**[START OF TRANSCRIPT]**

**Interviewer:** Okay. Beautiful. We are recording and I will be asking you questions about your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities and we’ll be doing something called a semi-structured interview which means I have my planned questions in my script, but I’ll be adapting them to follow our conversation, so they actually fit for what we’re talking about. Any questions?

**Interviewee:** No.

**Interviewer:** Okay. And if there are any things, any questions you don’t want to answer for whatever reason, perfectly fine. *“I don’t know”* is perfectly fine as an answer as well and feel free to bring things up as they come to mind.

**Interviewee:** Okay.

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

**Interviewee:** Andrew is a sensory seeker. He enjoys loud noises; he wouldn’t be fazed for instance by a fire truck or something like that. He might not even notice it. He definitely seeks out pressure or touch and that could involve tapping a wall as he’s walking by it, tapping people while he’s with them. He’s literally a kid we used to call, he used to hunt trees so he has, in kind of all areas almost. He likes kind of spicier, hot foods. The only thing which he is sensory averse to is some…he likes pressure vests and things like that, like I just mentioned. He is very stuck in what he likes to wear, it needs to be no designs on it, needs to be pretty much just cotton and easy pull-on pants. We only got him to start wearing jeans about, I don’t know, two years ago. Jeans or khakis, anything with buttons. His socks have to be put on exactly the right way, they have to be the same kind and he’s a kid who is more reticent now about being hugged but does seem to enjoy pressure of many kinds, including he has a lap pad for when he’s sitting online, on zoom and a regular, weighted blanket, so a weighted lap lad, I’m sorry. So, I would say his sensory sensitivities are he does not like rain, he does not like snow, he’s very bothered by them. Touching his face or kind of anything like that.

**Interviewer:** He doesn’t like things touching his face?

**Interviewee:** He likes not something that’s as inconsistent as that, like for instance, he likes to wear a mask. The mask wearing has been easy for him because of the pressure but if you walk out and it’s raining, it’s not the same as consistent pressure. That’s how I would describe his sensory profile.

**Interviewer:** Awesome. Thank you so much. I really appreciate that. Do you mind if I ask some follow-up questions?

**Interviewee:** Sure.

**Interviewer:** Thank you. So, I’m gonna kind of go in order of what you’ve just talked about. So, you said that he enjoys loud noises and you gave the example of a fire truck, so that’s more of a machine-ish noise, what about human noises?

**Interviewee:** Yeah. Yeah. I mean it could be in a large crowd, like one of the things I put in one of the notes is he likes going to concerts. I actually sent you the link to that. They’ve always accommodated him because he does like the loud noise, he likes a lot of singers and going to the TD Garden, they always put us in a box wherever. So, I would say that noise does not bother him at all. In fact, he seems to thrive on it and he has very limited interest and music is one of them but if I tried to put him in a seat in the middle of a row at the Boston garden, he would absolutely lose his mind being that close to people so the noise, in and of itself, he would enjoy but sometimes, I wanna wear earplugs and he’s like happy as a clam so what we do is we have had headphones for him, noise-cancelling headphones to just kind of get up through security and things like that cause that is a time where it’s a lot of people around him and things like that. But, yeah, I don’t think he would do well if it was just a really crowded place and even when we’ve taken him to Story Land and things like that, it’s got to be not a busy time even though they do have a special pass for kids with special needs. It’s hard.

**Interviewer:** Yeah. I’m sure. Awesome. Thank you. And will he turn up volumes on the TV or on a radio?

**Interviewee:** He always wants everything higher.

**Interviewer:** Got you. Thank you. And for touch, you talked a lot about him enjoying deep pressure, what about lighter pressure?

**Interviewee:** Not so much. I feel like it’s almost annoying to him but at the same time one of his stims is he’ll tap you very, very lightly. But I’m not sure what he gets out of that for himself but, yeah, if I just came up and gently touched his shoulder, he really wouldn’t like that. Now maybe if I hugged him from the back and gave him a big bear hug, he would like that.

**Interviewer:** Got you. Thank you. And you also talked a lot about him enjoying seamless with his clothing, and you mentioned cotton or particular socks, is that a texture thing or is it just what he likes thing?

**Interviewee:** It’s anything soft. It’s a texture thing. We do a lot of cutting labels out of things and things like that. But, yeah, just really soft things, pull-on pants, things like that.

**Interviewer:** Got you. Thank you so much. And what about smell? Any sensitivities or aversions to particular smells?

**Interviewee:** No. No.

**Interviewer:** Yeah. And what about visual…sorry?

**Interviewee:** No, I’ve never noticed if there’s an intense smell that he likes, no.

**Interviewer:** Awesome. Thank you. And what about visual stimuli?

**Interviewee:** He can get fixated pretty easily on, and this is one of the things we knew he had autism or thought to get it checked out. He still likes fans, he still likes rolling wheels on a truck, I mean I’m sitting here, this is really his desk and he likes lining up his figurines and they have to be lined up in a very specific way and if that changes, that is upsetting to him or if somebody else changes it.

**Interviewer:** Got you. Thank you so much. And these sensitivities and preferences you’ve described, have they changed over time?

**Interviewee:** Not much. No. I mean they’ve stayed pretty consistent and that’s with tons and tons of OT. No, they’ve definitely pretty much stayed about the same.

**Interviewer:** So, no increases even and no decreases?

**Interviewee:** I would say, if anything, he’s more tolerant to kind of louder, consistent things like say, a concert or something like that but it’s always because there’s the combinations that are there. But, yeah, like even thinking about the clothing, he’s always, always, always, he was a Gymboree kid, Gymboree outlet kid cause it’s 100% cotton and it’s all pull-on, he won’t wear anything with a character on it, a lot of those things have just been the same. I actually just went back and I looked at his 2 ½ year old testing for the public school and there was a fire drill during the middle of it and I remember it very clearly and he didn’t even notice it. And they had what was a REEL assessment, the teacher, OT, PT, he wasn’t bothered by it, I mean he wasn’t talking then either, but he didn’t seem fazed by it at all. Whereas it’s blaring to the rest of us.

**Interviewer:** Absolutely. Thank you. This might not be super applicable from your previous answer, but this increased tolerance as a change that you described, do you think that’s related to any independence that he’s gained over time?

**Interviewee:** I think so. I think he feels a little bit more confident and I think he knows that the people around him are going to make sure that we’re going to set situations which are going to enable success for him because we’ve learned over the years what does and doesn’t work so I think he’s pretty reliant on that.

**Interviewer:** Okay. So, he’s reliant on your accommodations to feel okay in those scenarios?

**Interviewee:** Yeah, or his teachers. **[To son]** I’m talking to my friend Rachel, Andrew. I know, it’s silly to be on a zoom call on a Sunday. Go back to bed. It’s fine. **[To Rachel]** Sorry.

**Interviewer:** No, no. Don’t be sorry. I appreciate his sentiment.

**Interviewee:** Oh, I thought this time was okay for you, I’m sorry.

**Interviewer:** No, no, no. I’m teasing. I’m teasing. **[00:10:57]** No, no. this is perfectly fine. I’m happy to be flexible. Just conceptually, I understand what he means. This time is absolutely perfect. I don’t mind at all. You’ve alluded to this but how either does your son cope or manage or handle his sensitivities or how do you help him manage or cope with them?

**Interviewee:** Oftentimes if things are not in a place where he’s feeling comfortable, we always call it, it looks like he’s crawling out of his own skin. So, what he would do is try to escape the situation. What we would do is he has a neoprene vest, it’s not a pressure vest, it’s not a weighted vest, it’s a pressure vest, it’s called a Bear Hug, so you just give him kind of a hug using the weighted blanket, using joint compression kind of stuff like that are all things that we’ve, those have been pretty consistent over the years, especially during times of transition, times we know that are going to be hard for him sensory wise and they seem to have a lot of efficacy.

**Interviewer:** That’s great. And has he received specific interventions or therapies to help him with his sensory sensitivities?

**Interviewee:** Yeah. He’s had OT since he was four months old. Always with the sensory goals.

**Interviewer:** Always with the sensory goals. Is that what you just said?

**Interviewee:** Yeah.

**Interviewer:** Got you. And do you think it’s helped him?

**Interviewee:** I do. I do. I mean I think they taught him how to put his socks on to the way that makes sense. I mean he’s still on slip on shoes which is fine with me, but they taught him to tolerate other materials and fasteners on clothes, like the pants, the jeans, for instance, right? Cause that’s not always soft so they’re unfortunately very specific jeans, you know, from the Gap but they really did a lot of just lots and lots of preview, and you know, *“hey, we’re gonna wear something for…we’ll try the socks for ten minutes,”* or *“we’ll try it for five minutes”* and like really building up that tolerance so yes, I do think it’s helpful.

**Interviewer:** Yeah. That’s wonderful. I’m glad.

**Interviewee:** Putting a hat on his head, things like that.

**Interviewer:** What about the hat? Could it be inconsistent pressure that you mentioned?

**Interviewee:** Yeah. It’s because it’s not a daily thing so I feel like if it were part of the routine, this is what we do every day, put a shirt on every day, put a hat on…it’s inconsistent. It’s not all winter, right? It’s just really cold days so it kind of throws him off a little bit but just kind of working on desensitizing him too cause I think he likes how it feels in the end but there’s a lot of stuff kids have to put on before they get on the bus. You have to wear a mask, you have to…so I have a whole task analysis behind me, there’s a whole board behind me, it’s over here. Steps you have to do in the morning so, but they work really hard.

**Interviewer:** Yeah. I’m sure. And you said the mask was okay though even though that’s a new thing?

**Interviewee:** Well, no, it’s because it’s an everyday, all the time thing. He knows he doesn’t have to wear a mask in our house. He actually often chooses to wear one in the car cause I think he likes how it feels. But yeah, he’s never been one of the kids who had an issue with it. The only issue he’s had is if the elastic isn’t quite as comfortable as it could be or it’s not adjustable but as far as the feeling of the mask on his face, I think he loves it.

**Interviewer:** Got you. That’s a good thing to like right now.

**Interviewee:** Yeah. I could be fighting a whole other fight.

**Interviewer:** Yeah. And then when your son is in a scenario where he’s faced with sensory things or experiences that he doesn’t like or finds aversive, does that cause or increase anxiety?

**Interviewee:** Yeah. It makes him very anxious.

**Interviewer:** What does that anxiety look like for him?

**Interviewee:** It’s a lot of repetitive stims, a lot of echolalia, echolalia-like phrases, *“can we go, can we go, can we go, can we go.”* It’s a lot of trying to separate himself from the crowd or the people, like even when people are not too close to him, like we had to get the COVID test yesterday and there was almost nobody there, I think there were five times as many workers as people but he’s good with staying with me. He knows he can hold my hand. Six feet, it’s much better when they have the little dots down right, but he definitely got more nervous because not only was it a lot of people, it was a lot of people he didn’t know so I think that that’s been difficult for him.

**Interviewer:** I’m sure. And when he does experience this anxiety-related sensory experiences, how does he or how do you help him manage that?

**Interviewee:** A lot of deep pressure around his shoulders, hugs, lots of positive reinforcement. *“Andrew, this is gonna last X amount of minutes. How exciting is this. Mom’s gonna have it done first then you’re gonna…”* just lots of the Floortime techniques, just highly animated language cause he seems to respond to it.

**Interviewer:** Absolutely. Thank you. And has this specific anxiety changed over time or has that also been consistent?

**Interviewee:** It’s been pretty consistent.

**Interviewer:** Perfect.

**Interviewee:** And he takes meds for anxiety but I dare only think what it would be like if he had nothing?

**Interviewer:** How long has he been on those anxiety meds for if you don’t mind?

**Interviewee:** I would say eight years.

**Interviewer:** So, a good chunk of time.

**Interviewee:** Yeah.

**Interviewer:** Thank you. And then looking towards the future and thinking a little bit more broadly, what goals or hopes do you have for your son regarding his sensory sensitivities?

**Interviewee:** I hope he’ll be able to, when the world gets back to normal, right, he’ll be able to run into a store with a list and pick up one or two things and deal with the fact that there are gonna be other people that are there, that he’ll be able to kind of navigate, that he’ll be able to have a wider repertoire of clothes because it’s hard to find clothes that are totally…it was easy when he was in kid sizes. I mean now we’re buying Hanna Andersson adult size pajamas which are $54 each piece so I hope that that can with that kind of sensory need be, he can grow to the point where he’s able to tolerate different and more.

**Interviewer:** Absolutely. Thank you. We’re going to shift gears to our next chunk of questions. So, thinking about community, as your son has grown up and aged a bit, how was his and your community reacted to his sensory needs?

**Interviewee:** Well, boy, that’s a hard question in the middle of COVID. Well, we haven’t done anything in a year. Just overall, I think his community, which is our community as well, I think the good friends that we have and the people that he knows, they understand that, they understand what he needs. We have two little pods of people we see and of course, **[00:20:16]** I work in special ed, so all my friends are special educators and he’ll walk into her house and he’ll just wander. He needs to go see every room, he needs to kind of just kind of just touch the wall and things like that and she gets it, so I think that our community and his community, it’s quite small right now because of COVID but do I think that even before that, people adore him. He’s a really endearing kid, I mean he has his moments, but they really like him, so I mean I think it’s a positive thing to say that he walked for his certificate of completion, I mean clearly he’s still in special ed till he’s 22 and he had a bunch of his old aids and teachers even come, they really like him.

**Interviewer:** Yeah. That’s really great. Thank you. And was his or your community more or less accepting of his sensory needs when he was younger?

**Interviewee:** Less accepting and I would say especially with family. We’ve really cut ties with a lot of our family members because they were not even trying to understand a lot of the sensory needs, a lot of the sensory/behavior, I’m not really sure how to pick it apart but *“why can’t he just wear regular sneakers, why can’t I just get him...”* I mean his grandparents were horrible, lots of really sad losses for him because of that so I would say, for him, we really go by in our family the phrase “friends are the family you choose” if that makes sense.

**Interviewer:** 100%.

**Interviewee:** Yes.

**Interviewer:** I’m sorry to hear that. But you said school was really accepting of him and supportive?

**Interviewee:** I think his school’s great.

**Interviewer:** That’s wonderful. That’s wonderful. Pre-COVID, were there any other spaces or places in the community that were more or less accepting of him?

**Interviewee:** I would say that because we had season tickets to that concert venue, they were super accepting of him and they knew him cause we don’t go on vacation and things like that so that’s kind of the one thing. He loves music. I love music. My girls like music so they were super, super accepting. I would say around town, most people know him, like even yesterday at the COVID test, even if they hadn’t had known him, he’s clearly, if you meet him, has autism so I would say, people have been in the community. Yeah, you’re gonna find the jerk or two in the middle of CBS or we don’t go out very many places but you’ll find some people who just don’t get it. *“Why’s he getting up, why’s he walking around”* but most people have been wonderful because I think from a sensory perspective, I think the walking, proprioception, I mean that is all good for him so we do try to accommodate as we can and not to try to, I’m not trying to change my kid from having autism, he is who he is. We just wanna make him as successful as possible so we use accommodations and part of that and that’s hard. We had to get a handicap plate, that was his doctor’s idea just so he wouldn’t bolt but a lot of these things have really allowed him to become a much more independent person.

**Interviewer:** That’s wonderful. How so in your mind?

**Interviewee:** Because he’s able to go to a new place now, like yesterday, for example. He had never been and instead of walking a whole parking lot, be right close to the door. I mean he brought his teddy bear who he was hugging for support and everybody there just got it so I would say does it happen all the time? No. Does it happen around the people that we happen to know who might be working things like that? Absolutely, which is great.

**Interviewer:** Yeah. Absolutely. Thank you for sharing that. So, again, thinking broadly, more globally, towards the future, what hopes or worries do you have regarding how his community will react to his sensory needs?

**Interviewee:** My worry is that depending on the whole thing of I’m gonna die someday, right is that the people he knows are much more generally older, so he doesn’t have that friend set. He wants it and he does tons of recreation, but my fear is that people will not understand and will expect far more rigid expectations than he’ll be able to accomplish and then his anxiety and stress will just grow, it’s the one mother’s cry at so yeah.

**Interviewer:** Are you okay?

**Interviewee:** Yeah.

**Interviewer:** Thank you for sharing that. I do appreciate it. We’re gonna move onto our next chunk of questions if that’s okay.

**Interviewee:** Can you just give me one second just to go make sure he’s okay?

**Interviewer:** Yes. Absolutely. I’ll pause. Take your time. Don’t worry about it.

**Interviewee:** I’ll be back in like one minute.

**Interviewer:** Take your time.

**Interviewee:** I got more coffee too.

**Interviewer:** Oh good. That’s very important. We can stop now if you need to…

**Interviewee:** No, he’s fine.

**Interviewer:** Okay. Cool. But truly, if something pops up, we can stop. No pressure at all. My job is to be flexible. Alright, so, now that you’re caffeinated…

**Interviewee:** Half-caffeinated.

**Interviewer:** Approaching there. So, in our next chunk of questions, we’re gonna talk about transition and independence so in the transition to adulthood, where do you see your child?

**Interviewee:** I see him living at home the first few years and I see as we come up with more and more opportunities and different ways to serve the adult population with ID and DD, I look at him as being in a house or apartment with two or three other people and a caregiver. Maybe going to a program half the day and working half the day but having a staff member there to help with things. I mean he can do simple meals but to help with the big picture. But it’s different Rachel than it was. My vision was a sad as it is to me that he would turn 22 and transition in the fall. COVID has just put a mess into all of that because he’s not even working vocationally, right? Because he can’t. He was working at the EcoTarium, he’s done Meals on Wheels, he’s done tons and tons of things so I think we’ve just gone and pushed back a few years and his school was one of the first to go back to regular school which was July full-time, but he’s still missed so much. They set him up with an office and he’s the only one there who has an office, nicer than mine but they don’t really have online jobs and things like that. We’re doing a lot of making up materials and things like that so I mean where I see him is working with people, he likes people. He doesn’t like large groups of people. You know if he met you and I told him he could, he’s memorized the calendar for 500 years, he’ll tell you what day of the week you were born on if you tell him your birthday. He is a smiley, happy guy so I see him in some sort of shared living opportunity, working somewhat and then being part of a program for part of the day.

**Interviewer:** Got you. Sorry?

**Interviewee:** I said he’s a great kid.

**Interviewer:** He sounds like it.

**Interviewee:** I’ve got to stop calling him a kid. I mean he’s my kid, he’s a great human.

**Interviewer:** My mom calls me her baby so you know.

**Interviewee:** I think that’s just what mothers do.

**Interviewer:** I think so too. So, you said he’s been pushed back, is that because COVID has just limited his opportunities to interact with a quote-unquote typical world?

**Interviewee:** Everyone. Yeah. I mean they’re limited even in their school. He only interacts with people in his classroom and two of them are on devices which he is clearly not for speech. He’s the kid in the middle. We’ve tried four different programs throughout these transition years. The first one had the best peers for him so he wasn’t loud but the academics were way too high for him. Then he went to a day school, they hurt him and then they strip searched him so that didn’t go very well and now we’ve finally found a place which has really helped him with a lot of trauma. But no school’s perfect, I’m a special ed advocate, no school is perfect but we need to find the right one. I just hope he’s in a place with trusting people and people care about him.

**Interviewer:** Yeah. Absolutely. Thank you for sharing that. I’m sorry that he had and you had some really hard experiences before. That’s tough. I’m sorry. Thinking about independence, what quote-unquote stage is he? **[00:31:57]** What are some things he can do by himself and what are some things that he needs some help with?

**Interviewee:** With prompting, I would say, usually but sometimes without, he can get dressed with deodorant and kind of all of that stuff. He can certainly put something in the microwave himself safely. He is able to hang up his coat and his mask and do all those things and with prompting, he’s able to do laundry. He can independently unload the dishwasher, loading it is a different thing, and put things back in the proper place. He moves very slowly and I think that’s part of the processing speed of his IQ as well but he has some nice skills. He can take a shower, still not sure how to use the soap. He can’t shave by himself which is a real bummer so we’re trying to work on that. But, yeah, so, independently, I think you asked about strengths or what I see, he really needs a lot of help around and certainly going out into the community which is something we can’t even practice right now safely in my opinion.

**Interviewer:** Yeah, absolutely. And at pre-COVID times, was he able to help you with grocery shopping and things like that?

**Interviewee:** In pre-COVID times, he would come grocery shopping. I would always cue him to keep one of his hands on the cart and would try to go through a grocery list that I had set up very, very specifically, like aisle by aisle by aisle and to have him get the items, wait in line and help with the payment. Waiting in line was hard but, yeah, in pre-COVID times, and certainly if we walked into, they love him at Dunkin’ Donuts but we don’t go in anymore, he was able to kind of do that, keep space from people around him, people can be really nasty to him because it’s one thing when you have a six-year-old who is tantruming on the floor and clearly sensory overloaded and X, Y and Z. Clearly has autism. I mean he got diagnosed right when autism was on the cover of Time and Newsweek and kind of all these things. When he’s 21, people don’t quite understand, I cannot even tell you the number of times I’ve had to, and I don’t even keep the privacy shield on his handicap placard like the police officers and other people have said, *“what’s wrong with him.”* If we’re in a place that’s not familiar, we’re much more likely to have an episode like that and that’s really upsetting to me and to him and then they interact with him and they know right away. But God help me if another cop comes up. Here’s this person, they’re the person in the picture, why do you have to say anything, like why?

**Interviewer:** Absolutely. That must be very frustrating.

**Interviewee:** It is especially because it’s very clear the name, the expiration date, things like that so they know there’s no, if they have eyes.

**Interviewer:** You hopefully would have eyes.

**Interviewee:** One would hope. Yeah.

**Interviewer:** Thank you for sharing that. Thinking back to independence a bit. Earlier you mentioned that he does a lot of recreational activities or did, did he or does he manage a social life to some extent or have friends?

**Interviewee:** Not really anymore. I mean I feel like when he was at LAB, he had friends and we would do things with their families. His sister, who’s now off for college, a year younger but she’s a sophomore at uni, she’s studying to be an SLP, really, really just very much did tons with best buddies and things like that. None of those things exist anymore. So, I would say social circle for him are my friend’s kids or my friends, most of whom he loves. But he does the recreation program online, through **[00:36:59 inaudible]** which is one of our local DDS providers but it’s online like four days a week so it’s not the same. So, the week before the world shut down, he did a pyjama night, to watch a movie, he’s done the Best Buddies dances, he did their snowflake dance, snowflake ball, I’m sorry and lots and lots of in-person stuff, bowling, things like that, he really likes it so hopefully when the world opens up again, he’ll be doing that.

**Interviewer:** I hope so. I hope it happens soon.

**Interviewee:** I hope all of us get to do it, right?

**Interviewer:** I know. And you mentioned him doing a lot of vocational work. Through those activities, did he gain or learn anything about money and money management?

**Interviewee:** A little bit. I mean he worked at Yogibo.

**Interviewer:** Where?

**Interviewee:** Yogibo.

**Interviewer:** What’s that?

**Interviewee:** They have all the big cool pillows. He did a lot of facing and cleaning and things like that but I think he did a little bit at the cash register. They have a simulated cash register at school but the world is really not about cash registers anymore, it’s really about using your card right. So, he learned a little bit I think there and then the other rogue pieces, it was Meals on Wheels, it was working with elders and seniors and delivering a meal to them and then working at the EcoTarium. So if the question was money, I think the answer to that…sorry.

**Interviewer:** Does he understand when you swipe a card, your money goes away?

**Interviewee:** No, I think he understands that, we put it back in his checkbook. I’m still myself somebody who writes things down in their checkbook. My girls I’ve taught poorly apparently but we do put it in his checkbook because you can’t have that much money because he does get SSI.

**Interviewer:** Absolutely. That makes sense. And does he ever express interest in wanting to have a job of some sort some day?

**Interviewee:** He does. He wants to be around people.

**Interviewer:** Yeah. Awesome. And does he ever express interest in wanting to live more independently or not with you anymore?

**Interviewee:** He does sometimes. He says it when he’s mad at me or he says *“mom has too many rules”* but I’m not sure he’s at the place where he’s ready for it. I mean eventually he is going to have to but, yeah, it’s not going to happen at 22.

**Interviewer:** Understood. Do you see him gaining more independence one day?

**Interviewee:** Yes. I mean I think that once, just like everything with Andrew, we have to really systematically, whether it’s through DDS, whether it’s through myself, we have to systematically teach him the skills to be kind of a really valued member of your community and kind of the things he needs to do but we can’t do it right now. But yes, I do, and I want that. I don’t want him reliant on me. I mean there’s a lot of discussion, I’m not sure his sisters are in a place where they want to have that responsibility all the time too so I think guardianship is hard, right and his sister who is at UVM for two more years, I think probably around the time she’s done with her undergrad, she’ll probably come back here for grad school cause you need a grad degree to be an SLP is where we’ll kind of start making some big changes assuming the world opens up again this fall. I’m not hopeful for the summer and I had New Kids on the Block tickets at Fleming which we’re supposed to go, I think the reschedule date is June, I’m not hoping anymore. **[00:41:40]** They’ve done such a horrible job with rolling out this vaccine so…

**Interviewer:** I understand you. I share your pessimism. Unfortunately. I wish I didn’t.

**Interviewee:** I do think if people behave and don’t do stupid things but people keep doing stupid things. Let’s just say tonight it’s Super Bowl, I don’t even care about football. When it was Tom Brady, I cared about it. But do I think people are going to have huge gatherings inside? Of course, I do. Do I think they’re going to listen? Nope. Do I think that that just pushes us back? Yeah, it does. I don’t care how many of you have your one vaccine which is basically most people, it’s not going to do anything so and I worry. They talked about prioritizing, the state talked about prioritizing kids who turn 22 before December 2020 which I get right, like they’ve got pretty much nothing, and young people in day programs and things like that but what about the kids like Andrew who are turning 22 in six months, they’ve got in nothing for a year and it’s going to be months and months and months. It’s terrifying to me.

**Interviewer:** Yeah. Absolutely. And I don’t think you’re the only parent who feels that way, at least from the parents I’ve spoken to.

**Interviewee:** Oh no, I’m not and I’m on a bunch of advisory committees for the state. I mean this is what I do. So you’re talking to me as the mom and I am pushing the Arc bill forward which would give people like me and him priority. People with ID do not do well with corona and the caretakers who are unpaid, so we’re not the PCAS, we’re working with these kids all the time. I’ll get off my high horse.

**Interviewer:** That’s okay. I understand and I share your opinions of your high horse. Thinking back to your son and his independence, what do you think will help him move into adulthood a little bit more, whatever that may look like for him?

**Interviewee:** Moving him there or getting him there?

**Interviewer:** Move as in not physical but what do you think will facilitate him approaching adulthood more?

**Interviewee:** Direct skills training. I really think that having a job again for instance, I think having some homebased support. I mean I can whip up the best behavior plan on the planet but I’m still mom here, I’m not the special ed teacher, right? So, I think that we’re going to have to really, I wouldn’t say start from scratch but I would say start at a place which makes sense for him so he can be employable. The one thing and this is the place I’m going to say it during this interview that disgusts me about just lots of programs, and it’s not just his school, I don’t need him shredding documents, I don’t need him stuffing envelopes. That is just a waste of time for him. That will not be his job in the future. He’s great at computers, at data entry, doing spreadsheets, doing emails. He’d be a perfect greeter at many locations I could think of. They don’t know what to do. I’m the one who has come up with the simulator things for his office work, me. For my Christmas list, they had him put in the things himself for example. I really feel like I’ve been the one who’s pushed that and I really do hope that as he moves into adulthood and again, he’s priority one as far as I know from DDS, he’s going to get the maximum amount of services and supports. He’s going to need all of it. He’ll need that wrap around. The way I put it is this Rachel. We spend almost twenty years, twenty years, I’m trying figure out when the pandemic started, a year ago, teaching him social skills, teaching him how to interact in the world, in the community and we’ve had to unteach him all of that, we’ve had to unteach everyone all of that. *“You can’t go closer to this person; you have to be this far away from this person and that person”* and I think Andrew’s a kid who is wanting people. You’ll love this, there’s two kids in another classroom who he really likes and he has to walkie talkie them, he’s not allowed to see them so you talk about making friends. I just laughed going through half the reading forms because they’re not COVID-friendly, right? Where’s that pandemic playbook when you need it. But no, he wants to be friends with these other kids, and I’ve been working with the director of the REC program that he’s in to have some conversations with other kids, with their parent’s permission too. So, it’s good, he’s busy, I mean he gets on the van, he comes home at 4, he’s usually on something either from 4-5, or from 6-7 or 6-8 every night so it’s not like he’s not getting anything. He was so excited, so this will make you laugh because it wasn’t crowded. He was so happy to get his COVID test yesterday. He could go and talk to the guy who was at the door, he could talk to the people in the line, he could introduce his teddy bear to them, you can see he’s craving, I think all of us are to some extent. It was an easy COVID test too which is the only reason he got it. I wasn’t going to get into a fight with the school. I’m like *“I’m not getting him a test because he’s tired.”* But, anyways, it was fine. And he was a superstar, he was a superstar, and the best thing about yesterday is, like I said, there weren’t very many people there to get a test, it was a lot of staff, a lot of people from the board of health and from the ambulance company and stuff like that. They all clapped for him. They gave him thumbs up. They wanted to give him elbow bumps. *“Way to go, bud, you did a great job”* cause they clearly knew, it’s pretty clear and he had his teddy bear and they gave the teddy bear a COVID test.

**Interviewer:** Oh, that’s so sweet.

**Interviewee:** That’s just the way humanity should be.

**Interviewer:** Absolutely.That’s lovely. Thank you for sharing that.

**Interviewee:** Yeah. It was a nice... I don’t know. I’ve never seen a child so happy to be getting tested for

**Interviewer:** I hope he’s always so positive and so good.

**Interviewee:** I am lucky. Oh my gosh. All my white hairs. Okay.

**Interviewer:** Don’t worry about it. You look great. You’re more put together than I am right now. So now putting these two things together, his sensory sensitivities and his transition to adulthood, how do you think they intersect for him?

**Interviewee:** I think he’s going to have to work on a lot of the coping strategies with his sensory needs and find a vendor agency and find that right fit to make it so he’s able to access adulthood. Even post-COVID, back to life was, you can’t go up to somebody and say, *“what’s your name, when’s your birthday”* and even touch. He doesn’t touch inappropriately, but just touch their… They intersect in so many ways because it would be sharing space with someone else, **[00:51:33]** it would be learning to live with people who aren’t his family and while he’s flexible, like I could take him to a hotel, we went away a few times over the summer, into the middle of nowhere frankly, prohibited to go anywhere, he’s fine but he needs that familiarity so I think that the sensory piece for him, the difference is I know what to do so I guess the easy answer to your question is whoever is going to be his caretaker, that group of people, are also going to know and going to require some significant planning.

**Interviewer:** So, they’ll have to know all about his sensory needs in order to accommodate his new life?

**Interviewee:** Correct.

**Interviewer:** Awesome. Thank you. Sorry?

**Interviewee:** No, I think that makes sense.

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

**Interviewee:** I don’t think of them as an obstacle so much because he doesn’t avoid so often. I think that could be a little of both meaning that if an ambulance or a fire truck or a police car was coming down the street and he was walking, he wouldn’t necessarily know to move over. But I think that his skills with people aren’t that different from many people’s skills with people. In a non-COVID world, I mean, I grew up in Burlington which is this tiny little town next to where we are now, people are very friendly, they’re just friendly and I think he’s going to have to be retrained not just to say *“what’s your name”* but *“hi, my name is Andrew, what’s your name?”* Nobody has ever reacted badly to that. Ever. Ever. Ever. Ever. But I think that his skills of wanting to make connections are going to go really far and that’s a lot of the sensory piece too. As long as he has the right accommodations, I think they could be strengths for him. I mean he’s not a kid who eats three foods, right. He was when he was three. But he’s not anymore. You can bring him to an Indian restaurant, he’ll get the spiciest thing and he’ll put spicy things on it. Do you know what I mean? I feel like he could use some of those to his benefit and yeah, I mean, the other half of it is he’s going to have a teddy bear. He loves his teddy bear. He has fifty teddy bears by the way but he’s one very special one so and I learned a long time ago from an autism parent, who’s been there twenty years before me, she just said *“it’s okay.”* She said *“I let my Eddie just carry around Thomas the Tank Engine trains.”* You’ve got to pick your battles. Am I trying to normalize him into society? No, that’s not my goal. My goal is to make Andrew the best Andrew he can be in society. I don’t need him to be normal. I don’t even know what normal is, even for my girls. I feel like I want him to be happy, what makes him happy is something like, I don’t know, going for a walk around a pond that’s not crowded which is not happening right now, going out to dinner, things like that. Those are things he thrives at. He thrived doing in-person REC, thrived. He thrives when he’s in his office with a staff member. He thrives.

**Interviewer:** Got you. Thank you.

**Interviewee:** I hope I answered your question.

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

**Interviewee:** Being able to make choices about I guess simple things like clothing, right? Not saying, *“I don’t like that right away because it’s not the right material.”* Also, what will be challenging again will be the if there’s a police car or a fire engine or an ambulance, that will be challenging for him to even note it, more or less respond to it.

**Interviewer:** Absolutely. Thank you. And in this intersection, what do you think will help your son?

**Interviewee:** I think a lot of direct support from DDS, and from MRC, and from myself and from his sisters who love him some days and want to wish he wasn’t here, it’s hard, I think being an autism sitter is pretty hard.

**Interviewer:** I believe it can be. Other than the direct support you just described from you and your family, are there any other services or interventions that you think could be beneficial to him in this intersection?

**Interviewee:** No, I think vocational training like I mentioned is going to be the biggest.

**Interviewer:** Absolutely.

**Interviewee:** Yeah, that’s it.

**Interviewer:** That’s perfect. Thank you. Do you feel like there are gaps in the available services and interventions for folks like your son?

**Interviewee:** Yes. Absolutely. I feel like beyond just COVID, not allowing anyone to be prepared for anything, I think a lot with school, even the way it was, kind of not being as creative as I would have liked them to be, to try to prepare him. I feel like and it’s only cause I do this job that I know what to do. I think DDS has been fabulous. A long time ago, mass rehab commission, you couldn’t have two agencies, you could only have one so now you can have two which is wonderful, so I feel like mass rehab commission also has the people and the locations and things like that to do training. I think that those together will be really helpful.

**Interviewer:** Wonderful. Thank you. That’s very helpful for me to hear. And now again thinking broadly again, how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he navigates adulthood?

**Interviewee:** I think they’ve, in some ways, given us a good path as a family for things which are healthy and good to do, like going for hikes, like going to the beach, walking along the beach just because things can be a little bit distant for him so he’s not rubbing up against people and things like that. He’s taught me more than I’ve taught him. I’ll tell you that. He’s definitely impacted our family in ways and because of his sensory needs, I hate to say it, and we’ve never taken advantage of it. He gets his box seats every time we go to the TD garden cause he literally can’t handle being in a regular seat. He’s been able to show flexibility in places I never thought he ever could with his sensory needs and with the girls and I think that that’s kind of awesome. He co-chaired the autism speak squad for two years which meant standing on a stage, with him glued to me, in front of 5-10,000 people giving an opening remark which is huge with David Wade from Channel 4 and a DJ and things like that.

**Interviewer:** That’s amazing. That’s not trivial for anyone.

**Interviewee:** And he gave a huge speech when there was a fundraiser, I mean not huge. Very simple, it’s a PowerPoint and it’s not a lot of words but to me, it’s huge.

**Interviewer:** It is huge. And that’s a wonderful accomplishment, that’s amazing. Thank you. Last chunk of questions, we’re almost done. So finally, as a caregiver, a mom, a parent of someone with autism but also sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** **[01:01:29]** It means that he’s going to have a chance at life and it means that what I have done or not done for him matters and that it’s a huge responsibility to just kind of make sure he is as ready as he can be and I don’t think the transition to adulthood, I don’t think it’s linear, I mean I think there are bumps, certainly now, it means that the people in his life have put in place the things that are going to make him successful for life.

**Interviewer:** It sounds like you have done that. It sounds like you’ve done a lot to help your son along the way. Has this perspective changed over time for you?

**Interviewee:** No. No. It hasn’t and I’m the parent who, when we got the diagnosis, at two, was happy to get the diagnosis because it meant he got extra help. I don’t blame autism or his sensory on anything, it’s just who he is. He’s an amazing human. No, it hasn’t changed.

**Interviewer:** Got you. Thank you. He does sound amazing. So, what do you see happening in your son’s future?

**Interviewee:** Like I said, I do see him living with similar mates, with a caretaker, working part time and being in a program part time.

**Interviewer:** Awesome. Do you see him finishing off his school program?

**Interviewee:** Oh yeah. He tells them all the time. August 14th is a Saturday so I’ll be done on August 13th.

**Interviewer:** Perfect. It’s helpful to have a calendar.

**Interviewee:** Yes. Yes.

**Interviewer:** Do you ever see him having a family of sorts? Family can be flexible, friends, support system.

**Interviewee:** Yeah. Yeah. I mean my best friend is like his aunt. Yes, yes, I see lots of supports that continue to be there.

**Interviewer:** That’s great. And last final question, this perspective you just described, how have his sensory sensitivities impacted that perspective if at all?

**Interviewee:** I think it all goes back, it’s a complicated question, to the fact that he’ll still have the supports and the people around him who know what those sensory issues are and able to practically address them or even if something does happen, know how to address it after. Does that make sense?

**Interviewer:** It does. That’s perfect. Thank you. That was it. Anything else you’d like to add?

**Interviewee:** No, I think I just talked a long time.

**Interviewer:** You did. No, but it was wonderful. Thank you. It was so lovely to learn from you. I did learn a lot so thank you for providing your time and your insight.

**Interviewee:** You’re welcome. So, I did all the surveys, I think?

**Interviewer:** Yes, you did. You absolutely did. You’re all good. And I can manually input that last question for the SRS so you’re golden.

**Interviewee:** So, what do you guys do? You send me a gift card or something?

**Interviewer:** Yup. So as soon as this audio renders, it will take a little bit so I’ll probably email you tomorrow morning.

**Interviewee:** No problem. Is it Amazon? I wasn’t sure what it was.

**Interviewer:** Yeah, it’s an Amazon gift card. It’s $50. It’s been wonderful. Thank you. Would you like a copy of any of the reports you filled out as well? Would that be helpful?

**Interviewee:** Sure, because I have to fill them out over and over again and it’s probably just easier to, like I sent you.

**Interviewer:** Yeah, no, thank you. I so appreciate that. Happy to do that.

**Interviewee:** That’d be great.

**Interviewer:** Yeah, of course. Anything else I can do to help you or any questions I can clarify?

**Interviewee:** No, thank you so much Rachel. Good luck with your project. I hope I helped.

**Interviewer:** You did. 100% you helped. This has been great. Do you actually know anyone else who might wanna participate? We’re still looking for a couple more participants. It’s okay if you don’t. I’m sorry?

**Interviewee:** What were the ages again?

**Interviewer:** 16 to just under 26.

**Interviewee:** Send me the link and I’ll send it to a few clients.

**Interviewer:** Beautiful. I will do that. Thank you for making time this morning and filling out the surveys so early in the morning.

**Interviewee:** No problem. It was a pleasure to meet you.

**Interviewer:** Pleasure to meet you. Anything that comes to mind, you know where to find me and please don’t hesitate to reach out.

**Interviewee:** Thanks Rachel. Take care.

**Interviewer:** You too. Have a great day.

**Interviewee:** Bye. You too.

**Interviewer:** Bye.

**[END OF TRANSCRIPT]**