:** Absolutely. And that’s medication for his OCD, you said?

**Interviewee:** OCD, he takes medication for OCD, he takes medication for aggressive behaviors, Olanzapine, he took Risperdal for a few years and then came off of it successfully, so that was good. So those, if he didn’t take those…before he started taking medication for aggressions, he was hurting himself and others constantly, he would have *hundreds* of aggressions a day, *hundreds!* So yeah, those things are a factor for him.

**Interviewer:** Totally. Good, Well I’m glad they’re helping him, that’s wonderful, it’s what they’re there for.

**Interviewee:** Yeah, I held off on medication for a long time and then finally his developmental pediatrician was like, *“I’m calling it in.”* Like okay.

**Interviewer:** And then putting these two things together, his sensory needs and his transition to adulthood how do they intersect for your son?

**Interviewee:** I think transition to adulthood is transition…typically people think of it as transition to independence, right? I see it more as transition to connection to the world, so he can be part of the world in his own way. Unless something changes drastically, he’s always gonna need some level of support around, so he’s not gonna be independent in the traditional way. But if he’s connected and able to connect to things like cross country or working in a gym, places where he might have an interest, and he’s able to…when he’s in those settings, the sensory needs that might interfere, create some sort of sense of he’s not a safe person to be around, he’s able to manage those and then feel comfortable in his home setting or wherever, to engage in sensory seeking behavior, to meet the need, I kind of see that as to me ideal. And he’s exhibited you know, he can do it, he can hold it together and then come home and just let it all go. And so if he’s gonna be connected and in the community, for the sensory issues that can be problematic, be able to manage those. For those that aren’t problematic, like his ears, sound things, like who cares! With that, I just hope that he can be who he is and we can educate the world to not see those types of sensory seeking behaviors as problematic because they're not. It’s no different than me tapping my leg or doing whatever I do for sensory **[00:53:56 inaudible]**.

**Interviewer:** Absolutely. You kind of answered this, but would you consider his sensory needs an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** I’d say probably a bit of both, leaning towards obstacle.

**Interviewer:** Why obstacle, why vehicle?

**Interviewee:** So vehicle, if he can feel calm and good, then he is able to connect, which is the goal. The obstacle is all about safety and not engaging in behaviors that are perceived as dangerous or *are* dangerous for others or himself.

**Interviewer:** Absolutely. And then what do you anticipate as being challenging for him as he does gain more independence in regard to sensory needs?

**Interviewee:** I think just being able to differentiate between those that are appropriate for public and those that aren’t, that's probably the biggest challenge.

**Interviewer:** Yeah, absolutely. And what do you think will help your child in this intersection?

**Interviewee:** I think we really need to work on teaching him over the transition years and beyond, about what he can do safely and what he can’t, and where.

**Interviewer:** Do you think other than you and your family teaching him that, do you think there are particular services or interventions that could help with that process?

**Interviewee:** Yeah, I definitely think his applied behavior analysis program is definitely…in conjunction with the OT and the PT, all those things working together, that’s a big part of what they’re doing to help him transition into adulthood, so yeah.

**Interviewer: [00:55:40]** And for kids like your son, do you think there are gaps in the available interventions and services to help them in this intersection?

**Interviewee:** Oh yeah, for sure. So I’m biased, but Nashoba is an incredible program, he's been there since he was 4 and it’s top notch in providing individualized services. Like it’s not a cookie cutter like, *“oh we do this for kids with autism,”* they very much see who he is, they interact with his medical team, they all work very well together and they interact with us too as part of the team. So, it’s just a very holistic, wonderful approach. I think 99% of kids with autism don’t access to that, it’s an out of district program, you know, it costs like $80,000 a year, like he’s very privileged. I think kids who have severe autism like he does, especially kids who are transitioning to adulthood, what happens to them is they get to middle school or even maybe late elementary and they get disciplined for inappropriate behaviors that are really more sensory seeking, and they end up either they get kicked out of school or their families just end up pulling them out of school because of safety issues. And some of that is just if the sensory stuff was addressed, they would be much safer and they’d be able to be the community. And then the other piece too is if they get older and they’re a little bit more high functioning perhaps, the interface with first responders is so dangerous, like it can be because of misunderstandings. So, it’s horrifically bad out there. I’m Debbie downer, but it is.

**Interviewer:** You are not the only one who feels like that. I think all but one parent thinks there are gaps, so you’re not alone in that feeling.

**Interviewee:** I heard a thing recently where people were talking about awareness, and I definitely am a strong supporter of autism awareness and I still think there needs to be a lot more of it. People are like, *“oh people are aware.”* Not really. They are aware of their own understanding of autism, but there’s still a lot more work to be done there, but awareness is not a term of action, right? It’s just, *“okay, I’m aware,”* but what’s the action? The action has to be we do have to provide supports to help kids with severe autism and young adults transitioning into adulthood to be able to be safe and happy and connected in the world. And the sensory engagements, they can be so misunderstood and problematic.

**Interviewer: [00:58:47]** Absolutely. Thank you for sharing that. And then again thinking broadly, how have your son’s sensory needs impacted your goals, hopes and expectations for him as he navigates adulthood and independence?

**Interviewee:** I think when I’m thinking about goals for him, my initial maternal response is fear, like oh, if he does, is this safe? Is it going to get him into trouble in any way? But I have to stop, and that’s why working with the team that’s really good helps a lot. I have to stop and kind of ground myself and think beyond that and think okay, we’ve learned, he’s worked really hard how to manage them, we still have a long way to go but…and enjoy them in the appropriate setting, then it’s not a problem.

**Interviewer:** Yeah, absolutely. And then onto our last chunk of questions, we’re almost done. As a caregiver, as a mom, as a parent of someone with autism and sensory needs, what does transitioning to adulthood mean to you?

**Interviewee:** So, to me it means trying to do what we can to face the world without the services that he receives as a child. So, what do we have to do to get him ready for that so he can be at peace, he can be part of his community, he can hopefully have a friend, live a happy life? So, putting all the pieces together to get to that point. And then for me, I don’t see adulthood as a destination, I think he’s constantly going to be transitioning to whatever’s next, so it's kind of a lifelong thing when we think about transitioning…oh I think the powers trying to go out.

**Interviewer:** Oh really?

**Interviewee:** Yeah, the lights just flickered.

**Interviewer:** Yeah, I saw that. Yeah, we’re in October.

**Interviewee:** Yeah, I bet there’s trees coming down because of the snow. Anyway. **[talking to person in the background]** did the lights go out? **[Talking to Rachel]** I’ll talk fast. **[Talking to person in the background].**

**Interviewer:** No worries, we’re almost done.

**Interviewee:** But anyway, I think what we do right now it's less about, for me, academics, more about being able to take care of himself, be able to be safe, connected, those things.

**Interviewer:** Totally. Has this perspective changed over time?

**Interviewee:** Yes, definitely. When he was younger, we definitely were hoping he would speak, he would read, do math, even if he wasn’t verbal, be able to do some things academically. So yeah, but then when he really got to be around 8 or 9, the reality just… I saw his unhappiness, he just seemed miserable because we were working so hard to get him speaking. And then I finally just came to a place of peace like, okay let’s work with him where he is, and then maybe the speaking will come and maybe it won’t. So I met with his team at school and said, *“hey, we need to look at* ***[01:02:39 inaudible]*** *communication that’s individualized for him, we need to look at his physical health, like is there something going on physically where he doesn’t feel good?”* So measurable… I said 30 minutes of cardiovascular a day to help with that proprioceptive seeking, so just kind of pivoted a little bit away from, *“okay, we’re gonna learn to identify letters, we’re gonna learn how to say things,”* and just struggled through that day after day. That is like, you know, I finally came to the realization that’s like me trying to do the hardest calculus problem possible, where you’re just like, *“my brain hurts, this is too hard,”* and he was having to do that all the time. So, you know, it’s a struggle because you don’t wanna underestimate your child, you want to encourage them and provide them with opportunities, but finding the balance, really recognizing when they're miserable and for him as I said, that’s the point in time where he was having hundreds of aggressions a day, he was done.

**Interviewer:** Absolutely, thank you for sharing all that. I just have two more questions, we’re almost done, I promise. What do you see happening in your son’s future?

**Interviewee:** I see him probably being part of…working through the transition to adulthood to develop skills, probably skills like you know, cleaning, service work, that kind of stuff, continuing to enjoy music, continuing to run, continuing to be a vibrant part of his family and his program at Nashoba. And then once he turns 22, I think he’ll probably continue in a similar kind of life but just as part of a day program or whatever that looks like. And hopefully that day program will be going out into the community, doing some kind of work. I think he probably will not get paid, which kind of makes me a little…because everyone keeps on insisting on getting rid of a sub minimum wage, but there is place for it for some people, so he’ll probably never be paid anything because of well-intended advocacy. But anyway, I don’t know that he cares anyway it’s in his bank account, so that’s fine. But I think he’ll… it’s interesting, his sister has always been the kind of kid who always wants to stay busy, hard worker, never had to tell her to do anything, and I really see Jack has the same energy, they have different types of abilities but he needs to be busy and he needs to have something to do. And something that he enjoys. I am old school, in that my first job or things that I did, it wasn’t like my dream job, and I don’t think there’s any different for someone like Jack because sometimes you have to do work where you’re like, *“well this is boring,”* to get to where you want to be **[01:05:56 inaudible]**. And so I think that will be something that will happen with him too as we walk the path.

**Interviewer:** Do you see him staying with you? Do you see him transitioning to a group home, anything like that?

**Interviewee:** That’s hard. So, I think he needs to transition out of our home at some point, because I really think it would be unfair to him to keep him close and introduce him to him being away from us and then us dying. He’s gonna live probably 30 to 40 years on the planet without us, so I think it would be a disservice for me just to be like, oh Jack. We could probably…we could keep his behaviors under control and everything, just keep him at home, but I don’t think that’s fair, I think it’s going to be hard for me though to really know when the time is to make that move.

**Interviewer:** Yeah, that makes sense. And then final question, how have your son’s sensory needs impacted this perspective he just articulated about what it means to transition to adulthood?

**Interviewee:** I think they are the sky that we walk under all the time. Sometimes it’s cloudy and awful and uncomfortable and then sometimes it's sunny and warm, but it’s the sky we walk under *all* the time. And sometimes it’s dark and sometimes it’s light, sometimes it’s stormy, sometimes it’s beautiful, but it’s the sky.

**Interviewer:** That makes sense, thank you. I appreciate you sharing that with me.

**Interviewee:** I’m gonna cry now.

**Interviewer:** I’m sorry, are you okay?

**Interviewee: [01:08:00 inaudible]**

**Interviewer:** Oh no **[audio cuts]**

**Interviewee:** Are you back?

**Interviewer:** Hi, yes I am.

**Interviewee:** Oh, you’re back. Ok

**Interviewer:** Hello. Are you alright?

**Interviewee:** Yeah, I’m alright.

**Interviewer:** That was actually it for my formal questions, I’m sorry to end on such a hard note…

**Interviewee:** No, I actually am crying because I think it’s beautiful, actually I didn’t think about it that way, so no.

**Interviewer:** OK. It’s a beautiful analogy and it sounds very apt.

**Interviewee:** Yeah, when I was like, yes, it’s the sky.

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

**Interviewee:** I feel like the world is turning upside down, this is gonna be a fun recording to watch. No, I think we covered it. But, I do wanna say, something that didn’t come up as we talked, when he was younger, Jack did go through periods of time where he would touch certain things, like he was attracted to touching certain textures, but that was pre-transition younger and you know, and we had that kind of thing too to teach him when it was appropriate to do it and when it wasn't, very much kind of like the smiling thing but touching. But that really from puberty and has not really been an issue, but I wanted to tell that to you, I don’t know if I included that anywhere.

**Interviewer:** That’s okay. When he was touching, what things did he touch, do you know? Or was it like consistent?

**Interviewee:** Yeah, it was. So he liked like really soft, velvety kind of thing, so like blankets or things like that. And then just walls, mainly just walls, just over and over, constantly touching, more than would be normal, you know, tapping, touching.

**Interviewer:** And he doesn’t do that anymore, you said?

**Interviewee:** Mh-mh, he hasn’t done it for years.

**Interviewer:** Anything else? That was wonderful, thank you.

**Interviewee:** Nope, that’s it.

**Interviewer:** Okay, thank you so much for taking time on your Friday to talk with me.

**Interviewee:** I apologize for screwing up the Zoom, and I will fill out the questionnaires and get those back to you too.

**Interviewer:** Perfect, thank you. Awesome, and as soon as I get those, I will send you a gift card as a big thank you for your time and effort and for sharing everything.

**Interviewee:** I know, I really don’t want a gift card, like…

**Interviewer:** Oh, I have to give it to you **[chuckling].**

**Interviewee:** Okay, I didn’t know you had to, I was going to say you can save it for somebody else if you want to.

**Interviewer:** Oh, that's really sweet. I’m pretty sure I have to give that to you, I could check.

**Interviewee:** If you don’t have to, just keep it, but if you have to, send it, we’ll put it to good use.

**Interviewer:** Alright. Well, thank you so much, it’s been so wonderful to talk to you and to learn from you. Before I go, can I do anything for you? Can I answer any questions?

**Interviewee:** No, just keep up the good work.

**Interviewer:** Ah, thanks. You too. Alright, happy Halloween, happy Friday.

**Interviewee:** Bye

**Interviewer:** Bye.

**[End of Transcript]**