**[Start of Transcript]**

**Interviewer**: Alright, we are recording, and I will be asking you questions about your perspective about your child’s transition to adulthood in relation to his sensory sensitivities. And will be doing something called a semi structured interview, and this means I have my plan questions here, but I'll be adopting my questions as we go to follow our conversation to make it actually fit for what we're talking about. Do you have any questions?

**Interviewee**: Not yet.

**Interviewer**: OK, cool, and if there are any questions that make you uncomfortable or you don't want to answer totally, fine, we wanna make this as positive as possible. Awesome. So could you please start off by telling me about your child's sensory sensitivities and sensory interests?

**Interviewee**: Yeah, he's a sensory kid for sure, especially when he was younger, he's outgrown a few things. Do you want to hear about the younger years?

**Interviewer**: I was gonna ask you about when he was younger too, so that would be awesome, thank you.

**Interviewee**: OK. So he never developed speech, so there's a big oral motor thing going on and think things are tied into each other. So when he was young, his big thing was always…he put everything in his mouth. There was a lot of Pica, and that's all he did, like all day long. So, we were really worked really hard to get him interested in other things to divert that attention. It was…they call it stimming, self-stimulatory behaviour. So it actually agitated him, you know, 'cause he would get over stimulated at some point.

**Interviewer**: So…

**Interviewee**: Go ahead.

**Interviewer**: I was going to clarify. So you mean putting things in his mouth would overstimulate him or not being able to?

**Interviewee**: It *would* overstimulate him, but he couldn't stop, you know. I think he was also very hyperactive. Still, you know his…if he wasn't mouthing things, he was running everywhere. So yeah, that went on for a very, very long time. And it was problematic in the classroom, 'cause, you know, he would like…and it would change a little bit to licking to chewing on. Like, he still has a craving for licking basketballs, you know, but he worked really hard. He hated…he knew how people responded to that **[phone ringing]** sorry. You know, he understood that it was very off putting. A lot of people had…some people had more trouble with it than others, so he worked really hard on stopping. And one thing that really helped was giving him Theraputty, making his hands busy.

**Interviewer**: **[00:03:12]** And then were there…are there other sensory interests or did he have other sensory interests?

**Interviewee**: Well, that dominated everything. He had a very self-restrictive diet. He ate like nothing. I had to take him to a feeding clinic. **[Referring to phone noise]** get the noise off here. Like in the beginning he had like Cheerios, **[00:03:46 inaudible]** There was…and like nutcrackers, that's basically it. You know, like people think…always thought I was exaggerating, but that was basically his diet, and milk, which is what saved him. So that got better over time, you know. It's still restrictive now, but you know, it was for a long time he hardly ate anything, it was carbs.

**Interviewer**: You say it was all carbs?

**Interviewee**: Yeah

**Interviewer**: And what will he eat now that’s different?

**Interviewee**: He eats pretty well now, I mean he does…there are some fruits and vegetables he’ll eat and some meat. I don't know what it is. My phone hasn't rung all day.

**Interviewer**: No, it's OK. Do you need to take that? We can pause.

**Interviewee**: No. I have the volume low, but it's just when…I guess…I don't even know how to turn it off. Alright, we’ll just ignore it.

**Interviewer**: It’s OK, not a problem.

**Interviewee**: Yeah, so food was a problem. Like when we travelled, I'd have to like bring my own food. I mean, he was you know, people would offer him a lollipop and he'd start crying, so.

**Interviewer**: Yeah. What about sounds or smells, was he sensitive to those or is he sensitive to those?

**Interviewee**: Yes, he craves…he's got a thing for smelling people’s hair, like if he saw your hair he'd really want to smell it.

**Interviewer**: It smells good **[chuckles]**

**Interviewee**: It smells good. He's got a thing for that. Yeah, he does crave all of his unusual sort of smells…not unusual, but. There are issues with hygiene and…let's see…like light, he's not so bad with lights. When he was younger, I really didn't have a problem taking him in crowds or fireworks or anything like that, but later on he became kind of sensitive to loud noises. I know in school he wears headphones, but I'm not sure if that's anxiety or the sound itself.

**Interviewer**: **[00:06:14]** Got you. When did you notice that change?

**Interviewee**: I think he just became more aware of what was going on around him.

**Interviewer**: Absolutely. And then you said that he still is interested in like licking certain things. What things is he still interested in for that?

**Interviewee**: So, you know, since the lockdown, you know, he usually had a very busy schedule, going here and there, and he was kept very busy. But now he's spending a lot of time on the computer and he needs…he’s still using Theraputty. But I notice that he's getting it on his month, so he's probably liking it in some way. His mouthing has really gotten so much *[better]*, it's not really an issue anymore.

**Interviewer**: That's excellent.

**Interviewee**: But you know, these things come back. They go away for a while and then you see like little spurts of it coming back.

**Interviewer**: And some of these changes that you’ve seen, do you think they're related to any independence that he's gained overtime?

**Interviewee**: Yes.

**Interviewer**: How so?

**Interviewee**: Just expanding his interests, getting him more interested in speech, using his mouth for speech, using his hands in different ways, getting him interested in artwork. Yeah, getting involved in a lot of sports and things

**Interviewer**: That's excellent. And then you touched upon this briefly with like the Theraputty and the headphones. But how does he cope with or how do you help him like manage these sensitivities?

**Interviewee**: So, when he was younger, we went to a feeding clinic at Mildly Hopped, I think we added one food, which was yogurt.

**Interviewer**: It’s good calories.

**Interviewee**: Yes. Later on, one of his therapists went to a conference and came back with a program that really worked for him, which was just giving him pea size things to try every day. And you know, just making it very incremental, you know. Also, his teachers worked on it, I know they were having him eat bananas. So just overtime he became more curious. Yeah, he just started…and then he started adding things on his own, things that we were eating.

**Interviewer**: **[00:09:08]** That's excellent. And this therapist you said who introduced that new program, was she occupational therapist? Was she a feeding specialist?

**Interviewee**: Speech therapist.

**Interviewer**: Speech therapist?

**Interviewee**: Mhh-hm.

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

**Interviewee**: Yeah. Well, you know, there were…I had a lot of different speech therapists over the years and they did different things. One of them try to like get him to play with food you know, with his hands, like play with pudding and like accidentally have him lick it, you know, desensitizing things, we tried a lot of that.

**Interviewer**: Do you think it helped?

**Interviewee**: Yeah, it probably all helped a little, you know, breakdown his fear overtime. It just…it took a *very* very long time in the beginning and then at some point it just picked up speed.

**Interviewer**: Do you know when that was? Like how old he was? Or like school?

**Interviewee**: I'm trying to think. He was at least 10, I'm thinking 7th or 8th grade, maybe 12th.

**Interviewer**: Awesome. And then in your demographic form that you filled out you indicated he also had OT and an IEP with his sensory sensitivities. Could you talk a little bit about that?

**Interviewee**: Yeah, well, they had a sensory diet at school. He went to a private school initially and they would do that brushing and joint compressions every day. I don't know if that helped. You know, school helped a little bit with his food aversions. Although you know, they seem to always add like junk food **[laughing]** When he's not eating anything even like potato chips is something new, you know? So, what else sensory…?

**Interviewer**: I have some more questions if you can't think of anything, that’s OK

**Interviewee**: Yeah, I'll think of it along the way.

**Interviewer**: And also like if there are…like as I ask more questions, if you think of something, feel free to jump in, it doesn't need to be so linear this conversation, doesn’t matter. And then his sensitivities, do they cause or increase anxiety?

**Interviewee**: Oh yeah, a little bit. He’s not…I don't think of him as very anxious; they cause frustration and agitation. And like I said, he gets over stimulated. So I do consider…like the OTs would always do a lot of swings and you know, getting proprioceptive things running, I don't. I guess that's supposed to get him regulated. Yeah, I was gonna say he's it's really been hard to get him regulated to where he could sit. He's good now. I think some of it's maturity and he's learned in school to sit for longer periods of time, and he's gotten more engaged in the academics. But it's never…like we can't take him to a restaurant because sorry, 'cause he eats his dinner in two minutes and then like I wouldn't have a good time 'cause I'd have to worry about him getting into trouble, probably not worth it.

**Interviewer**: **[00:12:55]** Yeah, that makes sense. You just said that he gets like frustrated by his sensitivities or like agitated. What does that look like for him?

**Interviewee**: Irritable, just it…he just doesn't look comfortable. And then it's hard for him to…harder for him to focus.

**Interviewer**: And would you say that these sensitivities have never really caused anxiety?

**Interviewee**: He's never been like someone who would not want to go to school or like not try things, like not go to therapy, I never had trouble with that. I think he has some anxieties in social situations.

**Interviewer**: That makes sense. And then what are your goals or hopes for him in terms of his sensory sensitivities?

**Interviewee**: So, I hope they're just managed to where he can participate and it not being a problem for other people, it doesn't interfere with the functionality, that's all I know. If he has to have headphones or petty like that, I think that's OK. Doesn't really hurt the situation.

**Interviewer**: Absolutely. And then shifting gears a little bit as, your son has grown up and aged a bit, how has his community and your community reacted to his sensory sensitivities?

**Interviewee**: Well, we've been very lucky in his school placements, 'cause you know, he's…like I said, he had a private school placement and the ratio was 2:1. He got a lot of attention, yeah. So we've gotten a lot of support at school. I've always had a lot of professionals working that were very helpful and he's kind of been in a bubble, so I'm really concerned about where he's going now, 'cause, you know, I feel like I've been able to protect him. And I think I have a lot of things about what's coming now, how that's going to work because he's not very independent.

**Interviewer**: So it's actually one of my questions, so you gave me a great segue. What are your hopes and worries about how his community will react in the future regarding his sensory sensitivities?

**Interviewee**: I'm concerned 'cause from what I hear, you know, it's very hard to get a day program if you have any issues. You know, they're not…if you have behaviors, you're not going to have a lot of good choices for housing. So I'm really concerned.

**Interviewer**: **[00:16:09]** Absolutely, it's very valid. And then thinking a bit back to when he was younger, was your community more or less accommodating and accepting of him?

**Interviewee**: I think accommodating, yeah. I thought they were very supportive, yeah.

**Interviewer**: That's lovely. And it seems like they're also very supportive now.

**Interviewee**: Yeah, I love his school now. I wish he could be there for another 10 years.

**Interviewer**: It's so great. I'm glad it's been so positive. So we talked about school, are there other like spaces or places that are accommodating and accepting of him?

**Interviewee**: Yeah, our local JCC has been wonderful. They have an inclusion camp in the summer. That's amazing! I don't know if you're familiar with it?

**Interviewer**: Well, I mean, I worked at a JCC camp for like seven years and I went there…I think I was there for 14 years between myself as a camper and a counsellor. So this my heart is at JCC.

**Interviewee**: Exactly! And they have the most amazing staff, they’re so motivated and compassionate, you know, and the morale is very high, so. And also **[00:17:21 inaudible]** he takes swim lessons there. And I feel like I've gone to a lot of sensory friendly activities that I didn't feel were that sensory friendly. I felt like he still had to be quiet and you know, everybody was well behaved. But you know, the JCC I just feel like everyone welcomes you and you know, it's not so unusual for them to see odd behavior. And I’d say they’re understanding. So I just feel like that's the most welcoming place, it's very comfortable for us to go there.

**Interviewer**: That's excellent, I'm so proud you felt that.

**Interviewee**: Me too **[laughing]**

**Interviewer**: Kind of shifting again, in the like transition to adulthood, where do you see your child?

**Interviewee**: I would like him to have a *[day]* program so that it can continue without me. I think that it's gonna be hard 'cause from what I hear, they just don't have a lot for someone that needs that much help. And most people you know, most of his classmates that have gone on, they've done like a…they have a self-directed program where you…but you have to keep hiring people and finding the activities yourself. So, which I'm happy to do that, I just want to put something in place that will continue easily.

**Interviewer**: And what do you think about his independence skills? What are his independence skills?

**Interviewee**: He's very capable of a lot of things. He's coordinated, he can…as long as someone…he seems to be very…right now he's still very dependent when an external voice to initiate. An so you know, part of it I think is you know, we create that, because for example, for speech, you know, we want to reinforce his language, so we encourage him to ask for everything instead of getting it himself 'cause we want him to get that practice. So, some of that's going on. Some of it is I don't…I mean, I supervise him all the time 'cause I'm worried about him and I…he's probably more capable than the freedom that I give him.

**Interviewer**: That makes sense.

**Interviewee**: Yeah.

**Interviewee**: No, but he's…it's just, it's mostly is the communication 'cause like if he gets lost outside, you know, the typical person isn't going to know how to communicate with him.

**Interviewer**: **[00:20:21]** Yeah, absolutely. How are his daily skills? Like you talked about hygiene in the beginning very briefly.

**Interviewee**: He again, he can do everything on his own, but he…even like, you know, brushing his teeth, he wants me to be there even though he does it by himself so, you know, he showers by himself, but someone has gotta get him to move on. He might be able to do that on his own, you know, if we really worked at it.

**Interviewer**: Absolutely. And then is he able to prepare like very simple meals like using microwave or like pour a bowl of cereal or something like that?

**Interviewee**: He can. Although you know, like with the microwave, one day he puts the right time in and the next day he doesn't. So, I mean you still have to keep an eye **[chuckles]**. It’s just his attention now, it varies.

**Interviewer**: Absolutely. And then what about friends, does he have friends from his school?

**Interviewee**: Well, you know well we define friends a little differently than with…You know, I think he has friends in school, there's no one that like comes over on the weekend. And that's a communication issue, and also he doesn't really share interests. A lot of things that he does requires like a teacher or like if he's playing basketball, someone's got to lead it or…and he can't really like talk about things.

**Interviewer**: Yeah, absolutely. And do you think he'll be able to achieve more independence in the future?

**Interviewee**: Yeah, well, you know, he communicates with me very well and an all the professionals 'cause you know, he can type on a keyboard. But you know, someone has to know how to help him focus and how to help him organize his thoughts and move along. So, I think maybe when he's older there might be a…you know, the good thing is that he’s been able to do that with more and more facilitators, it's not just me and as his speech therapist now, there's several people at school that he does it with, and so that's encouraging. And it's also his skill keeps getting better, we're doing that. So it's going in that direction. It depends on the people that are around him, how hard they try and how much support he has and **[00:23:20 inaudible].**

**Interviewer**: Sorry?

**Interviewee**: Just how, you know, it depends on how things go for him.

**Interviewer**: Absolutely. And then, relatedly, what do you think will help him move into adulthood?

**Interviewee**: He has a very good program that he’s in now where they do on the job training and I feel like he's really gained a lot of independence. Like over the lockdown, I've seen a lot more independence on his part, a lot more maturity. I feel like a lot of that is from the direction in school.

**Interviewer**: Could you give an example?

**Interviewee**: Yeah, he'll get dressed on his own pick. Pick out his own clothes and he'll go down and get breakfast, you know. Sometimes he'll take the initiative to help me with the laundry and he just seems to like understand, he understands what's going on with all this, he's gotten a hold on using Zoom

**Interviewer**: That's a great skill **[chuckles].**

**Interviewee**: Right. There is…I just feel like he's been very helpful around the house.

**Interviewer**: That's wonderful. Other than this job training you just talked about, do you think there are other services or interventions that would help him move into adulthood?

**Interviewee**: Like what? Can you give an example?

**Interviewer**: Like I mean like some people have talked about OT. Some people have talked about like an executive functioning coach.

**Interviewee**: Yeah, I mean, there's been…there's a program that we've been using. It's like a workshop, it's one of the…it's an adult program, but they…it's open for transitioning youth on school breaks in the summer. So the job is taking care of horses at a stable, so like…so he's participated in that over the last year, and that's really helped him a lot **[00:25:43 inaudible]** like a lot of job skills, mowing the lawn and stocking the vending machines and that kind of thing. But the thing I worry about is with the adult services is that a lot of them are – and he doesn't mind doing these repetitive physical labor type skills, but he really needs some mental stimulation. And now I really notice that during the lockdown, and it was…I did all the schoolwork with him, and if that wasn't there, I would find my own. But he really needs that to regulate and you don't…it's hard to find, because either you can be independent. And he's been taking classes at a Community College, there's a program at our Community College for disabled individuals that he's been…the school has supported him, so there's a school aid that goes with him there, and he’s taken some interesting classes there. That you know, that's a good thing. But I was just wish there were like more programs that could help him or that focused on mental challenges like tips that could continue the things that schools do, helping him grow in that way instead of just, you know the menial tasks what I would consider – I don’t know how to say that 'cause there…like a lot of these jobs are important to do, but you know, you want you want to use your brain skills too.

**Interviewer**: Yeah, absolutely. And now kind of putting these two things together, sensory sensitivities and sensory interests with this transition to adulthood. How do they intersect for your son?

**Interviewee**: Can you repeat that?

**Interviewer**: Yeah, how do his sensory sensitivities like intersect with his transition to adulthood? Or how do these two parts of his life interact or impact each other?

**Interviewee**: It's hard to untangle his sensitivities with like his compulsions. Do you? Do you have any thoughts on that actually? Because like there's times when he just has this compulsion to touch things balls, you know. Right now, he's got this thing about touching my arm and you know, particularly now I'm a little worried about how people will react to that. And it's only like one time, but he's had a lot of OCD issues where he's had a…he's done things like four or five times before he could move on.

**Interviewer**: **[00:28:46]** From what I know about autism, it's not uncommon for people to have these like you know, people with autism, they have repetitive and restricted interests and I think sometimes it hangs together with rituals like touching things multiple times or doing things in a particular pattern. And a lot of also…there are a lot of comorbidities with other diagnosis, so I don't think it's uncommon to see a diagnosis of OCD aligned with the diagnosis of autism. Likewise, it's not uncommon to see like autism ADHD. There's a lot of overlapping symptomologies there. So I mean it, it seems like it kind of fits the profile, so to speak, and I'm sure like if you are concerned about it from like a safety perspective, 'cause like it's probably not very safe to touch strangers’ bodies in public you do not know, I'm sure like that therapist could probably help tackle that as like to redirect that behaviour.

**Interviewee**: Right. So there was a lot…a lot of those things when you're little, people are a lot more understanding, but once you get to be a certain size and you know, he's nearly six feet, it's very threatening and yeah, so that I'm worried about.

**Interviewer**: Yeah, absolutely, that's totally valid completely. And would you say his sensitivities and like sensory interests are an obstacle, a vehicle, or a bit of both towards independence?

**Interviewee**: An obstacle.

**Interviewer**: Mhh-hm. How so?

**Interviewee**: Because he gets hung up on it, you know, without focusing on what he needs to get done, you know. And then there's that dependence on someone to lead him through.

**Interviewer**: And like on hang him up, so to speak?

**Interviewee**: Exactly, yeah.

**Interviewer**: And then what do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities and sensory interests?

**Interviewee**: What do I anticipate?

**Interviewer**: As being challenging.

**Interviewee**: Oh. Just following rules in society really.

**Interviewer**: What do you think will help him in this arena?

**Interviewee**: Yeah, it's just having support around him. You know, I don't know what it's gonna look like with adult programs and the staffing and I know there is…they're not very well paid. And he's kind of an outlier and well, with this communication. And I think also socially, he has a lot more challenges in that arena.

**Interviewer**: **[00:31:57]** Absolutely. And do you think there are particular services or interventions that could help him like navigate this intersection of sensory sensitivities in this transition?

**Interviewee**: Well, yeah. I mean those few people that are interested in helping that you know, the more those kinds of challenges are amazing if you can hook up with them, you know, if you can get surrounded in that bubble.

**Interviewer**: Do you feel like there are gaps in the available interventions for this?

**Interviewee**: I'm still learning. I know some are out there, like for example that stable job, you know, that's an adult program and it was put together by a group of parents that couldn't find services for their children, you know. Everyone there needs a lot of help, and the staff gets it. But I don't know how many others are out there, and I don't know that that's the right program for him. Yeah, that that would be good for him everyday, maybe part of it.

**Interviewer**: And then how has your child's sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee**: Well, there's been some challenges at school, you know. He just started doing off site job training at a hotel. So it did, you know, like this OCD that was really going strong right before the lockdown, it's gotten better. But yeah, that was really interfering in what he could do.

**Interviewer**: Were there particular things that he was focusing on?

**Interviewee**: Yeah, he might have been kind of bored with the job, you know, it’s the recycling and cleaning up. So you know, he’d get hung up on doing repetitive things and not going with the program.

**Interviewer**: Yeah. What were the repetitive things that he was doing?

**Interviewee**: Just you know, like not getting off the bus, you know, getting up and then going back to the chair and getting up again, and you know, getting in those loops. Or even like probably when he was recycling, he would put it where it was supposed to go and then he would take it back, you know, and that would go on for some time, and it's really exhausting for the person that has to work with that.

**Interviewer**: **[00:34:54]** Absolutely. And like then thinking about like this transition to adulthood, do you think about like his other sensory habits like the licking you talked about or the aversion to some noises?

**Interviewee**: So at this point they've gotten much more kind of in the background, he does hardly any mouthing and it's not hard to get him out of it if that comes back, so I feel like he's really overcome that, which I'm really happy about, that was a really hard one.

**Interviewer**: Yeah, that's wonderful.

**Interviewee**: The thing with the sensory stuff, it's always hard to find a substitute 'cause that's the only way you could beat it, is to find something better that replaces it.

**Interviewer**: Yeah, absolutely. I mean, the putty sounds like a fantastic substitute.

**Interviewee**: Yeah, I mean I've tried every fidget toy on the market **[laughing]**, they’re just like sitting in the drawer.

**Interviewer**: Well, I mean, I'm sure in quarantine it's kinda nice to fiddle with something now. And then moving on to like our last chunk of questions. As a caregiver, as a mom, as a parent of someone with ASD and some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee**: Well, it means that I probably have less control, yeah. And there's just not as many choices, there’s not enough money, not…and I'm worried about where he's gonna live. It's very complicated, you have to learn the state system and every year it changes, so you have to keep learning. Like from what I hear is – and what I see is that you have to keep going to those meetings all the time to really stay on top of things, you know. That's a big job that if it's not your child, you know…my husband and I are a lot older, you know, like he has two half siblings that are in their 40s, so you know, I worry about that a lot, how things are gonna go on when we’re not here 'cause we don't have other family in this area.

**Interviewer**: Yeah, that’s a very real concern.

**Interviewee**: You know, how to set things up. But I mean there are…we're in a good state for services, so I'm hoping things will fall in place. I know there's some good things going on.

**Interviewer**: **[00:37:57]** And has this perspective changed overtime?

**Interviewee**: Yeah. Well, he turned 18 last year and that's when the focus was more on the transition, it's been very frustrating, the agencies that are supposed to help you transition, or, you know, I've been like through six different coordinators 'cause there's a high turnover. That's been very frustrating. So we hired a consultant.

**Interviewer**: Was that helpful?

**Interviewee**: Yes, it's very helpful.

**Interviewer**: That's excellent, I'm glad.

**Interviewee**: Yeah, I like right now, you know, with the lockdown, I'm kind of stuck, you know. So like I was in the process of setting up visits to see different places, different programs and housing.

**Interviewer**: Which is much harder now.

**Interviewee**: Yeah, they're not operating the way they normally do, so it's not a good time to go see them.

**Interviewer**: Yeah, you wouldn't see them in their true state.

**Interviewee**: No.

**Interviewer**: And then what do you see happening in your child's future?

**Interviewee**: Well, hopefully he'll have a little bit of a job that keeps him busy. He needs to be very busy, so he'll have some kind of physical activity, some kind of creativity, a little bit of…maybe take a class, you know, in the afternoon and have some kind of supportive environment, you know, where he's living.

**Interviewer**: Absolutely. And do you see him in like a day program? Do you see him with you when he's older?

**Interviewee**: Well, no, I'm gonna get him get on the list for independent living as soon as possible 'cause I know it takes a long time and I don't want him to go through that alone, yeah. So, I'd like him to be there while I'm still around to help him adjust to it.

**Interviewer**: Absolutely. And then for my final question, how have your child sensory sensitivities impacted this current perspective that you just articulated?

**Interviewee**: So, I feel like it's going to be a little bit of an obstacle too. I'm a little worried about his school record, how that's going to impact the programs that I apply to, that they may not want to deal with it. So yeah, I’m worried about it.

**Interviewer**: No, that makes sense, totally. So it's actually all…oh, go ahead.

**Interviewee**: I was gonna say, I feel like the public at large is more sensitive to it, but they kind of…their information flows from people that are in the Asperger’s group, you know, wherein it's more about lights and certain accommodations for those people and it's harder to find accommodations for people that need more help.

**Interviewer**: Absolutely, and that makes sense. So that's actually all I have for my questions. Would you like to add anything else like you just did?

**Interviewee**: I'm good. You know, I'd love to learn from other parents and that's the best way to find out **[00:41:54 inaudible]**.

**Interviewer**: Absolutely, that makes sense. Well, thank you. I appreciate all of your time and your insight and sharing about your family. It's very helpful for us and the work we're trying to do.

**Interviewee**: What are you trying to do?

**Interviewer**: Just trying to…oh, sorry.

**Interviewee**: You're gonna, I mean, your product is going to be some kind of report, or you’re just trying to present what the issues are?

**Interviewer**: So ideally this will turn into like a scientific paper, like it's called a manuscript, and ideally because right now there isn't a lot of research on how these two things intersect. Like we know a lot about sensory sensitivities, we know some about parent perspectives, but we don't know how those two things impact each other, so hopefully just adding to the literature. And I think at least my hope is that by understanding how these two things interact, we can support and provide evidence for the need for interventions that actually help people who need help in this arena, 'cause without evidence, you can't design something. So, kind of the first steppingstone in an intervention would be like my personal hope.

**Interviewee**: Do you find from your interviews that it becomes more of an issue as they get older or more of a concern?

**Interviewer**: That's a really great question. So, this is my 21st interview, it’s about halfway done. And it seems like the issue…it's not related to age, it's related to severity. So, the more interfering the sensory sensitivity or like sensory desire is, the more it matters. Like an example would be someone liked to smell things and that's not interfering at all, like it's not problematic by any means, versus another person articulated that their child liked the sense of things in their mouth. And sometimes they put unsafe things in their mouth and that has a much larger impact on their transition to adulthood as opposed to their age. So it kind of seems like the context and severity of this sensory seeking or sensory desire is a larger factor here.

**Interviewee**: Yeah, have you found about like what's supported that those issues? Like what kind of…did you feel like people were getting help from private, their private professionals or groups or government agencies?

**Interviewer**: **[00:44:33]** I’m trying to think. So it seemed like the parents who were the most concerned about their child's sensory sensitivities in this…in regard to their independence, they had to do a lot of legwork themselves, and they had to put a lot of pressure on the available resources, like that family I just spoke about, they spent a lot of time trying to renovate their house to make it liveable and make it safe, so that way their child could live there forever, effectively, in a safe way. Another family spent a lot of time trying to find available resources, and again, that parent spent the bulk of her time trying to build a world around her family that would support him long term. So, it seems like it's a lot of independent work, unfortunately.

**Interviewee**: Right, OK. Alright, thanks.

**Interviewer**: Yeah, well thank you for your time. Do you know anyone else who might want to join our study or participate?

**Interviewee**: You know, I'll think about it and forward the information to them.

**Interviewer**: Yeah? That'd be lovely, if you don't mind, but if you have any questions for me in the future about anything related to this or unrelated, let me know, I'm happy to help in whatever way I can, 'cause you're helping us.

**Interviewee**: Oh, I appreciate that.

**Interviewer**: Yeah, yeah, of course. And very soon I will send you a thank you email, but also a gift card for your time and your effort, you’ve helped us tremendously.

**Interviewee**: OK. Good luck with your research.

**Interviewer**: Thank you. Stay safe.

**Interviewee**: You too. Bye.

**[End of Transcript]**