**[Start of transcript]**

**Interviewee:** Sorry, I was in another meeting, so I had my background on.

**Interviewer:** Oh, you can keep your background. It doesn't matter to me, whatever you're comfortable with. I don't have a fake background. This is my life.

**Interviewee:** Yeah.

**Interviewer:** And I will be asking you 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 I think you're familiar with. And this means I have my set questions in my script, but I'll also be adapting them to follow our conversation, so it fits for what we're talking about. Any questions?

**Interviewee:** Uh-huh.

**Interviewer:** Okay, wonderful. If there's anything that you don't want to answer for whatever reason, that is perfectly okay. *“I don't know*” is also a perfectly fine answer, so don't feel pressured. And if there's anything that comes up later in the conversation from earlier, feel free to jump in, it doesn't have to be a linear conversation.

**Interviewee:** Okay.

**Interviewer:** Alright. Thank you. Could you please start off by telling me about your son's sensory sensitivities?

**Interviewee:** Yeah, so he's -- I mean, some of it is insensitive, some of it's sensitive. So, he -- and then some of it is just not quite processing right. So, all growing up he was never really able to tell us whether he was sick, what hurt, things like that. And he's better at it now, but he gets bruises and stuff like that, that he doesn't know where it came from. He's also like he's got ADHD, so some of it, I'm not sure whether it's the distraction or if it's the hypersensitivity, so lights and sounds are highly distracting for him. So, he has a very hard time shutting it out. So, he just can't focus on his work or if I mean, anything that he's doing, like he's making a sandwich, he can't. I mean, everything that he does, he always stops and stares off into space. And then we're like, *“Okay, he can keep going.”* And if someone says something or if the TV is on or the cat meows or whatever, he just can't focus. So, if he does homework a lot of times, we'll have him come and sit at the table to do it. But nothing else can be going on around him because then he can't concentrate or he has to have headphones on. And then he's really picky about foods. There are certain textures that he just can't handle, gags and **[03:00]** he has to put pepper on everything, like enormous quantities of pepper.

**Interviewer:** Like black pepper?

**Interviewee:** Yes. I mean, he doesn't like really spicy food, but he likes the taste of pepper, so yeah. I mean, at least it's not salt, so that's good. And let's see, he says… smells he does get really grossed out by smells, way more than most people would. But he does also… and again, I'm not sure if it's the ADD or the sensory, he's always had amazing hearing of something across the house that is this tiny little thing, and he as a baby would run across the house because he knew he heard whatever that tiny little thing was. And not being able to block out noises of the microwave or whatever. So, and then he's clumsy, uncoordinated. He also has a major fear of heights. The high school has an open stairway in the front of the building. When he started, he used to grip the railing the whole way up and walk up really slowly and he's finally able to walk after a couple of years, he was finally able to just walk up the stairs without a problem, but getting in an elevator he stops and he's sees that gap in the floor and he's like -- or he has a hard time getting on an escalator, and so anything with balance or being off the ground at all, he has a hard time with that too. But I think he does like deep pressure. So if he's upset, I'll ask him if he wants a hug and he really likes to be squeezed really hard. And when he was -- he's always been like that his whole life and I remember when he was a baby, we had a fitness ball and the only way we could get him to stop crying was to just bounce really hard on that ball up and down where you have like that feeling. And he had one of those bouncy chairs too, that we would -- he was like, I don't know, maybe from the time he was like three months to 12 months, he didn't sleep through the night and we used to have that little bouncy chair next to the bed and one of us **[06:00]** would lie on that side with a **[inaudible – 00:06:01]**to come over and bounce it all night long. And then you'd fall asleep and he'd wake up, he'd start screaming again and you'd start bouncing. So yeah, he really likes that kind of strong movement.

**Interviewer:** Yeah, definitely.

**Interviewee:** I don't know. Is that all the senses?

**Interviewer:** I think you got them. I'm going to ask some follow up questions if that's okay with you.

**Interviewee:** Yeah, sure.

**Interviewer**: You talked about him being very distracted by lights and sounds. What type of sounds? What type of lights?

**Interviewee:** Yeah, I think really, it's any kind of sound distraction. Certain things like TV, definitely, he can't size off of a TV screen if the TV is on, no matter what. And the cat meowing, he has to do something about it. And his sister talking, because that annoys him, so he can't focus with her talking. Light, it's bright lights usually. And like he can't sleep with any kind of lights on especially, he shares a room with his brother, and if his brother is playing a game on his computer or something, the lights are kind of flashing in the room. So, he has a real hard time with that.

**Interviewer:** Yeah.

**Interviewee:** Yeah, I think, and then like flashing lights we're like in a busy place someplace, he does get overwhelmed in big places and big crowds and stuff like that.

**Interviewer:** What about sunlight? Would sunlight bother him as well?

**Interviewee:** No, not so much.

**Interviewer:** Okay.

**Interviewee:** Sunlight is okay. Yeah.

**Interviewer:** It's more like light bulb lights or screen lights?

**Interviewee:** Yeah, yeah.

**Interviewer:** And going back to sound, so it's not just loud sounds, it's also like quieter sounds like the cat?

**Interviewee:** Yeah. Loud sounds he does startle, pretty easily. Yeah.

**Interviewer:** What about like more mechanical sounds like maybe a car going by or something?

**Interviewee:** No, he's okay with that. And we're in the woods, so we don't really hear that. He does like if it feels outside using a power tool. My husband, he does have a hard time focusing through that. So if he's trying to concentrate on something that he doesn't want to do, like homework.

**Interviewer:** Fair. And you mentioned that he has a certain preference for textures or like lack thereof what textures are okay for him? What textures are bothersome for him? **[09:00]**

**Interviewee:** Slimy. So like cooked onions is his big thing.

**Interviewer:** Isn't he **[inaudible – 00:09:06]**

**Interviewee:** Yes. Is that… there better not be a clipped onion in his vicinity.

**Interviewer:** Okay.

**Interviewee:** So, we have to make sure those are really hidden in the food, otherwise he tries to pick them all out. So yeah, things that are kind of slimy like that, he seems to have a problem with the texture of it.

**Interviewer:** Got you. And what about -- oh, sorry, I didn't mean to cut you off.

**Interviewee:** Yeah. I'm not sure if it's any other textures.

**Interviewer:** Sure.

**Interviewee:** Yeah, I don't think so. I mean, I know like certain clothes and stuff bother him, tags on the clothes or stiff kinds of clothes, you'd much rather wear sweatpants and t-shirts and that kind of thing.

**Interviewer:** And what about smells? You said certain smells are hard for him.

**Interviewee:** Yeah. It's just if there's an unpleasant odor, he really overreacts to it. So, it's not like certain odors he can't handle, it's just like he seems to smell them a whole lot more or he just reacts a whole lot more.

**Interviewer:** I see. Thank you. And how have his sensitivities changed over time?

**Interviewee:** Good question.

**Interviewer:** Thank you. It's my job.

**Interviewee:** Yeah. I'm not sure that his actual sensitivities have really changed, maybe it's like the awareness, the self-awareness I think is what has kind of developed where he's better able to express himself around it. Whereas, as he was younger, it was just like tantrums all the time, whereas now he can be a little bit more specific about what it is that's bothering him.

**Interviewer:** Totally.

**Interviewee:** But I don't think -- I think he's a little less startled than he used to be. He used to be startled by stuff all the time, for a couple years he couldn't go outside in the fall because leaves blowing. He was freaking out about a leaf moving and he didn't know why it was moving.

**Interviewer: [inaudible – 00:11:35]** mean.

**Interviewee:** Yeah. And vacuums, he used to be terrified of too, but I think he's better able to manage himself a little bit better now too. So, I don't think the actual sensitivities have changed though.

**Interviewer:** That makes sense. **[12:00]** Thank you. And then this increase in self-awareness, increase in self-management. Do you think those changes are related to any independence that he's gained over time?

**Interviewee:** Yes. And it's been very gradual and only kind of recently in the last couple of years. So he's 17 now, so it's like up until he was 12 or 13 and stuff, he still couldn't really say what it was that was bothering him. He would just be irritable and react to everything. But in the last year or two, he's gotten a little bit more specific around things that bother him, and a little bit more willing to try strategies like putting headphones on to concentrate. Yeah.

**Interviewer:** And you think that willingness is due to independence that he's gained, or connected?

**Interviewee:** Well, I don't know if that's just a natural part of his maturity.

**Interviewer:** Yeah. Totally. You gave me a great segue to my next question, so thank you. How does he manage, cope and handle with the sensitivities? Or how do you help him manage, cope, and handle them?

**Interviewee:** Yeah. So yeah, trying to avoid the stuff that he can, if he can. We've also made it pretty clear over the years that he can't complain about the onions. He can quietly pick them out of his food, that he can't sit there and explode about the onions because onions are good. We're going to cook them in our food. And he's just going to have to learn to deal with that. So yeah, that has gotten better. And he was coming home with my sister one day and she used a grater to grate up the onions to put in like her neat little for whatever. And he loved that. So like if he helps to cook, he will grate the onions instead.

**Interviewer:** That's wonderful.

**Interviewee:** So, little things like that, that he's figuring out. I did get some ear plugs in a mask, if he had a hard time sleeping, I don't know if he's using those or not. I mean, he does have some accommodations at school too, if it's too noisy and he needs a quiet place to work, he can go to another room and work, things like that. **[15:00]**

**Interviewer:** Yeah. With the staircase, was that kind of just like exposure that he had to do it?

**Interviewee:** Yeah, yeah. Because if we go to another place with an open staircase, he's going to have the same problem again.

**Interviewer:** So, it's like not… hasn’t generalized.

**Interviewee:** No.

**Interviewer:** Got you. Okay. And then has he received any specific interventions or therapies for his sensitivities?

**Interviewee:** He was doing OT for -- I mean he started probably when he was like two or three, and then he did that until, I don't know, maybe sixth grade. He hasn't done it in several years.

**Interviewer:** Yeah. Do you think the OT helped him when he was in it?

**Interviewee:** Yes. Yeah. I think that did help a lot. They also worked a lot on fine motor skills too with him.

**Interviewer:** Yeah, totally.

**Interviewee:** And just stuff that we've tried over the years too, like the squeezing when he's upset, things like that. But yeah, he's, I think now it's a matter of through counseling you've kind of talked about coping over the years instead of directly addressing any sensory issues.

**Interviewer:** Got you. When he was in OT, when he was receiving that for his sensitivities, how did that help him? What did they do for him in that regard, if you recall?

**Interviewee:** Yeah. That's a good question. I'm trying to remember.

**Interviewer:** It's okay if you don't.

**Interviewee:** Yeah, it's been a long time.

**Interviewer:** Yeah, definitely.

**Interviewee:** Yeah, I don't know if I can remember anything specific right now. Yeah.

**Interviewer:** That's alright. Not a problem. Thank you for trying. When your son is exposed to a sensory environment that subversive to him, like perhaps too loud, some photos are not pleasant. Does that cause or increase anxiety for him?

**Interviewee:** Yeah.

**Interviewer:** Yeah? How so? What does that look like?

**Interviewee:** Yeah. Like if we go to a mall which that's not a very common occurrence around here, or if we go to Boston or something where he gets very tense, because there's just so much movement, there's so many people walking by, there's so many noises, honking and he's just very tense as he's moving around.

**Interviewer:** Totally.

**Interviewee:** And irritable.

**Interviewer:** How does he manage that? Like sensory specific anxiety? **[18:00]**

**Interviewee:** Not that he does.

**Interviewer:** Alright. Perfectly fine. Thank you. Has this sensory specific anxiety changed over time as well?

**Interviewee:** I guess just as a process of aging and him developing more skills when he was five, he would be screaming, whereas like 10 or 12, he'd be complaining loudly and just repeating himself over and over and he might have his hands over his ears or something. And now it's down to some irritability and complaining and very tense body. So yeah, he does respond a little bit differently now, but I think those problems are still there. It's just that as he's matured, he's gotten a little better at handling them.

**Interviewer:** It's like the presentation is different.

**Interviewee:** Yeah.

**Interviewer:** Got you. Thank you. And then thinking more broadly, what are your goals or hopes for your son in terms of his sensory sensitivities?

**Interviewee:** That he's able to manage things in a way that it doesn't interfere with his functioning, because he's got so many other challenges. So just reducing the amount of challenges that he has to deal with. Because I think sometimes it makes them shut down and not want to try. So yeah, I think that would probably be my number one goal for him is to be able to manage things well enough that he can get past it and deal with all the other stuff.

**Interviewer:** Got you. Thank you. We're going to move on to our next chunk of questions. As your son has grown up in age, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** We've been pretty lucky. We live in a small community where a lot of people know each other. He went -- K through 5 was one school that was less than a hundred kids in there. So he was with the same 12 kids for six years. So they were very tolerant of him. And the school was also it also had the day program for the whole district. So there was a very high proportion of kids with IEPs in that school. So he wasn't like an unusual kid **[21:00]** the way he would be in another school of a hundred kids. He wasn't one out of a hundred, he was one of 20 out of a hundred. So he was lucky in that way that he was never really made fun of or bullied or anything like that because of the way that he acted differently and responded to things. I think people just recognize that's Aiden, that's who he is and that's how he's going to act. And there have been times in high school where he's at a bigger school, I think 700 kids for four grades which is still relatively small, but for me, that's a bigger school. So there of course people didn't know that he had autism, people kind of suspected he was just kind of an odd kid and some things would be a little bit weird about him. But he has disclosed that to more kids now. And so they kind of understand why he does some weird things sometimes.

**Interviewer:** Yeah. Well, I'm glad your community has been so positive. That's really great for you and your family.

**Interviewee:** Yeah.

**Interviewer:** Would you say that the community was more or less accepting when he was younger?

**Interviewee:** Probably less because he was more disruptive when he was younger. It was like tantrums all the time, meltdowns and people would like look at him like if it was like an eight-year-old kid having a three-year-old meltdown they would look at him weird but that was just like in the store, people who didn't know him. But no one was ever mean or anything like that. He just got a lot of looks.

**Interviewer:** Got you.

**Interviewee:** And now he does have some outbursts. So it's hard to tease apart the sensory stuff from everything else that's going on, he has autism, he has ADHD, he has a mood disorder, he's got all these things going on. So he started drinking cough syrup and he was going -- one day a week, he'd go to the high school, another day of the week he would go to the technical center, because he was doing a pre-engineering program there. And they have a zero-tolerance policy there. So, on his way **[24:00]** over one day on the bus, he was drinking like, I don’t know, five shots of the cough syrup and kids saw him and were concerned, they reported him. So he -- of course there is a whole lot of sensory stuff going on when your body is doing some weird things because of all of those chemicals in your body, and he reacted very badly. He wrote a letter to the principal there that was threatening and yeah, so that was last week. That's why we haven't been having a very good week.

**Interviewer:** Oh, I'm so sorry to hear that.

**Interviewee:** So yeah, he lost his spot in that program. So that was the other thing. He didn't realize that he would get kicked out, and it was like the one good thing he had in his life, he felt like everything else in this life sucks. This is the one good thing. And then they took it away from him. So, yeah, so he does still occasionally has some outbursts in public where people don't always respond to him very well because they shouldn't, but for the most part, he doesn't look as abnormal as he did when he was younger.

**Interviewer:** Sure. Thank you for sharing that. I'm sorry. It's been a hard couple of days dealing with that.

**Interviewee:** Yeah.

**Interviewer:** Well, I appreciate you showing up here and still being open to this.

**Interviewee:** Yeah, sure.

**Interviewer:** I appreciate it.

**Interviewee:** Yeah.

**Interviewer:** So you've talked a lot about like school, were there other spaces or places in the community that were more or more or less accepting of him? Like family, religious groups, if you're part of them?

**Interviewee:** Yeah, well family. Yeah. When he was very little, my parents had kind of a harder time accepting that something was different about him.

**Interviewer:** Sure.

**Interviewee:** They're from the generation that you don't talk about those kinds of things and of course there's nothing wrong with our grandchild. So it took them a while to come to terms with the fact that even we were getting evaluated, let alone the diagnosis. So but they were still very loving and accepting of him and he does have really good family support.

**Interviewer:** Wonderful.

**Interviewee:** Yeah. So that's been very good. And he hasn't really been involved in anything, we've tried to encourage him to try out different things and he just doesn't want to **[27:00]** so he's not really engaged in the community in any ways. He does do -- my dad is in the lion’s club and they have a youth group called the Leos. So he is in that. So at least that's one thing that he participates in and the organizer of that group, her son has autism. So she is very supportive of him too, which is good.

**Interviewer:** That's wonderful. That's great. Thinking of broadly again what are your hopes or worries about how his community will continue to react to his sensory needs in the future?

**Interviewee:** Yeah. I know all parents worry about the worst possible thing that could happen, but I have a real worry about how he's going to react and how the world's going to react to him especially if he gets overwhelmed in a situation, he messes up and he gets called out on it for it and he can't handle that. But then there's other things that are, like other sensory kinds of things, it's loud in there, or his boss is yelling at him or he gets pulled over and a police officer is yelling at him or whatever. He's not going to respond well, he's going to, he's probably going to explode and that's going to lead to some really bad consequences. I really do see a good chance of him getting arrested. And that's terrifying to realize that, yeah, your kid might end up in jail, and it's not like this horrible, long shot fear that every parent has deep down that your kid could do something that this is realistic. There are some fairly good odds here.

**Interviewer:** Absolutely. Thank you for sharing that.

**Interviewee:** Yeah. And then the -- is he going to be able to adjust and keep a job? Is he ever going to be able to have friends and how many relationships and things like that? So yeah, there's an awful lot we worry about with transitioning to adulthood.

**Interviewer:** Yeah, sure. Thank you. I appreciate that. And we'll to our next chunk of questions, but that again was a lovely segue. So thank you. In this transition to adulthood, where do you see your son?

**Interviewee:** Still floating.

**Interviewer:** Floating?

**Interviewee:** Yes. So he waits for life to happen. He has very little initiative except for the things that he really wants. He's hyper-focused on games, video games. So having a phone **[30:00]** so he could play video games, that's all he thinks about. He has some ideas of things he might like to do for career. I'm not sure how realistic any of them are. He got his permit two weeks ago. He hasn't asked to drive once since then. He was thinking about college. He hasn't done anything about it. He hasn't made an appointment with his guidance counselor. He just waits for everything to happen to him. And we keep trying to teach him that this is not how adulthood works. You want something, you have to work for it and make it happen. So, yeah, I think I would characterize transition right now as floating and terrifying because it's finally becoming a reality to him. He's starting to see that this is only a few months away. I mean, he's a senior and we've already explained to him that when he turns 18 and graduates, he has to live somewhere else. He can't live in our house anymore because we have two other kids and it's hard for them to have him at home too. And we need to raise them too, so we've told them we will help him transition to whatever is best for him. If he wants to go to school, we'll help him with that. If he wants to get an apartment, we will go through all the paperwork and help him apply for funding and whatever. And so we're going to help them with those things but yeah, he knows he's not ready. He knows he doesn't have the skills that he needs, so he's kind of paralyzed with fear too.

**Interviewer:** Got you. Thank you for sharing that as well. Could you talk a little bit about the skills that he does have versus some skills where he still needs some support, like for example, like daily hygiene, or chores?

**Interviewee:** Those are not skills that he has. Those are ones that he's missing.

**Interviewer:** Okay. Fair. Well he does not do it? Does he need reminders from you?

**Interviewee:** Yeah. So both. His hygiene is really terrible unless we constantly nag. Chores, at this point, even his brother has said, *“I will do his chores. He just doesn't do them right and I don't want to wait around for him.”* So his brother is doing the **[33:00]** chores.

**Interviewer:** And that's his little brother, right?

**Interviewee:** Yes. Yeah. So Aiden doesn't do an awful lot in the way of chores because it's just too much of an argument, and now I still make him once a week to help cook a meal so he's learning some of those skills.

**Interviewer:** That's great.

**Interviewee:** So for this, one of the skills he does have is if he's interested in something, he is super focused and very persevered, he really works at something that he wants and he is creative. He is curious, so he does have some skills, he's also very articulate. I mean he also, sometimes he talks the way that people write in books. So he'll say things like she replied and so it does sound a little bit weird sometimes in conversation. And he's very polite too to other people, especially teachers, so teachers love him.

**Interviewer:** That's wonderful. That's great. You mentioned that you were helping him learn how to cook by making him cook a meal once a week with you. Is he able to prepare things by himself now to some degree?

**Interviewee:** Not really on his own. I mean he can make a sandwich but even using the microwave, he won't think twice about putting something metal in the microwave just because it wouldn't occur to him. So he might think, *“Oh, well, this peanut butter was in the refrigerator and it's too hard. I'm going to put it in the microwave to soften it up,”* but oh it has a metal, some wrapper left around the top, that's going to start a fire. So yeah, so I don't entirely trust him in the kitchen on his own. But he can do some things, like he can cut some things up, take some really long time to get anything done. But he's gaining some skills there.

**Interviewer:** That's wonderful. What about going shopping or preparing a shopping list for things you might need?

**Interviewee:** Preparing lists, no, he hasn't done that. Yeah. I should make them do that. But he is -- I do make him go to the store with me and I'll give him, *“Alright now, go get these three things. Okay, now go get these two things.”* And he goes off in the store and finds them. So he's getting much better at that.

**Interviewer:** That's great. **[36:00]** How is he with like money and money management? Does he understand what money is?

**Interviewee:** Oh, he's terrible. He understands money. He can't keep track of anything. He's also made some really bad choices, he signed up for an eBay account when he was 16 and he wanted a phone, and he started bidding on phones and he said something to me and I'm like, *“Okay, let's go look in your account and sit down and look.”* And he won six phones. That he now is on the hook for buying all of them and I'm like, *“Oh my God.”* And of course, he's freaking out because he doesn't have the money. And so I called eBay and explained everything to them and they're like, *“Well, just don't respond to the sellers, and we will disable the account.”* And so and I made him write himself a letter around, this is how I feel right now and this is the lesson I learned and all this and two months later, he's back on eBay bidding up. Oh my God. He just doesn't learn. Yeah, so he's really not good with money.

**Interviewer:** Got you. Thank you for sharing that as well. Does he express interest in wanting a job when he graduates high school?

**Interviewee:** Oh yeah. He wants a job and if we let him, he would be still at work right now. He was working at Hannaford or grocery store stocking produce. And he was actually, they said he was doing a good job there.

**Interviewer:** Wonderful.

**Interviewee:** Which was awesome. But then once the pandemic hit, since he has such bad hygiene, we can't take a chance of him not sanitizing. And because both my husband and I are at risk and my dad and so he hasn't been at work and we're willing to let him have a job where he's not around the public, but he hasn't found anything.

**Interviewer:** Got you. But he would work if he could write down?

**Interviewee:** Yeah.

**Interviewer:** Great. How does he feel about having his own space in a few months and like moving?

**Interviewee:** Yeah, he's looking forward to it. He does want to be able to have his own apartment. He's a little frustrated about that we're looking at group homes and things like that, where **[39:00]** he doesn't want to live with those kinds of people and I'm like, *“Aiden you are those kinds of people.”* So, he wants to have his own place. He doesn't want to share with a roommate or anything. And I'm like, *“Well, if you want to go to college, do you have to live with a roommate? You have to learn how to get along.”* Yeah.

**Interviewer:** Got you. Does he have a social life that he manages to some extent?

**Interviewee:** No. He has not had friends in years. So, he had those elementary school friends, and then when he went to a different school, he just says he doesn't like anybody, but I think it's the just can't make friends.

**Interviewer:** For sure. And then do you think your son will be able to achieve more independence in the future?

**Interviewee:** I hope so. Yeah, I think when he wants something bad enough, he worked hard for it. So right now, he doesn't need to because he still has a roof over his head.

**Interviewer:** Yeah.

**Interviewee:** He's still getting fed. He's still getting clothed. He's still getting driven where he needs to go, but when he needs to, I think he will rise to the occasion, but it's going to be messy and he's going to mess up a lot. And I'm just hoping that the messing up isn't so bad that it's permanently ruins his life.

**Interviewer:** Yeah. What do you think will help move him into adulthood?

**Interviewee:** That's a good question because we tried so many things.

**Interviewer:** Yeah.

**Interviewee:** Him wanting and him taking initiative on things and seeking help, part of it is that he doesn't want to ask for help with a lot of things, but you can't do it on your own, when you want it, you got to ask for help. And we were just talking yesterday about his hygiene and how he smells, he's got body odor really bad. And he's like, *“Well, I wash my armpits in the shower and I put on deodorant.”* And I’m like, *“Well Aiden obviously whatever it is, it's not working. We got to come up with a solution. So what do you propose?” “Well, I don't know.”* And I'm like, *“Okay.”* So, he has a caseworker at school who does a really great job with him. I said, *“Ask Mrs. Delphine how you smell. She's going to give you an* ***[42:00]*** *honest answer.”* And I said, *“And if you want to, you can ask me any time if you stink, if you need to put on deodorant or something.”* So this morning when he's getting ready, he asked me four times, he came over and he's like, *“Do I smell okay? Do I smell okay?”* I'm like, *“Okay.”* So first you need to go put on some deodorant. So he goes, he puts it on and he's like, barely tickling. I'm like, “*No Aiden, you have to like rub it off.”*

**Interviewer:** To get it --

**Interviewee:** But it's okay. So maybe this is why you stink because you're not actually putting on the deodorant. Yes. So, he needs to ask for help and he need to want it.

**Interviewer:** Yeah. Do you think there are any services or interventions that could help him move into adulthood?

**Interviewee:** I'm hoping, I'm trying to reach out for anything. We have a community case manager who is helping with some stuff. So she got us connected with getting a referral for neuro psych testing for, qualify for anything. She's getting like the social security paperwork and stuff together, so he can apply for disability when he is 18. She's looking into housing options. So she's helping us find what's available. Although I've heard that the adult services here are terrible and that there are waiting lists for everything. And like for housing people wait for years, for housing. Well, he's got to go somewhere. Yeah. So yeah, this is a whole new realm. We did go – I think it was in January. The main Parent Federation had a training on order **[?]** decision-making and with the main disability rights council. So they could kind of explain, what is guardianship? And that main actually has one of the highest rates of guardianship and the legislature is trying to reduce that, they want more people with disabilities to be independent adults. So, they passed this supported decision-making legislation that basically says, “*You have to be independent when you're 18, unless you can prove otherwise.”* So **[45:00]** now it's not like you automatically become a guardian when the child turns 18, you have to prove that they need the guardian. Otherwise, you go through the supportive decision-making and you help figure out where do they need help with stuff. So like and he went to that training with us, which was good. Like, he recognizes he's going to need a medical proxy. He recognizes he's going to need us to help him make financial decisions. So, we've kind of started looking at what some of those things are and what the options are.

**Interviewer:** Got you. That's wonderful. I'm glad you're beginning that process. We're going to go into our next type of questions. Putting these two things together, his sensory sensitivities and his transition to adulthood, how do they intersect for your son?

**Interviewee:** I think it's just one more thing that's overwhelming him. And one more use [excuse?] for him to stay frozen and not take action. Because he's got so many things that are a challenge for him. And then it's the biggest things inside are the emotions and the attention, and then the sensory stuff, and you can't get past, unless he can handle those three. He can't actually function. So I think we're working on the emotion stuff. We're working on the attention stuff through counseling and medication. The sensory stuff, I'm not sure what else we can do about that. So yeah, I think it's going to be a hurdle.

**Interviewer:** Great segue again. Do you view his sensitivity his sensory sensitivities as an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** I think an obstacle.

**Interviewer:** Yeah.

**Interviewee:** Yeah.

**Interviewer:** In what way?

**Interviewee:** Well, like I was saying that it's one of the, kind of when you're looking at Maslow's hierarchy of needs, it's not really a hierarchy and he didn't explain it that way, that you have to meet one before you can go to two and -- but if Aiden had a hierarchy of needs, his ability to regulate sensory input is right at the bottom with his ability to regulate **[48:00]** his emotions and his ability to regulate his attention. And if those things aren't in the way he can't move on to something else. He can't function and be productive. So it's definitely an obstacle.

**Interviewer:** Yeah. Thank you for articulating it that way. It was very clear. Relatedly, what do you anticipate as being challenging for your son as he does gain more independence in relation to his sensory sensitivities?

**Interviewee:** Probably that he's going to avoid things. I mean, he's probably going to become a hermit because he'll avoid crowded places. So I think he's going to have a hard time meeting people. He probably, it might impact what kind of job he's willing and able to have, if the noises are too much and too distracting in the workplace it depends on what kind of job he's doing. He might not be able to handle it. So he might not be able to keep the kind of job that he wants to. So yeah, I think there's going to be a lot of things that could be impacted.

**Interviewer:** Totally. And then what do you think could help your son in this intersection?

**Interviewee:** Well, self-awareness. He still needs to develop more of that.

**Interviewer:** Totally.

**Interviewee:** And I think coming to terms with his disabilities is going to be really important too, that he really doesn't like his disabilities. He doesn't like that he has autism. He doesn't like that he has ADD. He wishes that he didn't, he wants to be like everybody else.

**Interviewer:** Sure.

**Interviewee:** So I think he needs to accept who he is and that it's not all about limitations. It's about, you are this species from this planet and you want live here, you need to adapt to that climate and it's not a matter of *“you’re deficient,”* it's *“you don't fit.*” So once he can kind of accept that about himself, I think he'll be able to start seeking out more support and help instead avoiding.

**Interviewer:** Totally. Thank you. Are there any services or interventions that you think could help him in this intersection besides these kind of like more self-guided processes?

**Interviewee:** Yeah, actually I think maybe if he did do OT again, that I think might be helpful for him. **[51:00]** Yeah, that would probably be a good idea. And counseling too.

**Interviewer:** Totally. Absolutely. Do you think there are gaps in the available services and interventions for children and young adults like your son?

**Interviewee:** Oh, absolutely.

**Interviewer:** Tell me more. Why do you feel that way?

**Interviewee:** Oh gosh. I mean, the transition planning should start at least in eighth grade and --

**Interviewer:** **[inaudible 51:42]**

**Interviewee:** Yeah. And the federal law for IEPs is 16 years old, is when you start -- you have to start it by then. Aiden had 14 years. And they removed them and they don't really take that 14-year-old transition planning seriously. All they do is because he had that when he was 14, they started that where it's just another page on the IEP where they say, *“Oh, what are your long-term goals? Do you want to go to college? Okay, let's write that down.”* That's it, that's all there was for transition planning. And we, Aiden and I went to an autism conference in Portland a couple of years ago and we found out about youth employment services through folk rehab and that you're eligible for that at 14, but there's nothing around us. It's only down in Portland and they have job coaching, they have job shadowing, they have temporary employment. They have all these things that if you're 14, you can get started with all of these things, and you start to understand the world of work in a safe way where it's not you mess up, you lose your job, it's you mess up and you have a lot of support there and you learned from that experience, where it's not like, all right, you're dumped into 18 and good luck with that. So yeah, there really should be way more in terms of transition and helping families understand what the financial options are, when a student with a disability turns 18, what are they eligible for? What are you going to have to pay for? And what kinds of housing options are available out there and yeah. There really should be a lot. I thought I was being proactive with getting these things going, but I'm like, *“Oh God, I should’ve done this a long time ago.”*

**Interviewer:** But if you don't know, how can you be proactive?

**Interviewee:** I know. Yeah.

**Interviewer:** You're doing your best. Thank you. Again, thinking more broadly **[54:00]** how have your son's sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Well, I think it’s part of what makes him drift, that because he avoids, and I think part of that is, comes from avoiding unpleasant sensory experiences.

**Interviewer:** Totally.

**Interviewee:** So not wanting to engage in things. And then part of it is the emotional stuff that's in his way, and part of it is the attentional stuff that's in his way and the executive function stuff that's in his way, but I think the sensory stuff contributes to that whole thing that gets in his way from being able to initiate everything.

**Interviewer:** Yeah. Absolutely. Thank you. We're going to go into our last chunk of questions here, almost done with the shortest ones. As a caregiver, as a mom, as a parent of someone with autism, but also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interview:** [loud sigh]Freedom…

**Interviewer:** [laughs]Okay!

**Interviewee:** I say that jokingly, but really this has been an extremely intense 17 and a half years. It has been a roller coaster ride and I'm ready for a break.

**Interviewer:** Totally.

**Interviewee:** Or maybe just like a gentler ride.

**Interviewer:** Yes. Like a kiddie roller coaster?

**Interviewee:** Yes. So I know he's not going to be out of my life completely. I know what I'm still going to be going through these ups and downs with him, but I can't do the Superman roller coaster ride anymore. It's exhausting. And I'm hoping to be able to have him not occupy 100% of our attention so that we can give some attention to our other kids too. And that we can actually have some more normal in our lives. So I don't know if it's realistic at all, it's probably not. It's probably going to continue to be that the hellish rollercoaster ride, but that's what position means to me. Yeah. **[57:00]**

**Interviewer:** Thank you for sharing that. Has his perspective changed over time?

**Interviewee:** Yeah, because I learned pretty early on when he was getting diagnosed, that the only way I could get through was not looking at the future. I had to give up my ideas of what it meant for my child to grow up and be an adult, because we have these ideas, when you become a parent, you see that baby and you see college and marriage and whatever and part of the grief of the diagnosis was letting go of all of those hope for the future. And we have three kids and the youngest is developmentally disabled and she actually has more severe disabilities than Aiden does. But she's so positive. So it's a very different experience with her and she's not disruptive the way that Aiden is. So I've been going this whole time, just really not looking at the future and just trying to make it through one day at a time. And it's been the last, let's see I think he was 13 in eighth grade when we actually had to hospitalize him. And we started at that point thinking, *“Okay, five more years until he's 18.”* And so yeah, my view started to change of, okay, the way to cope with this is that we need to get him ready to be independent when he's 18. So that's kind of how my transition thinking has changed.

**Interviewer:** Got you. You may not be able to answer this and that's okay. Just part of my script. But again, you don't have to answer it if you can't and that's alright. What do you see happening in your son's future?

**Interviewee:** [Sighs loudly]I see crashing planes and burning buildings and crying babies [laughing]. Yeah, I hope for independence and happiness or if not happiness, at least satisfaction and fulfillment. But I also worry about the trauma, the damage, the chaos, all of the other things that **[60:00]** Aiden's track record has shown us for 17 years, that he's not going to turn 18 and become a different person.

**Interviewer:** Yeah, absolutely. Do you see him, so you see him moving out, you've talked about that. Do you see him having a job when he's out of the house or later?

**Interviewee:** Yeah. But it will probably be something menial, like stocking shelves at the grocery store. Probably minimum wage. He wants more than that, but I don't know if he's ever going to be able to get himself together to do something like that.

**Interviewer:** Do you see him finishing his high school program?

**Interviewee:** Yes, he is very close. He's got to get through his classes this year and he'll graduate and there's really no reason why he shouldn't. He's talked about dropping out but we also pointed him that until he's 18, he's going to school if he lives in our house because if he drops out, he's going to adult ed or he's not living in our house. And at that point, no, he does have to find his own place.

**Interviewer:** Do you see your son having a family of sorts later on in life?

**Interviewee:** I don't know. I mean, my brother looking back, we all think that he's autistic. Not as severely, but he's a computer engineer and he's on his fourth marriage. He has not had luck with relationships and I don't see Aiden having good luck with the relationship there. He might be married at some point. But I don't know if that would be a lifelong thing.

**Interviewer:** Sure. Last formal question. How have your child's sensory sensitivities impacted this perspective of what it means to transition into adulthood?

**Interviewee:** Well, I've also become more aware of it too. That's one of the things about Aiden is that I'm always learning and I'm always trying to learn more. And he has made me a better teacher because I don't assume about students anymore. And I'm learning more about the brain and I learned so many things about autism and about ADHD and about executive function **[63:00]** and about mood disorders. And a lot of what we've been doing with him is behavioral focused. And also, by understanding executive functions, it also helps me to understand why he does certain things and things that are just like nonsensical to us that are like the simplest thing in the world but they're just not connecting in his brain. And so sensory stuff has been on the radar for most of his life, but when we went to that conference a couple of years ago, I brought Aiden with me and we went to a session around some sensory experiences and autism, and he was really into it because he was like, *“Wow, that sounds like me.”*

**Interviewer:** That's great.

**Interviewee:** And then I think I mentioned to you, I went to learning in the brain last weekend and we went to another session around sensory from an OT and so it is kind of helping me to understand a little bit more that it's really is at some of the root of some of his problems that it's not just the attention and the other executive functions and the emotion. Those are not the only two things that are at the foundation. It's also the sensory stuff that's at the foundation that is contributing to those things.

**Interviewer:** Yeah, absolutely. Thank you.

**Interviewee:** Yeah.

**Interviewer:** That was wonderful. That is all I have for my formal questions. Would you like to add anything?

**Interviewee:** Actually, I don't know.

**Interviewer:** That's okay.

**Interviewer:** Yeah, I was really kind of negative about -- so yeah, there have been some really wonderful moments with Aiden, like a rollercoaster ride, there are some terrifying moments, but there are also some thrilling and exciting things too, but yeah, unless you live through this, I don't think you can imagine what it's like to parent a child like Aiden. And what it's like to try to get him ready for adulthood. So I'm so glad that you're doing this kind of qualitative research where you're able to kind of help people understand what are some of these real challenges that families are dealing with and numbers just don't do it. Yeah, it's enough to say, here are the resources available and here are the number of people that need it and obviously there's a mismatch, but what does that really mean to the family? Yeah.

**Interviewer:** Yeah. I think qualitative data is so important when you're talking about real life experiences, because numbers are a nice summary, **[66:00]** but they're not what's really happening.

**Interviewee:** Yeah.

**Interviewer:** Well, thank you too. This has been such a pleasure to learn from you and I really appreciate you making time in what seems like a hard time for you. It's been such a pleasure to learn from you and I really have-- you are helping because now we can talk about this and data and research and present on it.

**Interviewee:** Yeah.

**Interviewer:** Do you know anyone else who might want to participate? We're still looking for more participants.

**Interviewee:** Okay. And what is the age range?

**Interviewer**: It is 16 to just under 26. So, 25 and 11 months is our cutoff.

**Interviewee:** Oh, okay. So I do have a friend who has a young adult son with autism. And I don't think he's 26 yet. So, can I just give her your email address?

**Interviewer:** Yeah. If that's what's easy for you, that sounds perfect. I could send you a flyer. You could send me her contact. Whatever's easiest for you and for your friend.

**Interviewee:** Okay. Alright.

**Interviewer:** Would the flyer be helpful or just?

**Interviewee:** Yeah, I think the flyer would be helpful. Yeah.

**Interviewer:** Great. I will do that for you. Thank you. We appreciate it.

**Interviewee:** Yeah. And there's the main parent federation, which is a nonprofit for families with special needs. And they have a newsletter that they send out, they also have mailing list, that you might be able to recruit on, as well as the autism society of Maine. They also will post recruitment stuff too.

**Interviewer:** Wonderful. I will reach out to them. Thank you.

**Interviewee:** Yeah.

**Interviewer:** I'm going to quick check to see if I got that. I get an email whenever you finish the surveys, I'm going to quick check and make sure it went through.

**Interviewee:** Okay.

**Interviewer:** We'll take a hot second. Yes, I got it. Beautiful. Thank you. So as soon as this video renders or an audio file renders, I will send you a thank you gift card and a thank you email for all of your help. And it should be done before 4:30 PM today, if it is not I'm taking some time off for the holidays, so it'll be in your inbox on Tuesday at the latest.

**Interviewee:** Okay.

**Interviewer:** But just know we appreciate you and you --

**Interviewee:** Sure. Yeah. Well, thank you very much.

**Interviewer:** Of course.

**Interviewee:** I'm very glad that you're doing this research project.

**Interviewer:** I am too. It's been wonderful. Can I do anything to help you, would reports from the surveys you filled out? Would that be helpful?

**Interviewee:** Yeah, sure. Yeah.

**Interviewer:** Okay, great. Have you anything else to help you, any clarifying things?

**Interviewee:** I don't think so. When you -- how long are you planning to collect data for?

**Interviewer:** Great question. So right now, our original N, our original sample size was going to be 45 and we've increased it to at least 75 now. So you're in my 51st interview. **[69:00]** So about 25 more participants. I think it went pretty fast, so I anticipate doing those in maybe about four months I do about.

**Interviewee:** Great.

**Interviewer:** Yeah, I go -- it's been fast.

**Interviewee:** Yeah. Good for you.

**Interviewer:** Thank you. Yeah. So hopefully finish up in a couple of months and then finish up data analysis by the summer is kind of my personal timeline and goal.

**Interviewee:** Yeah. Cool. Well, send me any results that, even if they're preliminary, because it'd probably be like two years before you get anything published, so and I'd love to see anything that you have.

**Interviewer:** Yes, absolutely.

**Interviewee:** Yeah.

**Interviewer:** I just submitted last week. Do you know what InSAR is?

**Interviewee:** Hmm.

**Interviewer:** So I just submitted to InSAR for their conference in May. So if that gets accepted, you will see the poster in your inbox hopefully around May.

**Interviewee:** Nice. Cool. All right. Awesome.

**Interviewer:** Wonderful. Well, you have a great rest of your day. Good luck on your doctoral stuff as well.

**Interviewee:** Thank you. Yeah. And have a wonderful Thanksgiving.

**Interviewer:** Thank you. You too. If anything, send me an email, send me a text, you know where to find me.

**Interviewee:** Okay. All right. Thanks Rachel. Okay.

**Interviewer:** Bye.

**[End of transcript]**