**[START OF TRANSCRIPT]**

**Interviewer:** Okay, we’re recording. And I will be asking you questionsabout your child’s transition to adulthood in relation to his sensory sensitivities. And we’ll be doing something called a semi-structured interview, and this means I have my planned questions in front of me in my script but I’ll also be adapting them to fit our conversation so they actually make sense for what we’re talking about and make sense for your family. Any questions?

**Interviewee:** No.

**Interviewer:** Okay. And if there are any questions…

**Interviewee:** I guess just one thing is I am here alone right now with my son; I’m watching him on a camera but if I have to get up for a minute is that okay? My husband’s supposed to be home shortly so I’m just keeping an eye, making sure he’s okay.

**Interviewer: [00:00:42]** Of course. I mean we can also, if you prefer, we can…

**Interviewee:** No, he’s watching TV. He’ll probably be totally fine but it never fails when I think he’ll be fine and he needs me so…

**Interviewer:** Yeah, no, not a problem. Feel free to get up as soon as you need to. Thank you for telling me but that’s super okay.

**Interviewee:** Okay.

**Interviewer:** And if also we have to stop in the middle because of something that comes up, we’ll find another time to finish. Don’t worry about it.

**Interviewee:** Okay.

**Interviewer:** Where was I? Oh, yes, so, also if there are any questions that you don’t want to answer for whatever reason, that’s perfectly okay. *“I don’t know”* is perfectly fine as an answer and if there are things that come up later from earlier, feel free to jump in, it doesn’t have to be perfectly linear.

**Interviewee:** Okay.

**Interviewer:** Alright, shall we?

**Interviewee:** Mm-hmm.

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

**Interviewee:** About his what? His?

**Interviewer:** Sensory sensitivities?

**Interviewee:** I thought you said *“unsensory,”* I was like…

**Interviewer:** Oh no, oh no.

**Interviewee: [00:01:40]** So his main sensory sensitivities…I would say are auditory, certain sounds upset him, specific sounds, not just volume just certain specific sounds. He has got some olfactory sensitivities and he really kind of craves and looks for certain smells. He has taste, definite taste sensitivities, everything is super super spicy to where I probably couldn’t eat it. But it’s not enough for him. No tactile sensitivities at all. I think he has visual stims like a typical kid with autism does but, I don’t… he doesn’t seem bothered by bright lights or fluorescent lights, I would say he doesn’t have any of those. I think I covered them all.

**Interviewer:** Could you…yes, that was perfect, thank you. Could you talk a little bit about the specific things that he is sensitive to like for the sound and what he seeks out for smells?

**Interviewee:** So, for the sound, it is number one are babies crying, children crying, anywhere between the ages of 0 to probably about 8, that kind of still high-pitched crying, it can be squeals of excitement as well, very, very, very upsetting to him. Yet he will seek them out on different devices that he watches and then get very, very, very upset. So that’s his absolute biggest number one sensitivity. He also has some dogs barking which can upset, agitate him and concern him, a little anxiety I would say. And then just loud voices like people that are anger, angered…that also creates a lot of anxiety. The smells…my hair is a big one, he’s, everyday always smelling my hair, it just seems mine for some reason. But a lot of people he will smell, he’ll come up and like smell their arm, especially if it’s bare skin, their knee, tends to be more female and definitely younger. The younger, the better. And then, I said the taste. He really, really does not like bland foods, anything like oatmeal, mashed potatoes, apple sauce, any of those that just have not a lot of flavor, he won’t eat them but anything that’s super spicy. Or, like he’ll drink pickle juice, anything that has a super strong taste, he seeks that out for sure.

**Interviewer:** Awesome, thank you. For babies crying or like younger children crying, you mentioned high-pitch, do other high-pitched things bother him?

**Interviewee:** Not really. He’s very tuned in to a child **[00:04:54 inaudible].** Dad’s home, okay. **[To husband]** Okay, hi, okay. **[To Rachel]** Yeah, it really is just, it’s children.

**Interviewer:** Got you. And then you said that he liked the smell of your hair, does he still like the smell of your hair if you change your hair products?

**Interviewee:** Yes.

**Interviewer:** Okay, so, it’s just your hair?

**Interviewee:** Yes. And he’ll go up to people sometimes that have like their hair kinda up and he’ll go to do it and like you can tell, it’s like **[imitates son]** *“yeah,*” not the same, even though of course, most people won’t let him do that, but like in our family, he doesn’t do it to anybody except for me. And yeah, change of hair products, it doesn’t matter but it’s definitely he’s definitely inhaling like he’s smelling that.

**Interviewer:** Absolutely, thank you. And then, how do you or how does your child like cope with or manage or handle these sensitivities, like do you help him with that?

**Interviewee:** Well, I mean we’ve had lots of behavior programs, so the smelling…obviously, unless it’s me, we really try and just redirect him. We try and give him a replacement behavior when he wants to do that, a way to greet someone, that tends to be how he greets people is to go up, if it’s a woman, and smell their arm or something so we’ve tried to give him some replacements for that. The crying…he’s just really not…you can’t communicate with him; we have tried desensitization programs where we have video taped ourselves crying and other people crying. If I’m just crying, crying, I mean it might concern him but it’s not the same. This is like…he’s self-injurious when there’s a baby crying, he will damage property, but he also seeks it out on a pretty regular basis which is very…a lot of behaviour therapists thinks he understands why. It’s always been very odd to me that he will get himself…he gags himself like puts his hands way down his throat when he hears crying, bites himself which is really the main reason we can’t take him in public because you never know, I never know when there’s a kid crying and he is on it. I mean I don’t have the best hearing; he’ll hear it before me and if I’m not like right physically on him, he’s gone. He’s looking for that child and he thinks, I know this from when he was younger, if he hits, shakes, something this person, it will stop making that noise, which of course just escalates the situation. So going to the pool was always really challenging and he loves the water but there are just so many kids squealing, it was just really challenging. And now that he’s so big, I just, I can’t risk, I’ve gotten in too many close calls so I can’t risk doing that. And then the taste thing, I mean he has a diagnosis of eosinophilic esophagitis, constant reflex and he’s on medication for that. But, boy, it’s hard. We are a pretty spicy family anyway so we eat lots of stuff and he literally like will take the bottles off and drink it if you’re not watching him. Anyhoo, sometimes, he’s definitely one to drink stuff after that but not like…I would not be able to tolerate that so he just has a very high sensitivity with that. So we just try and limit it.

**Interviewer:** And why do you try to prevent it? Just because it would be damaging to him, the amount of spice?

**Interviewee:** Yeah, I…if he didn’t have a diagnosis, I guess I wouldn’t worry but he can’t communicate to me like if he has heartburn or something is bothering him, he can’t communicate it, so we just feel like you know that’s got to be doing chronic long-term damage, so we try and minimize it. But it’s tough, I mean he’s pretty demanding when it comes to spicy stuff.

**Interviewer:** I’m sure. You talked a lot…you said that he’s had a lot of behavioral programs to kind of help him with the sensory things, can you talk about them?

**Interviewee:** Well, like I said, we had pretty much an ABA program with the crying when he was younger cause this was very early on where we tried and he used to have like a very strong sensitivity to the vacuum like same thing, he would gag himself, he’d fall on the floor, he would be self-injurious and we had a whole program of pairing the vacuum with something positive, like putting it on for a second and if he tolerated it, turning it off, you know, a whole bunch of negative reinforcement that way and building and building and taking the vacuum with us to his favorite places. It’s just **[00:10:12 inaudible].** I mean we did it all. We actually conquered that one because my husband had just had enough and he just one day vacuumed for like three hours, I am his mom, I could have done it, it let Jimmy go nuts and we just kept nonchalantly cleaning up any vomit, we just tried to make no deal of what he was doing and ever since that day, the vacuum has not bothered him. He actually likes to vacuum now.

**Interviewer:** **[00:10:41]** That’s great.

**Interviewee:** But we couldn’t deal with the crying, couldn’t deal with the crying so and I believe that stems from like early, his sister’s just fourteen months younger and she had huge amounts of colic, cried and screamed for hours and hours and hours and hours and I really feel like that imprinted on him at a very early age and it just and he knew like every time that would happen, mom would leave me, like there was a whole bunch tied up into that, into that crying that lead to this overall feeling. And then as we got older, as he got older, like I said, we had programs that we would specifically come up with a replacement behavior, like for the smelling, we did the fist bump cause that just seemed a little more appropriate than a high five. We haven’t really addressed the taste thing a whole bunch, we just try and monitor that ourselves. And because the crying, we did so much with that crying when he was little, I haven’t really tackled it in a behavior program per se as an adult, it’s more just how to manage the negative behaviors like how can we get, even trying to get him to say, *“I need to leave”* doesn’t work because he is determined to go find the source of that noise. So it’s really, and right now of course with Covid, we haven’t been out but like so we haven’t been out in a while, I don’t have any staff with me so it’s pretty much just me and for safety reasons, I just haven’t…we haven’t tackled that. And we’re very intimately working with the behavior therapist right now but we have some other things that we’re working on versus that.

**Interviewer:** Got you. Thank you. Do you feel like holistically these behavior programs have helped your son?

**Interviewee:** Yeah. I mean I think that… I mean I’m a big believer in behavioral therapy, I think with sensitivities though, I think it’s tough because it’s really layered in a very deep part of your brain that it’s not logical and when it’s not logical behavior, the person has a hard time then figuring out the funnel, you know, the trigger and the seed and then how can we replace it because there’s just something like so deep in there, I feel like that is hard to have a true success. I think if it was something that came on like suddenly, like all of a sudden, like he wouldn’t be able to stand having sticky hands and never did before, then I definitely think a behavior program, we could whip that into shape. But for something that’s been…he’ll be 24 in a couple of weeks, I mean it’s hard I think to come in for some of that stuff.

**Interviewer:** Absolutely, thank you. You gave me a nice segue so thank you, also. How have his sensory sensitivities changed over time? If at all?

**Interviewee:** Well, I think he’s…the auditory is less. There’s less things that bother him, so you know the vacuum doesn’t bother him anymore, the hair dryer used to bother him, fire trucks used to bother him or at least make him anxious so like there’s less, not that we have necessarily done anything about that, except just exposure, natural environmental exposure, but the babies crying hasn’t, that’s not gotten any better. And I think the olfactory stuff has gotten less as well. Now we have also, I need to think about this as far as behavior programs, we have tried to put in natural ways for him to benefit from this so like we use scented markers or candles, things that he can, Chapstick. The problem is that it gets messy, you know, the markers everywhere cause he’s smelling it so strongly but I think the idea’s to feed that, there’s some need there so to help feed that in natural and safe ways. We have like essential oils going a lot so I don’t know if that really helps that but I would say that’s probably the olfactory stuff I think has really calmed down. The taste thing is the same or more, it’s like the more he gets, the more he wants so yeah, he’s such a connoisseur of all types of different hot sauces so it’s like he’s very and he wants some of all of them, so I think that’s gotten actually higher intensity so the sound, the babies and the taste is higher. I think the olfactory has gone down.

**Interviewer:** Got you. Thank you. This question may not be super applicable to your son, but do you think these changes you described are related to any independence that he’s gained?

**Interviewee:** No, no, I would not.

**Interviewer:** **[00:16:38]** Got you. Thank you. And when your son is in a scenario with like crying babies or other things that make him…that may be unpleasant for him, does that cause anxiety for him?

**Interviewee:** Yes, yeah. It’s not that he’s seeking, while the auditory causes anxiety, the taste does not, the olfactory does not but the auditory absolutely causes anxiety.

**Interviewer:** And how does he, or how do you help him manage that anxiety?

**Interviewee:** We try and remove, either we remove him from the environment if we’re in public which hasn’t happened in a while or we remove the device that it’s on. Now going by myself, really hard for me to do that because he’s bigger than I am. If my husband’s here, yeah, we just take it away, try and clear the cash, make it harder for him to try and find it again although he always does. So we kind of just basically try and break the cycle and force him to take a break from that.

**Interviewer:** Absolutely. And has that always caused anxiety for him?

**Interviewee:** Yes, yeah.

**Interviewer:** Got you. Thank you. And then thinking a little bit more broadly, and like globally, what goals or hopes do you have for your son in relation to his sensory sensitivities?

**Interviewee:** Well, my really biggest hope is that he would be able to hear children upset and not be physically aggressive towards me or that person so that he could go out in public. That is, I mean we have other issues in public but that is the biggest safety issue that we have and I feel like if he could just figure out a way to tolerate that and he won’t wear headphones, we’ve tried that, I mean he will but not to drown and as soon as he hears that, it’s like game over, like *“no, I’m [not] listening to that.”* **[To son]** Go find Daddy, go find Daddy. **[To Rachel]** So that would be my biggest hope is that he would be able to be in the community again, either volunteering or working, or even just shopping which he loves to do without worrying about him hurting a person.

**Interviewer:** Absolutely, thank you. So my next chunk of questions are about community so they may not be super relevant and that’s super okay if they’re not. So as your son has grown up and aged a bit, how has his and your community reacted to his sensory needs and sensitivities?

**Interviewee:** Not well. People are not very understanding. It’s one thing when it’s a child or a little kid. But when it’s an adult and you’re trying to rustle him away from a sensory issue, then, yeah, I get a *lot* of negative looks, a lot of negative looks. You got to really put on a suit of armor. And he also has like a Tourette’s disorder so I mean he does a lot of yelling so people already are on edge around him and agitated but you know when somebody walks like, somebody just did that to me yesterday, we were outside…I mean they wouldn’t even come by my driveway until he was all the way up because he was having a little bit of a stim and he was loud…and they just wouldn’t go anywhere near around him so…

**Interviewer:** That must not feel really good, I’m sorry. So would you say the community was more accepting and accommodating when he was younger?

**Interviewee:** Yes because they couldn’t really… because he looks normal.

**Interviewer:** Were or are there certain places in the community that are more or less accommodating or accepting like different spaces or places?

**Interviewee:** Yeah, you would think like church would be more accommodating, that was the worst, yeah, they were very unaccommodating. In fact, they said we had to go to the ‘cry room.’ I’m like *“well, that’s really a problem.”* This was when he was like a teenager, I was just like *“I can’t take him to the ‘cry room,’ that’s the whole problem.”* Yeah, I haven’t…I mean obviously if you go to a community setting where there’s a gathering, but you know they’re so discouraged. I really haven’t found anywhere that’s really accepting.

**Interviewer:** Got you. And then thinking again a bit more globally and broadly, what hopes or worries do you have for how the community will continue to react to his sensory needs and sensitivities?

**Interviewee:** I think they will see it as a threat. I think they will see that his inclusion is not…especially since the target is such vulnerable, young people. I don’t see the community ever being really very accepting.

**Interviewer:** I’m sorry, that must be challenging.

**Interviewee:** Yeah, well, I mean I’m kind of over that point now but yeah.

**Interviewer:** Alright, we’re going to move onto a different chunk of questions, so we’re done talking about that. In the like quote-unquote transition to adulthood, where do you see your son?

**Interviewee:** **[00:22:21]** Well, so, he’s out of school and we tried going right into supported employment, that did not work at all. So now we’re kind of in this limbo and my hope is to get him into some type of like a day program. But there are not a lot of places that are willing to deal with any kind of behavior issues so unless you have a kid that really is sweet as pie and not gonna be a problem, it’s hard to find somebody. So transition has been…I mean it’s what I expected though, you know, I’ve been in the field long enough to know that this is exactly what was gonna happen but you just kind of keep plugging away.

**Interviewer:** Absolutely. Could you talk a little bit about the stage of independence that he’s at in terms of where are things that he needs some support on and what are some things he can do by himself?

**Interviewee:** Well, he can do some leisure activities independently especially if it involves devices so he can entertain himself for quite a while on an iPad or a cell phone. He doesn’t have a computer because he broke, he’s very destructive to property unfortunately. It’s kind of like a compulsion thing so luckily he hasn’t learnt how to take the iPad apart. So there’s leisure activities he can do on his own, he will go to the bathroom on his own which I’m so thankful for. With reminders, he’ll wash his hands, not great, but I don’t think any young man necessarily washes his hands that well but I still give him a shower, I still help him brush his teeth, I still help him get dressed. He doesn’t prepare any meals or anything like that. We do all that for him. So I say leisure activities and they’re very narrow but at least he is safe and supervised on his iPad so that’s good.

**Interviewer:** Absolutely. You mentioned that he loves to shop. Does he help you shop in some capacity or what does that look like?

**Interviewee:** Well, when we were shopping which has been about three, two, maybe two years now, he’d like to go to the thrift store because he is so destructive with…he really likes the sensation of pulling things apart and breaking things. We would go thrift store so I could get a toy for a quarter and he could take it home and destroy it and it wasn’t such a big deal so he liked…that’s where he loved to go, to the thrift store. He likes going to the grocery store but he liked just to be out and see various things. Taking him to a store was never like *“no, I don’t want to go”* it was more just *“did I have enough help”* with me that could help go with us to do that.

**Interviewer:** And in a scenario where you did have enough help, and it wasn’t Covid, could he help you grocery shop when you were there, like in some capacity?

**Interviewee:** Not without…well, I mean not without a lot of support. We were still…he would hold onto the side of the cart, if you told him to get an apple, it’s pretty much like throwing it into the cart…it wasn’t really very functional. But it’s something I think that he would have the ability to learn how to do with the right team and management of people, I think that’s something he would be able to do.

**Interviewer:** **[00:26:01]** That’s great. Is he able to do like simple chores, like put dishes in the sink or something like that?

**Interviewee:** He can…we’re working on rinsing out cups and so he can rinse out cups until the bubbles are gone pretty much. He likes to vacuum but it’s not very functional, he just does the same little… and again I know there are ways that we could work on that. We worked on like wiping counters for a long time but his just attention to detail was pretty poor with that. Yeah, he loves breaking down boxes for recycling, that was a big thing that we did yeah, so, that’s about it.

**Interviewer:** Got you. And you mentioned supportive employment briefly, does he express interest in his own way about wanting to do that again in the future?

**Interviewee:** Well, we never even got to the point of doing it. We were still just working on taking things he naturally enjoys like ripping things up and trying to turn that into something that would be employable like recycling or rinsing the dishes, watering plants, anything with water he was kind of all about, we even went to the car wash many times like teaching him that so we were still just kind of exploring that and yeah, I think he misses a lot of some of…he doesn’t verbalize it but I think he does miss a lot of that variety and interaction with people coming and doing things with him like that.

**Interviewer:** Yeah. And then in various therapies or support programs, has he learnt about money management or the concept of money?

**Interviewee:** We had him carrying a wallet for a long time and when he was in school, they did them up like *“give me something out of your wallet”* but it never…it never really clicked for him.

**Interviewer:** Got you. Thank you. Does he have any friends from like online things, I know you mentioned he likes devices?

**Interviewee:** Family is about it. Family in North Carolina. I mean everyday, I talk to my mom everyday and he has her sing to him at the end. He likes when we FaceTime but that’s family, nobody outside of the family does he really have friends and doesn’t seem to really express any desire for that either.

**Interviewer:** Got you. And then again like in his own way, does he ever express interest in wanting to live more independently than he currently is?

**Interviewee:** **[00:29:00]** No, no. He seems really pretty happy with me as his slave.

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

**Interviewee:** I don’t know. I kind of try not to set myself up for disappointment so I mean he will never live independently. I mean I know that. I have mixed feelings if he’ll ever live out of our house, we would like to set him up in his own house with staff so we can at least, we, have somewhat of a normal life. We don’t want him to live in a group home so it limits that a lot but he…I think he’d be perfectly happy just living here forever.

**Interviewer:** Got you. You mentioned that you think he could learn how to shop and do things like that. So what do you think will help him move into a little bit more independence or a little bit more into adulthood?

**Interviewee:** It would be getting some staff into work with him. Obviously, my husband works, has a job which I mean he’s working out of the house right now because of Covid but he is usually gone. I have a business of my own and the way that he would become independent is if I could find people that would come in here on a regular basis who knew how to deal with behavior issues and were willing to work with him. But, after 24 years, I realize that those are very hard to find. Very hard to find. Well, they’re very easy to find, very hard to get them to stay, past like the first day or two. The first blow up, they’re out, and they don’t come back. So I really think that’s what it would take, it would take some pretty intensive 40-hour weeks like when he was little, of people really and teaming up, I think it would take more than one person at a time like if he was to be able to go out in public again, it would be like two adults with him who really understood what was happening. And I do feel like with the right support, he could learn how to do that, it’s just the support is just not there.

**Interviewer:** **[00:31:33]** Yeah, for sure. And these people you imagine helping him, are they in your mind, like certain types of therapists, like who are they, what services are they?

**Interviewee:** Well, always a behavior therapist, one person that we have tried to keep on staff and then people that are kind of versed in employable skills, like how can you task, analyze a skill and break it down and teach him different parts and then somebody that would be able to go in and train with him. He gets some communication services now which I don’t feel are all that super helpful, but you know it chucks the box. But I definitely think like really it wouldn’t even take a huge amount of personal training, it just would take somebody really dedicated because the behavior therapist would be the one saying, *“okay, this is what you’re gonna do, and I’m gonna observe; I’m gonna be here to help you troubleshoot and I’ll teach you everything you need to know as we go along”* and I have somebody that would do that and he’s great. I just don’t have the *people* for him to train to do it. That’s the missing piece.

**Interviewer:** Thank you. And now putting these two things together, his sensory sensitivities and his transition to adulthood, how do they intersect for your son?

**Interviewee:** Well, I think that main auditory sensitivity is keeping him from successfully transitioning in a lot of ways. I think his lack of independent skills and lack of safety awareness, that’s also causing him not to be able to transition as nicely as he could but I think the fact that, well, his behavior’s number one for sure, I mean just in general, he’s just got a lot of behavior issues, but that sensitivity of being able to go out in the community, that’s the thing that’s really holding him back.

**Interviewer:** And your mind, is it because those sounds illicit challenging behaviors?

**Interviewee:** Yes.

**Interviewer:** Got you. Thank you. And then would you say that his sensitivities are an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** Oh, they’re an obstacle. Well, the auditory’s an obstacle, I don’t feel like the other two…the olfactory can be overcome and like I said, he can go into a store with bright lights and lots of people, and it’s crowded and that doesn’t bother him as long as everybody there’s no **[00:34:22 inaudible]** kid. So I mean I feel like he’s got all these great things that I know a lot of my previous students would be not be able to handle and it doesn’t even phase him but this one thing crushes it and it makes it just impossible to learn how to deal with.

**Interviewer:** Absolutely, thank you. And then similarly, what do you anticipate as being challenging for your son as he does gain a little bit more independence in regards to that sensitivity?

**Interviewee:** **[00:34:58]** Well, I think as he gains more independence, if he isn’t taught proper coping mechanisms that he’s just gonna learn even more clever ways to get to that sound, escape from where he is to go, even like he’s gotten out of the house a couple times because the neighbors next door were on the trampoline, things like that. The more independent he gets, the more his world widens up and then there’s more that I have to worry about too. And I guess because we’ve never had any success with coping or relaxation techniques, or anything when it comes to that one issue, then I find it hard to visualize him going into a grocery store and it's funny cause now I think about like with Covid right, like from 6-7am, only people 60 and over can shop and I’m like *“well, I might be able to…* **[00:36:09 inaudible] *…****take him to the store if they let me in”* because there won’t be any kids in there. The problem is though if he gets mad about something else and then you have all these frail, old people around and he has done that too, like lashed out at random people, not because of that sensitivity thing but just for other reasons. But, yeah, I just think the more independent he gets, it could lead to even more challenges in controlling his effect on others.

**Interviewer:** Absolutely, thank you. Is there anything that you think could help him again in this specific intersection? And that might be what you answered previously.

**Interviewee:** No but I’m always looking, always open to somebody, for example, the behavior guy I work with now was the first one who said to me. He’s like *“I think he does that for the same reason that you watch a horror movie or you watch a movie that you know you’re gonna sob at the end.”* You know, it’s like, sometimes, you just have to feel like we have to evoke this emotion and that causes these chemicals to be released in your brain and it's this whole cycle. I mean even though it upsets him, he has this need to feel that and so that’s…and it’s like…and what he’ll do is sometimes he won’t even like… he refuses to get on a device because he *knows* he can’t stop himself from going there. But he must not want to feel that but he knows he doesn’t seem…this is all my speculation, but it’s like *“do you want your iPad,”* *“no, no!”* and it’s like *“alright”* because we just went through three days of awful crying babies and all this stuff and so then he’s just like *“don’t even give it to me, I can’t even hold it.”* And there’s tonnes of other stuff he watches on the iPad, tonnes, but when he gets in that frame of mind, in that cycle he can’t break out of, it’s like he can’t even hold it anymore, he can’t even have it around. So, I don’t know if I answered your question.

**Interviewer:** **[00:38:15]** That’s okay, it was still a wonderful answer, nonetheless. So you said there…so you don’t think there’s anything that could help him in this intersection or nothing beyond a behavioral support team?

**Interviewee:** Well, behavioral support team is my only thought and they’re gonna have to come up with something I haven’t thought of which is totally possible…totally possible.

**Interviewer:** Absolutely. And then for individuals like your son, do you feel like there are gaps in the available in-services to help them?

**Interviewee:** Oh God, yeah! There’s huge gaps. Yeah, definitely.

**Interviewer:** Tell me more. What type of gaps do you foresee?

**Interviewee:** Well, in services you mean?

**Interviewer:** Mm-hmm.

**Interviewee:** Yeah, we just got a prude for like the highest level of financial support in Pennsylvania. It’s an unlimited financial support for him. I could spend $200,000 a year if I want. I can’t find a single person to come to this house and work with him so it’s staff, it’s physical bodies that have some idea…that weren’t just at the grocery store as a clerk yesterday, like they have to have some – they want to come in and just color with him and watch TV with him, and just, they want to take him shopping. They come in and they’re like, *“Well, we’ll go shopping and we’ll go bowling and we’ll go for a walk.”* I’m like *“ yeah, he’s not gonna do any of that.”* And then they’re not interested because they get paid such a miniscule amount that I have very little control over. And then, for sure, day programs that are willing to take kids that have challenges, like challenging behaviors that can be sometimes dangerous, that would be nice to have more of those. A group home that I would feel like even would be a safe option; don’t have any of those. I mean there’s plenty of group homes but just too many horror stories with that. And I do feel like at least I’ve always had really good luck finding behavior support like I’ve always had somebody in our team or life that is I feel like pretty good where that is concerned so and I think it’s because they get paid the big bucks. But I can usually pull them along. And for us, because Jimmy doesn’t have physical disabilities, it’s not lack of equipment or lack of modifications, it’s staff. It’s physical people that have some ability, have some training or some knowledge of adults and even less who have any idea of dealing with an adult. That is *the* biggest lack that we have.

**Interviewer:** Got you. Thank you. And again, thinking more broadly, globally again, how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Well, just the fact that he can’t go anywhere. I mean I just…I can’t go anywhere because he can’t go anywhere and so it would be really nice if the two of us could go shopping together; he’d love it, I would, that’d be great. So it’s really limited that. Any kind of travel is, you know, you can’t be on a plane, we could never put him on a plane, driving in the car can be really kind of dicey with him sometimes, not for sensory issues but behavior issues but you have to think everywhere you go, it’s like *“could there be crying kids there”* and if there is, “*do I have a way to get out safely*,” so I used to when he was younger, I would go where we were gonna go and I would kind of scope it out and be like *“okay, well, we could go this aisle, or go that aisle”* but now I just, I don’t even do that because he’s just too big. It’s just a lost battle at that point so…

**Interviewer:** **[00:42:36]** Absolutely. Thank you. We’re gonna move onto our next chunk of questions, we’re almost done. So, like finally, as a caregiver, as a parent, as a mom of someone with autism and also some sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** What does it mean to me or what do I want it to mean to me?

**Interviewer:** I said *“what does it mean to you”* but I’d also love to hear, if you’d like to answer, what you wish it meant?

**Interviewee:** Well, I mean what I had envisioned and tried to set up for was this transition from school into a job and my dream was that he would work like 3 days a week, 2 or 3 hours a day, I’m not talking like a 40-hour…I just thought cause I know him, I know what’s realistic so I thought if he could go do a job for like 3 hours a day several days a week and that was my job before I quit because of him is I would help people like him find jobs so I kind of had in my head I knew what this process could potentially look like and so that was my hope as I wanted him employed because I just felt like that was what you’re supposed to do. I didn’t want him to volunteer, I wanted him to have a job. And then, when that didn’t work, I’m like *“okay, well, volunteering would be just fine.”* I’ll take volunteering. And I think if I hadn’t lost my little team that I had at that time, we might have been able to find a couple of things but they kind of dissolved and moved on for various reasons and then I was left back at zero again. So, at this point, my transition to adulthood has changed in that I would like, and I said, after he left school, I’m like, *“I don’t wanna go back to a school situation,*” like where he’s gone from 8-4 every day. That’s just not what you do as an adult, although we do work that way. But he hated school so much, he was like *“I don’t wanna do that”* but now I’m like *“you got to go do something. You can’t just sit here all day every day.”* So now my thought is I can find a day program, again, it wouldn’t have to be five days a week. I think if he could just go enough to get mentally stimulated and to learn some routines and have somebody really work intensely with him then to be able to *“Mondays, you go here and Tuesdays, you go here,”* and each day you have a certain thing that you go do, not with me, but with some staff, then that would be really nice too. And all the while, still living at home. I still see him living here.

**Interviewer:** **[00:45:29]** Got you. And so it seems like your perspective on what this transition means has shifted over time? Is that a fair statement?

**Interviewee:** Yes, yeah. It’s definitely shifted. And I felt like I knew better than most. School is an entitlement, **[00:45:50 inaudible]** the first day you’re 21, you’re entitled to nothing anymore and I knew that, and I was prepared for that. But, boy, without physical people to help you and have somebody his size with his issues is just impossible.

**Interviewer:** I’m sure that’s really hard. So you mentioned that you…so my next questions are what do you see in your child’s future so you said you don’t anticipate him moving out, is that correct?

**Interviewee:** Correct. Well, I don’t know. I mean we have big dreams, but I would say no.

**Interviewer:** Do you see him being able to learn how to do a volunteer situation?

**Interviewee:** With the right staff, yes.

**Interviewer:** Got you. And then do you see him being able to create some type of like, I’m gonna say family loosely but that could mean like friends, do you see him being able to kind of create that a little bit for himself?

**Interviewee:** I really don’t think he has any social…yeah, I don’t think that is something he is looking for. But I do think he’s looking for something to do. I don’t think he cares about the people; I do think he’s looking for something to do. But the social interactions doesn’t seem to interest him much at all.

**Interviewer:** Yeah, absolutely. Thank you. Last question: how have your child’s sensory sensitivities impacted this perspective you just articulated?

**Interviewee:** **[00:47:38]** Well, I just never thought I’d be here 24, still fighting him over these crying babies. I just thought he would outgrow that. I thought once he got more understanding of what was happening, exposure to what was happening, he would naturally start to develop some coping skills so the fact that I’m living with this ticking time bomb all the time, I mean it’s totally changed everything that we do. Now, I have found a way to live with it very happily because I’m not gonna throw my life away just feeling like this is such a waste of an experience so we have definitely found a happy medium that, god forbid, if I had to live everyday like today, I could do it, I’d be fine, he’d be fine, he’d be safe, well-fed, happy, maybe nice for Phil as he could be but we all have prices to pay. But I just never thought that this would be an issue twenty years later. It just befuddles me that we haven’t been able to figure that out.

**Interviewer:** Got you, thank you. I appreciate you sharing that. So that was my final question. Would you like to add anything else?

**Interviewee:** No, except that I think examining the fact that this still exists in adults is really important. I think we spend a lot of time thinking about sensitivities in kids and teaching them skills of how to deal with all these and then for those that just never outgrow them, it’s like *“What? Are they just supposed to live like this”* and I feel lucky. I mean at least this isn’t something that…it’s not like a tag issue or a seam on the sock I mean I know that there are a lot of kids that have every single minute of the day, there’s something they’re battling. I have a very nice little isolated package that I can somewhat control so I’m very thankful of that. But, yeah, I don’t think there’s a lot of research out there about protocols or strategies to use when it’s been ingrained for so long. Like, you know, *“What do you do at that point?”* which is probably true of a lot of adult things… disabilities I just think there’s just not a lot… enough research out there on programs, really effective programs for adults.

**Interviewer:** I’d agree. Thank you for your time. It’s been such a pleasure to hear and learn from you. I really appreciate it.

**Interviewee:** No, I’m happy to do it.

**Interviewer:** Thank you. Just thank you, that’s all I got. So I believe you already shared our information online, I think.

**Interviewee:** Yes. I did. I shared it on my Facebook page and I’ll, in fact, if you think to send it, I’ll go back and look again cause I’ll, you know, you put it on Facebook and Instagram, it doesn’t mean that everybody sees it so I’m happy to reshare it if you’re still doing that.

**Interviewer:** We are. We’re still looking for…we need about 12 to 13 more participants so if you don’t mind sharing it again, that would be absolutely wonderful.

**Interviewee:** And what is the age again?

**Interviewer:** Yeah, absolutely. It is 16 to just under 26 so by the time we chat, the kiddo needs to be 25 in eleven months at the max.

**Interviewee:** Okay, alright, I will see what I can do.

**Interviewer:** Thank you. Would you like…would it be helpful if I sent you a flyer in an email, would that be helpful?

**Interviewee:** Yeah, that would be helpful, yeah. I can do that, that’d be great.

**Interviewer:** I can do that for you. Again, thank you for making time in your evening. And as soon as this audio processes, I will send you an email and it will contain a gift card for all of your time and effort.

**Interviewee:** Oh, thank you. I’m glad to help. It’s been a while since we’ve done one of these.

**Interviewer:** **[00:51:43]** Good. Happy to do that too. Is there anything I can do for you? Any questions I can answer?

**Interviewee:** No, that’s about it, I think.

**Interviewer:** Okay, well if you need anything, you know where to find me, I’m happy to help wherever I can.

**Interviewee:** Okay, alright.

**Interviewer:** Have a good night.

**Interviewee:** Thanks, bye. You too. Bye.

**Interviewer:** Bye.

**[END OF TRANSCRIPT]**