**[Start of transcript]**

**Interviewer:** All right, we are recording. And I will be asking you questions about your perspective regarding your child’s transition to adulthood in relation to his sensory sensitivities and sensory interests. And we’ll be doing something called a ‘semi-structured interview,’ which means I have my planned questions here. But I’ll be adapting them to follow our conversation to actually make sure they fit, and they make sense for what we’re talking about. Do you have any questions?

**Interviewee:** No.

**Interviewer:** OK, awesome. And then, throughout the conversation, if there are questions that make you uncomfortable or you don’t want to answer them, you don’t. We want this to be a positive thing. So don’t feel forced to answer anything you don’t want to. And if you think of something halfway through the conversation that you forgot to say, say it. This doesn’t have to be particularly linear; it can be circular, conversational. We want it to be informal but useful.

**Interviewee:** Awesome.

**Interviewer:** Any questions?

**Interviewee:** No.

**Interviewer:** OK, cool. So for my first question, could you please start off by telling me about your child’s sensory **[1:00]** sensitivities and sensory interests?

**Interviewee:** Well, he has a lot of interests that are probably more typical. He likes watching spinning things, bright lights. It’s actually one of the things that was one of the first indicators that there might have been something wrong with him when he was much younger. Because he’ll just stare at them for hours, I mean, windmills, ceiling fans, anything that spins. But he also has some things that bother him.

**Interviewer:** OK.

**Interviewee:** And it’s funny because sometimes they’ll bother him and other times they don’t appear to: such as one day, he’ll be like, “*I’m going to help load the dishwasher*.” He doesn’t say those words, of course, but he’ll help load and he’ll start it. And then the next day, he screams because the dishwasher is running. Same with, like, the washer, the dryer, those kind of things, so. And sometimes it seems like as he gets older, he gets a little more rigid as far as what seems to bother him. Because right now, it seems ridiculous, but we can’t run the dishwasher if he’s in the room. So we actually try to run the dishwasher when he goes to bed in the evening. You know, so just things like that. But there are also things that bother him and also seem to fascinate him at the same time, like sirens, motorcycles, loud cars, so he likes watching them, but he doesn’t like hearing them and he’ll cover his ears. If it’s really aversive to him, he’ll start screaming and running. And that’s when we might see some self-injurious behaviors.

**Interviewer:** Yeah. OK, so it’s like, he likes some sensory modalities of these things, but not other sensory modalities.

**Interviewee:** Yeah.

**Interviewer:** Got you. I think, in the form, you indicated he has, like, a touch sensitivity or touch interest?

**Interviewee:** He does. Now he does ... he doesn’t like to be touched, period, you know.

**Interviewer:** OK.

**Interviewee:** But at the same time, he has people that he will allow to touch him and me in particular—I’m basically his person. So he will come up to me and he’ll press his forehead to mine and he’s done that since he was an infant. As soon as he could pull himself up, he’s been doing it. And he’ll press really hard and it seems to be very relaxing for him. He’ll close his eyes and you can literally see, like, tension releasing from his body.

**Interviewer:** Yeah.

**Interviewee:** So he’ll do that. And he likes—from me only—the little butterfly kisses, you know, the little eyelashes, you know, and he’ll get … He’s taller than me now, but he’ll climb in my lap and he’ll have me do it or then put his fingertips on my eyelashes so he can feel it and so.

**Interviewer:** Yeah. Does he ... because you talked about, like, pushing on your forehead with his forehead, **[4:00]** does he like that deep pressure sensation in other contexts or just with you on the forehead?

**Interviewee:** We tried—well, his school district tried—a pressure vest at times, but it did not seem to make much of a difference. And I know as far as in the home environment … really, it’s just that there have been times when he was much younger, when we were going through OT, you know, we … they did the diet of the pressure. And so we did try it and he just kind of looked at me like, “*Why are you doing this?*” Yeah.

**Interviewer:** Yeah, absolutely. So you talked about how, like, there are some things he likes in some contexts and not others like the sirens, like, he likes looking but not hearing. Are there other types of scenarios where he has this contrast in like and dislike?

**Interviewee:** Well, it’s strange because, like, he enjoys going through the carwash.

**Interviewer:** Yeah.

**Interviewee:** So, he’ll be really excited to go through it. But at the same time, he’s going to cover his ears. So he likes watching it but, you know, it’s really loud for him. Sometimes it could be the vacuum, he might like seeing it, but the sound, “*Oh, we’re going to run and scream and pound* …

**Interviewer:** Yeah.

**Interviewee:** “… *over the vacuum, but at the same time we like it*.” So I can’t think of anything off hand other than like, motorcycles …

**Interviewer:** Yeah.

**Interviewee:** … and loud cars, you know. So he likes seeing them, but he doesn’t like hearing them.

**Interviewer:** How is he with non-mechanical sounds? Because it seems like, you know, vacuums, cars—those are more, like, mechanical noises. What about, like, people talking, singing, music, crowds?

**Interviewee:** He does not seem too bothered by people talking. Music can bother him if it goes … even if it’s not something I would consider loud, he might still be covering his ears. His twin brother plays trumpet. And there are times where he is perfectly fine with him playing trumpet. Other times, you know, the ears are covered and he’ll, like, start screaming “*Stop playing!*” He doesn’t talk very much. But he’ll be like, “*Stop playing!*”

**Interviewer:** So you know it’s real.

**Interviewee:** Yeah. And he loves going to football games because his brother’s in the marching band. He loves going to them. But, at the same time, the whole time he’s there … his little ears, he’s plugged his ears up. I mean, he’s actually crawled down, like, in the bleachers.

**Interviewer:** Yeah.

**Interviewee:** But he insists upon going. So it’s, like, “*Well, I guess you want to go, you just don’t want to listen to it*.” I don’t know. But …

**Interviewer:** Yeah. Are there other things that he likes sensory wise, like, you talk about spinning things, anything else that he really enjoys or seeks out?

**Interviewee:** No, that’s still spinning things. He likes tops.

**Interviewer:** That’s OK.

**Interviewee:** So, I was going to say that, but no, everything seems to be spinning. Any touch in particular that he seeks out? No taste …

**Interviewer:** Yeah.

**Interviewee:** As a matter **[7:00]** of fact, he doesn’t like … he likes five foods and that’s it, you know. So, sound wise, there’s not a particular sound other than his ... he may himself make a noise, you know, some kind of echolalia or something like that, where he’s making noise. But …

**Interviewer:** Yeah.

**Interviewee:** … otherwise no.

**Interviewer:** What about … so you just talked about taste—so he has a limited palate?

**Interviewee:** Very much so.

**Interviewer:** Yeah. What is …? Oh sorry, go ahead.

**Interviewee:** No, I was just going to say we’ve expanded it somewhat. So now he eats chicken nuggets and, like, eight sides, but none of them are healthy. So.

**Interviewer:** Yeah.

**Interviewee:** So we’re just excited to see him eat something else.

**Interviewer:** Yeah, totally. So he’ll eat chicken nuggets—and what else, like, what else … like what’s in his repertoire?

**Interviewee:** Well, he’ll eat Doritos, but only Cool Ranch; Fritos, but only plain; plain Pringles; Cheezits. And again, all of these things are plain, other than the Cool Ranch Doritos.

**Interviewer:** Yeah.

**Interviewee:** Let’s see … townhouse crackers, Saltine crackers, sometimes oyster crackers.

**Interviewer:** What are townhouse crackers?

**Interviewee:** They are oval shaped. They’re, like, you might see them with, like, cheese and crackers, kind of thing.

**Interviewer:** Are they kind of, like, Ritz cracker-ish?

**Interviewee:** Yes.

**Interviewer:** OK.

**Interviewee:** Yes. Only they’re ovals instead of circles. And he calls them ‘oval crackers.’ Chocolate Pop Tarts and waffles with no butter or syrup. So that is all the foods that he will eat.

**Interviewer:** Yeah. Is … do you know why he won’t eat other foods? Is it like a texture thing, a flavor thing?

**Interviewee:** I do believe … Now, obviously, he doesn’t tell me this, but I do believe some of it is texture. Because he doesn’t like anything that’s mushy. And he can write with a pencil, but he will not ... I mean, he just refuses to use utensils. So everything he eats is all … is with his fingers. So … and I don’t know why. We’ve tried, obviously, many times to get him to eat with utensils.

**Interviewer:** Yeah.

**Interviewee:** And when he was a baby, he ate a whole bunch of food, you know, baby food, and, of course, it’s soft and mushy. But no. Ever since he was a toddler, he just refuses. I mean, no ice cream, no pudding, nothing. So I don’t know if it’s because he is ... something with the utensils … that I don’t know if he’s fearful of it or whatever, or if it’s a texture.

**Interviewer:** Yeah. And so you talked about he would eat a lot of stuff when he was younger and now not so much. Can you think of, like, what caused that shift?

**Interviewee:** I can’t. I mean, other than because—and I think I mentioned earlier—he seems to get more into as he gets older …

**Interviewer:** Yeah.

**Interviewee:** “*This is what I’m going to do. These are the foods I’m going to eat. These are the sounds that I’m going to tolerate. These …*,” you know, “*This is what I’m going to do*.” And he kind of comes up with this thing and once he has it in his mind, “*This is what I’m going to do*,” then that’s what it is.

**Interviewer:** Yeah.

**Interviewee:** And it’s hard to kind of break that cycle because, I mean, we even did feeding **[10:00]** therapy, you know, to try to get him to eat more food and, you know, tried to sneak food in and all kinds of things and none of it worked.

**Interviewer:** What about smells?Is he sensitive to particular smells in the way he’s also sensitive to certain types of foods?

**Interviewee:** No. I have never noticed him being sensitive to any smell. I’m going to put a little disclaimer on that—and that is because smell is a migraine trigger for me, so our house is pretty … like everything we have is unscented, so.

**Interviewer:** Oh yeah, totally.

**Interviewee:** So I don’t know if that’s something that could be, like … if he’s in a different setting …

**Interviewer:** Yeah.

**Interviewee:** like, at school or whatnot. No one’s ever told me that. But I know here there’s not much for him to smell.

**Interviewer:** Yeah, totally. I was wondering that, like, maybe cooking smells, like … so I’m guessing you make other foods for the rest of your family members?

**Interviewee:** Yes. And no, nothing has ever seemed to bother him.

**Interviewer:** Gotcha. And so you’ve talked a lot about how things have changed over time, like you talked about increased rigidity, you’ve talked about, like, him like, being less flexible in his palate—have you noticed other types of changes over time?

**Interviewee:** Now, some of them, it could just be, you know, he’s getting older. But he, he used to want to be around the immediate family more often and now he is pretty much “*I’m going to go be by myself*.” But, you know, and I don’t know if that’s “*I’m 17*” or whatever. But, you know, he likes to spend most of his time alone, you know. So he’ll pop in on me a few times a day and hang out with me for maybe five or ten minutes at a time. And then he’s like, “*I’m done and now I’m out*.”

**Interviewer:** OK. Go ahead.

**Interviewee:** Oh, I was going to say I can’t think of anything else offhand.

**Interviewer:** Yeah. What about the spinning: has that always been a constant thing that he seeks out and enjoys?

**Interviewee:** It has been. I mean, that started probably as soon as he could crawl around …

**Interviewer:** Yeah.

**Interviewee:** … and choose his preferred toys or look at the ceiling fan kind of thing but yes, that has always stayed. And, you know, like, spinning the tire wheels on the, you know, the car tires and things like that … the helicopter just being able to maybe … **[crosstalk at 12:25]** So yeah, that’s always been there. I mean, he’s 17. And, much to our dismay, the Teletubbies have made a comeback in our lives. Only because of the windmill. He likes watching the windmills. **[inaudible at 12:38]**

**Interviewer:** Oh yeah.

**Interviewee:** It’s like, oh my goodness … you know, so it’s one of those ... as his parent it’s like, “*Yeah, I don’t want to. That’s so not developmentally appropriate, but it makes him so happy to see that windmill*,” so yeah.

**Interviewer:** Happiness is important, though, that goes a long way.

**Interviewee:** Yeah.

**Interviewer:** What about the lack ... he … so you said he doesn’t like to be touched by other people unless **[13:00]** it’s, like, you with the forehead?

**Interviewee:** Right.

**Interviewer:** Is that also pretty constant?

**Interviewee:** It is. I mean, like, people will try to hug him and they all laugh because he may allow them to do a backwards hug. So he’ll turn around and kind of back into them so they can give him that kind of hug. But yeah, I mean, he might hold, like, hold my hand or his dad’s hand when crossing the street or something like that. But that’s pretty much it.

**Interviewer:** Yeah. And what about the contrast in, like, liking, like, visually liking motorcycles but disliking the sound? Is that contrast also pretty consistent throughout his life?

**Interviewee:** Yes, very much so. Because loud sounds … he doesn’t like the loud sounds period.

**Interviewer:** Yeah, absolutely. And he always hasn’t liked loud sounds?

**Interviewee:** Yes. Unless he is the one making them—because he can be very loud.

**Interviewer:** Yeah, absolutely. And taste: has it always been a limited palate or have you been able to kind of expand it a little bit?

**Interviewee:** Oh, we have expanded it, but only with more of the same. I mean, there’s, like, four different crackers. They may have different shapes, but a cracker is a cracker, you know, so it … you know, maybe a tiny bit, but really, no.

**Interviewer:** Yeah.

**Interviewee:** If anything that has gotten more limited because, you know, even, like, when he was two or three, we could get him to eat ice cream or cereal or something like that, where we were feeding him with a spoon, but no. So other than that …

**Interviewer:** Got you. And then the sensory changes that you have noticed, like the increased rigidity, perhaps—do you think this is related to any independence that he’s gained over time?

**Interviewee:** Now it very well could be because I see him as he matures, you know, wanting to be more independent. He wants to do more, you know, so, you know, he’ll put the clothes in the washer and then he’ll run and he’ll be like—you know, it’s not a full sentence, but he’ll tell me to start the washer when he’s out of that room, kind of thing. You know, so he’s participating in it, but in his own way. The same with the dishwasher: he’ll load it, he’ll unload it, he’ll put the laundry—I mean, not the laundry, but the dishwasher tablet—in and, you know, then he’s like, “*Now you can start it when I’m up the stairs*,” kind of thing.

**Interviewer:** Yeah, so he wants to join in a way that’s kind of, like, sensory safe for him.

**Interviewee:** Yes.

**Interviewer:** Got you. And then … that’s actually a fantastic segue. That wasn’t even planned. How does he manage and cope with his sensory sensitivities? Or how do you help him manage and cope with his sensory sensitivities?

**Interviewee:** I think he knows on some level what he’s able to tolerate and he doesn’t put himself in situations, you know … to the point where “*I’m going to go hide in my room*,” or whatever. But he won’t put himself in a situation where he feels like it’s going **[16:00]** to be aversive to him. But we continue to take him … I mean, we don’t allow it to be something that interferes with his life too terribly much. One of our very first therapists, they’re like, “*Take him everywhere*.”

**Interviewer:** Yeah.

**Interviewee:** So we did and, literally, he has been dragged everywhere. So it’s like, “*OK. You may not like it, but you’re going*.” And we do have some headphones that he could wear. He usually doesn’t, but he has them. But we’ve noticed in the last year or so that he has not the sensory-type headphones, but actual headphones. And so he’ll plug in to, like, his phone or, you know, his tablet. So he’ll plug in there and he keeps his headphones on most of the time.

**Interviewer:** Is he playing ...? Sorry, go ahead.

**Interviewee:** Sorry. But no, I was just going to say, so he has figured out in the last year or so “*I can listen to this and then I don’t have to listen to whatever else*.”

**Interviewer:** What does he listen to when he does that?

**Interviewee:** Now usually … now, this is the strangest thing: I just told you how he doesn’t like the washer, but if I look at his phone—because every now and then I just want to see “*What are you looking at?*” …

**Interviewer:** Totally.

**Interviewee:** He’s watching a washer, literally watching …

**Interviewer:** Interesting.

**Interviewee:** … the washer. And I can hear the sound, but of course the sound is turned down.

**Interviewer:** Yeah.

**Interviewee:** But it’s still there, you know, and it could be … like, he enjoys Angry Birds, so he could be listening to the Angry Birds music or Mario, you know, Super Mario, he might be listening to that music, so … But yeah, just kind of things like that.

**Interviewer:** Yeah, absolutely. And you talked about OT briefly, you talked about feeding therapies—what other or what, like, services and interventions has he received to help him with his sensory sensitivities?

**Interviewee:** Now, he has speech because part of the speech also was to work on the oral motor. And some of that deals with the sensitivities as well, you know, because I know, at one point, we had the little chewies, and things like that, to help with the oral motor, because we did go through a period with ... where he liked to ... I guess I should have mentioned this, but I had kind of forgotten about it, but where he liked to chew on things. So he would chew, like, on his shirt, and, you know, mainly just his shirt. You know, so we tried a whole bunch of things, oral motorized with that, and he also received ABA therapy. And so they’ve done a variety of things to help over the years.

**Interviewer:** Yeah. Does he still chew at his shirt? Is that behavior still present?

**Interviewee:** No, he does not. That’s something that we were able to break many years ago, thank goodness. **[19:00]** And we had other things that he could chew. Now, he really doesn’t. But every now and then I will peek at him and he’s chewing on his headphones. But I noticed typically developing people that sometimes chew on their headphones too, you know, so he’s not tearing them up, but he does occasionally put them in his mouth.

**Interviewer:** Yeah. Do you feel like speech and ABA … do you feel like they helped him and gave him some tools for his sensory sensitivities?

**Interviewee:** Absolutely. I mean, even it just … if it included a replacement behavior for it, you know, “*Let’s do this instead of that*.”

**Interviewer:** Totally.

**Interviewee:** And some of it had to do with, you know, kind of forcing him into this situation, so that he could build up tolerance for it because, obviously, we’re going to wash clothes.

**Interviewer:** Yeah, you have to.

**Interviewee:** We’re going to wash dishes and, you know, that’s not going anywhere, so you may as well have some tools so that you can deal with that.

**Interviewer:** Absolutely. What types of, like, replacement behaviors did they teach him?

**Interviewee:** Some of it was just to leave, you know, some of it to ... because it used to be where he would, like, scream and, you know, not just put his hands over his ears, but he would scream and that’s when he would start hitting himself, you know. So “*OK, well, you can put your hands over your ears, but you can’t scream and you can’t harm yourself*.”

**Interviewer:** Yeah.

**Interviewee:** And we have tried to do things like … His self-injurous behavior is he’ll take his wrist and he’ll pound it, so in our household, we just refer to it as ‘pounding.’

**Interviewer:** Yeah.

**Interviewee:** But to the point where, you know, there’ll be, like, huge bruises. There’s been a couple of times that I thought he had broken his wrist, you know.

**Interviewer:** Wow.

**Interviewee:** He never has. I don’t know how, but that is his … you know. So we’ve kind of done other things to replace that behavior.

**Interviewer:** Totally.

**Interviewee:** At one point, we had some little drums for him to beat on, you know, just other things instead of harming himself.

**Interviewer:** Totally.

**Interviewee:** Kind of thing or to “*Go to your room and, you know, just kind of take your pillow and hit it or squeeze it or whatnot to kind of* …” because I don’t know why he does that, but, you know, “*Let’s do it in a way that’s safe*.”

**Interviewer:** Totally. And would he, like, use this, like, pounding behavior only in sensory contexts or in other contexts also?

**Interviewee:** That is the primary one.

**Interviewer:** OK.

**Interviewee:** It really is. Because it’s things like that … it just was, I guess, very overwhelming to him. So that’s the primary one. The other time is if something breaks.

**Interviewer:** Oh, like, a household item breaks?

**Interviewee:** Yes. So if one of his toys or, you know, his headphones, if they break, that will also cause a meltdown. But those are the only two situations where we would really see …

**Interviewer:** Yeah.

**Interviewee:** … the pounding and screaming.

**Interviewer:** You gave me another really great segue. So we’re doing really great. **[22:00]** Do his sensory sensitivities cause or increase anxiety for him?

**Interviewee:** Very much so. I mean, because he is either going to go somewhere by himself, which is … his room is safe, that’s his safe spot. So … and we have designed it so that he is very comfortable in there. So he’s either going to go to his room, or he’s going to do some kind of ... something inappropriate. And the pounding, the screaming, the jumping, you know …

**Interviewer:** Yeah.

**Interviewee:** … there’s a lot of things that it will cause. But we’ve, like I said, we’ve got the … his room, which is his safe zone. He knows he can go in there, close his door, put his headphones on and tune it all out.

**Interviewer:** Yeah, that’s great. So, again, you just gave me my next segue: how does he manage these anxieties?

**Interviewee:** So, his room.

**Interviewer:** Yeah.

**Interviewee:** That’s his main one—and putting those headphones on.

**Interviewer:** Yeah. How has his anxiety changed over time? Like, you talked about increased rigidity over time—what about the anxiety?

**Interviewee:** Oh, goodness.

**Interviewer:** The best that you can tell.

**Interviewee:** Yeah, that’s a hard one. It … I would almost want to say it’s decreased only because he … there’s some predictability to it, you know, so most of these … he’s able to kind of anticipate that it’s going to happen. Because even if we’re out and, let’s say, the sirens are coming, you know, there may be that, you know, “*I don’t want to hear them, but at the same time, I really want to watch the ambulance go by*,” you know, “*because that’s really fun*.” So there’s a lot of predictability. And I think sometimes, he realizes that, “*Even though some of these things are bothersome, at the same time there’s also parts of it that I enjoy*.” Like, he’ll actually ask to go to the carwash at times. You know, so he likes doing it, it’s … I would say it’s a preferred activity for him, but at the same time, he knows, “*OK, I know it’s going to be loud, so I’m going to have those headphones. So whenever … I’m going to put them on* …”

**Interviewer:** Yeah.

**Interviewee:** “… *and be OK with it*.” So he’s able to tolerate more now, I think because he … there’s the predictability.

**Interviewer:** Yeah. It sounds like he also has learned tools, so that way he can kind of manage the moments better when he knows they’re coming also.

**Interviewee:** Yes, very much so.

**Interviewer:** That’s great. And so, thinking a bit to the future, what are your goals or hopes for your son in regards to his sensory sensitivities?

**Interviewee:** We hope that he will continue to manage them. Obviously, we want him to be able to do some kind of meaningful employment to him, whatever that may look like, and, you know, in the workplace, there’s going to be noise. Right now we’ve got … well, we had to stop when COVID happened, but before then he was volunteering at the Salvation Army …

**Interviewer:** Oh, fun!

**Interviewee:** … which is something that he really enjoys doing, but you never know what’s going to happen there. There could be **[25:00]** loud trucks coming in with donations. Of course, there’s the people; there could be crowds at particular times. And, you know, of course, in the workplace, we don’t know if it will be something that he can wear headphones or not wear headphones kind of thing. So we just want to continue, where he can be more adaptable and more willing to be in those situations without causing a scene …

**Interviewer:** Yeah.

**Interviewee:** … so to speak. Because yeah, it doesn’t matter where he is, when he was younger, you know, if something happened, you know, the pounding and the screaming and the jumping is going to happen. So hopefully he can be in those situations without having that reaction.

**Interviewer:** Absolutely, absolutely. Thank you. We’re going to shift gears to our next chunk of questions. And so, thinking about the community—either his community, your community, whatever that means to you and your family—how has the community reacted to his sensory sensitivities and sensory interests?

**Interviewee:** Overall, I would say, very well. I think the school has been very supportive. You know, they’ve tried a variety of things, you know, with the occupational therapist or through ABA, you know, like, with the pressure vest. They were … they have given him, you know, little fidgets to hold instead, you know, “*As you get overwhelmed by something, you can do this*.” I know they have done special things with, you know, the fire drills and tornado drills, you know: letting him go out early, telling him, “*Ian, there’s going to be one today, so let’s go ahead, you know … it’s going to be at two o’clock, so let’s go ahead and be prepared for that*.” Sometimes they might let him leave the building early or, you know, “*Let’s go ahead and put some headphones on*,” just to kind of prepare him for those kind of things. He has a … that … we have a wonderful woman here, who has created a community group for individuals with special needs. So we’ve got him involved with that. He’s actually able to go bowling now and it’s funny because they’ll turn everything down, so the noise level, you know … because bowling noise can be loud.

**Interviewer:** Yeah.

**Interviewee:** You know, they bring out specialized equipment. You know, they’ll put up the little barriers …

**Interviewer:** Yeah.

**Interviewee:** so his ball ... so that he’s able to enjoy those things. And we also have other things, like our theatre. You know, our local movie theatre, will do the sensory-friendly movies. We have one of the Monkey Joe’s, you know, one of those jump places that, on Sundays, they’ll turn all the … they’ll turn the lights down, the music goes off and it’s just for individuals with autism to come in and enjoy those things. So we have various things like that. So **[28:00]** he’s able to go …

**Interviewer:** Yeah.

**Interviewee:** … and experience these things without being overwhelmed …

**Interviewer:** That’s awesome.

**Interviewee:** … which is wonderful. And our local, public safety also has times where they have the kids come up there, and it’s very sensory friendly, so that they can touch the fire truck and get in. And we take Ian and he loves it, but it’s also a way for him to not be fearful. “*In the event of an emergency, these are the people you need to go to—not run away from because you’re scared*.” So, you know, just a lot of things like that in our local community, where they try to make sure that these individuals are included, and feel welcome without being overwhelmed.

**Interviewer:** That’s so lovely. A lot of people have been having some negative experiences. So it sounds like your community’s been really supportive. That’s wonderful. That’s really great. What about when he was younger—was the community as accepting and as accommodating as they seem to be right now?

**Interviewee:** Probably not. I think there’s been a lot of movement—at least in our local area—where people are more aware. The parents have all kind of … have banded together. We’ve got some support groups here where the parents have requested these things. They, you know, they’ve taken the time to actually ask the local museum, for example, “*Hey, can we come in at this time*,” you know, “*and be safe? And yes, that means that our children might be touching some things*,” you know. So they might put those out, but they actually bring things out: “*These are things they can touch*,” you know. I mean, they’ve actually brought out, you know, “*Here, these are*,” you know, “*artefacts that are allowed to be touched*,” and they’ll bring them out for them, you know. So I think that our local community has a lot of outstanding people, who have kind of paved the way and made sure that the people in our community are aware: “*Hey, these people are here*,” you know, “*so let’s support them. But at the same time—guess what?—you’re going to get our business because we’re going to support you* …”

**Interviewer:** Absolutely.

**Interviewee:** “… *because you welcome our children there*,” you know. So it’s very important to us and therefore it is to them.

**Interviewer:** Yeah, that’s so great. I’m happy for you. That’s awesome. You just named so many different aspects of your community—are there other places, like, maybe where he used to volunteer and, like, any, like, religious groups or, like, family? How about these other aspects of community—how are they accommodating or accepting of your son?

**Interviewee:** Now we have some camps that will offer, like, a free week for individuals with special needs. Our local community theatre has a week where they have children with autism come and participate. Soccer … we actually have a special needs **[31:00]** soccer camp, I mean, soccer league, we have … The Miracle League, of course, is here. Several churches … I know our local, our church has a special needs ministry and it is designed … they actually specially train the staff members who—and they’re volunteers, so I say ‘staff members,’ but they’re all volunteers—to work with individuals with special needs, and so that their parents … Initially it was started so their parents could go and worship without worrying about their child, but they have so many activities for them to do so that they are welcomed and included and truly a part of the ministry. And I know our local church was one of the first ones to do it. But I’ve heard that there are many local churches around here who have a special needs ministry so that, you know, like I said, in some aspects it’s so parents can worship, but in some aspects it’s so that the children can worship in a way that’s meaningful to them …

**Interviewer:** Yeah.

**Interviewee:** … you know, because that’s going to look very different.

**Interviewer:** Absolutely. That’s wonderful to hear. And then, again, looking towards the future, what are your hopes and worries about how their … your son’s community will react in the future regarding his sensory sensitivities?

**Interviewee:** My biggest concern—and I have said … voiced this many times—is that what is cute when one is, you know, six or seven years old, goes away once you become an adult.

**Interviewer:** Totally.

**Interviewee:** You know, so it’s no longer cute when you’ve got, you know, facial hair, and, you know, and you’re tall, you know, so that’s my … one of my big concerns. Because I see that people are very tolerant with our younger people with disabilities and with individuals who have more of a visible disability, because autism very much can be hidden. Ian—sorry, I know we’re not supposed to say names—my child looks …

**Interviewer:** Oh no, I’m going to redact it later,

**Interviewee:** OK.

**Interviewer:** So you can say your child and don’t worry about it. I just try not to say the name so that way I don’t have to redact as many things, but don’t worry about it … I’ll redact the transcript.

**Interviewee:** OK.

**Interviewer:** It’s not a problem.

**Interviewee:** But no, he’s big, you know, and right now, it’s accepted. But he looks just like everybody else. I mean, obviously, you know … because you see a lot of people … even I’ve got family members who are, like, “*Oh, I just love so and so. They have Down’s syndrome and they’re just so cute*,” you know. So I just see that being so much more accepted, versus someone that looks like everybody else and that’s definitely hard. And one of our … and it’s actually a very big concern of ours … if he were not with us—and right now, we’re not willing to let him not be with us out in the public—if he were to do something **[34:00]** in a public situation that were misunderstood as far as if the police were called or something like that … So that is a very real fear of mine. I … right now, I will allow his ABA therapist … she’s actually the person who takes them to volunteer, so I will obviously allow him out with her. But that’s it. Otherwise, no, he’s with one of us. So that we can explain, “*No, this is an individual with special needs. He may not respond* …”

**Interviewer:** Yeah.

**Interviewee:** “… *the same way*.” So that’s definitely a big concern in our family.

**Interviewer:** Understandably. You just talked about police, but you also talked about how your public safety community, like, allows kids or young adults to, like, interact with, like, fire trucks and things like that.

**Interviewee:** Yeah.

**Interviewer:** Does that mitigate any of your fears or worries, in that maybe the community knows who he is, or is it kind of, like, a larger worry, like, what happens when he leaves your community?

**Interviewee:** Here I feel pretty OK. Because, like, when we go to the football games, you know, a lot of those ... the people who are working security are public safety officers. And they’ll be like, “*Hey*,” you know, and they’ll come up to him and they’ll start talking to him so I feel like they do know him. But yes, I worry as he gets older, you know, and, you know … because I don’t know if they do these kind of events for adults with special needs.

**Interviewer:** Yeah.

**Interviewee:** You know, are they going to forget who he is? Our state does have … he doesn’t have a driver’s license, but he does have a state-issued ID and there is a slot on the ID that says that he has autism. But I just worry, if he’s in an emergency type situation, that these things aren’t … are going to be overlooked. You know, because there are times where, unfortunately, he can be unsafe. Now he’s never harmed anyone else, just himself. But I know we had an incident—and this is a little off topic …

**Interviewer:** It’s OK.

**Interviewee:** … but we had an incident at the grocery store, where he went to the restroom and … My husband let him go to the restroom. He was at the end of the aisle in the grocery store and he came out. And my child is ... he runs and he, you know, he’s kind of all over the place. So maybe it is sensory, I don’t know, because he’s the kid who always runs everywhere. We’re working on it. He’s 17. We’re still working on it. But he brushed into someone who was stocking the shelves. She was bent over and her backside was in the air, you know. So she was bent over and he brushed into her and kept on running to him. I don’t even know if he realized he had done it. But she got up and literally started, like, screaming, “*He assaulted me. He touched my backside*.” And, luckily, my husband was right there.

**Interviewer:** OK. Yeah.

**Interviewee:** He knows, and witnessed the whole event and **[37:00]** so was another employee, who witnessed the event, and they’re like, “*No, what you think happened is ... well, actually, what happened … Yes, he did bump into you and I’m so sorry that that happened, you know, but* …”

**Interviewer:** Yeah.

**Interviewee:** “… *but no, he did not assault you. He certainly did not sexually assault you*.” And so yes, I’m concerned about that, you know, that’s why. And probably since that incident, I’m like, “*No, this child stays with me all the time*.” You know, because I think sometimes things can be misperceived and, like I said, **[crosstalk at 37:28]** I don’t even know if he was aware that he had done that, but yes, that has kind of made me nervous about what would happen.

**Interviewer:** Yeah. Absolutely. That’s a very real concern. It sounds very very real and very scary. Thank you for sharing that. So I’m going to move on to our next chunk of questions—unless you have more things you’d like to add about community?

**Interviewee:** No.

**Interviewer:** OK, awesome. So, thinking about, like, the transition to adulthood: in this transition, where do you see your son?

**Interviewee:** Oh, my goodness. We are still kind of navigating that. We don’t really know yet. The school system has already said that he does not meet the requirements to graduate from high school. So our plan is to keep him there until he ages out, you know, and hopefully to learn some more life skills and vocational skills. He is in a kind of a hybrid program, where he’s receiving some vocational training. Unfortunately, he can’t be certified in any of that because he has to be able to read the manual and pass the exam. Reading comprehension’s a deficit. So that’s not something that we see he’s going to be able to do, but we are having him volunteer with the Salvation Army. So I think that he could probably find some kind of … not necessarily employment, but something that he enjoys and is meaningful to him. We do have a center here that we have a personal relationship with as a family, who has already said that, when he is of age, and he is ready, that they will hire him on. And it is a place for individuals with disabilities to go and work there. They make like … they help prepare furniture and they make wooden Christmas ornaments.

**Interviewer:** That’s nice.

**Interviewee:** So they’ve already said that they have a place for him when he’s ready to do that. But I really don’t know how much he’s going to be able to do. And right now it’s probably so much more than I think—it’s just that my own anxiety plays a part there. So …

**Interviewer:** Absolutely.

**Interviewee:** But no, my plan is probably … I see him—because of my anxiety again—living at home versus living independently. I know we’ve kind of talked about the possibility of a group home at some point, but I’m not sure **[40:00]** that I’m going to be able to handle that.

**Interviewer:** Yeah, absolutely. It’d be scary.

**Interviewee:** Yeah.

**Interviewer:** How is he in terms of taking care of himself, like, physically, like, hygiene, things like that?

**Interviewee:** Now he will do it. So he’ll brush his teeth and put on deodorant, you know. We have kind of a little checklist in the bathroom of things that he has to do. And his private therapists have also helped him with some of these things. With that being said, he doesn’t always do a satisfactory job. So I try to let him be as independent as possible. And this actually is a sensory concern, but he will not take a shower, so I still have to wash his hair because he does not like the water on him and he’s actually terrified. Like, if we were to get into the shower, they ... the boys have their own bathroom and there’s been a couple of times where his twin brother has not turned off the shower. So you know, when we get in and turn the water on, the shower automatically, you know, comes out and he gets water on him and now he hates it. I mean that, like, I don’t know if he’s scared of it or what have you, but it’s something that he’s afraid of. So I do still have to wash his hair because he will only take a bath. And he loves water, so I’m not quite sure what it is about the shower, but yeah, it’s not happening. So he’ll do it. He just might need to, you know, have someone supervising to make sure it’s done correctly. Yeah.

**Interviewer:** And how is he with ... oh sorry.

**Interviewee:** No, no, it’s fine.

**Interviewer:** How is he with rain? Because you have talked about how he likes water in other ways but just not in the shower. Is he OK with, like, being outside in the rain? It’s kind of a shower in a way.

**Interviewee:** Yeah, no, he will run.

**Interviewer:** OK.

**Interviewee:** So yeah, if he gets out of the car, he’s not even going to wait for an umbrella or anything. He’s literally going to take off running …

**Interviewer:** Yeah.

**Interviewee:** … until he gets somewhere where he’s not going to get wet.

**Interviewer:** And has that been ... has he always disliked falling water in that context?

**Interviewee:** Yes. Now there were … now he likes the splash pad, so he likes that kind ... but I guess it’s still not getting on his face. He can choose how much … how far into the splash pad he wants to get. And yet he won’t … still wont allow it on his head.

**Interviewer:** Will he wash his face, like, in a daily routine?

**Interviewee:** Yes, he will.

**Interviewer:** Got you.

**Interviewee:** Because, yeah, in the tub, he’ll wash it.

**Interviewer:** Yeah, yeah.

**Interviewee:** But yeah, it’s just the … that sensation on it.

**Interviewer:** Yeah, absolutely.

**Interviewee:** Anyway, he will tolerate me washing his hair. I have to get a cup and, you know, rinse it that way. So he’ll tolerate it. But yeah, no shower.

**Interviewer:** Got you. Thank you. What about, like, cooking? Can he make himself food—things that he does like, I guess?

**Interviewee: [43:00]** He is able to. It’s not something he enjoys to do, but he is able to microwave his chicken nuggets. And one of his classes that he’s taking in school right now is some kind of life skills class. We actually had to make a video of him cooking. So it says for … some using the stove and he did it. He was, like, way far away from it.

**Interviewer:** But he did it. What did he make?

**Interviewee:** We just did scrambled eggs to start.

**Interviewer:** Nice. That’s a nice thing, though. Like, you could eat eggs and just … and survive for a long time.

**Interviewee:** No, he cooked them and then they were like, “*Do you want to eat it?*” “*No*.”

**Interviewer:** That’s OK, though. First step is making it.

**Interviewee:** Yes.

**Interviewer:** Second step is eating it.

**Interviewee:** Right.

**Interviewer:** That’s great. So his, like, vocational classes, like, what other life skills is he gaining through that or what has he acquired through those?

**Interviewee:** Well, he has worked on a horse farm, so he’s learning to groom horses and how to feed them and he loves it. That’s his favorite place to go because he enjoys their industrial size washer dryer.

**Interviewer:** OK.

**Interviewee:** Which again is weird because he doesn’t like the washer. But that’s his favorite part. And he’s learning to sort into categories. And he’s also been the napkin folder.

**Interviewer:** Nice.

**Interviewee:** So he loves it because it’s one of his favorites and it kind of threw me because he’s … I’m like, “*What did you do today?*” knowing that he had been on his vocational trip and he’s like, “*I went to California*.” Now he didn’t speak in this kind of sentence. But just to paraphrase, “*I went to California and made triangles*.” So he went to California Dreamin and rolled the utensils into triangles.

**Interviewer:** Does he like doing these jobs in these centers?

**Interviewee:** He does. He does. He loves getting out. He ... even just going to the Salvation Army to volunteer, he loves it. He is a child that would go all day if I let him. I mean …

**Interviewer:** Yeah.

**Interviewee:** Covid has hit him hard because we’ve been stuck at home, so, as you know …

**Interviewer:** I know.

**Interviewee:** … a lot of his favorite places are closed, so.

**Interviewer:** It’s a bummer.

**Interviewee:** Yes.

**Interviewer:** What about other, like, daily living skills, like money management or, like, chores, or, you know, things like that?

**Interviewee:** Money—we have been working on money for quite some time, both in private therapy and school. But I don’t think he understands the concept of it. I know he realizes that I have to have money or, you know … but most of us don’t have money anymore. We have cards. So. you know, it’s either our money or a card because, you know, I’ll tell him, “*I don’t have the money*.” I mean, because one time he put in my Amazon cart, which … he’s not allowed to purchase, **[46:00]** but he can still put things in the cart, even with the parental controls, it will go in the cart. He just can’t make the purchase. I woke up and there’s, like, $2,000 worth of things in the Amazon cart. And, you know, he’s like, “*Card*.” “*No, we are not. We do not need all these ceiling fans*.” And, you know, but … so I don’t think he has a concept of what that actually means. But he enjoys going and spending money. He’s very happy with that, so. But yeah, I don’t think he understands the concept. As far as chores, he has always had to have chores in the house, so there’s always things he has to do. He just finished learning how to sweep and mop. And, despite not liking it, just today, I made him go and do the laundry, including starting it.

**Interviewer:** OK.

**Interviewee:** I am that person: “*I know you don’t like it, but you still have to go do it*.” So, you know, I think he screamed “*No*” at me. And I’m like, “*Go do it*.” And he did. But yeah, so there’s a lot of things that he has to do in the house. I feel like it’s really important for him to have these responsibilities in the house.

**Interviewer:** Absolutely. Absolutely. I know you said that you anticipate him living, like, with you pretty long term or in a group home: does he ever express interest in his way about wanting to live in a different setting?

**Interviewee:** No, he has never said anything about it.

**Interviewer:** And then, like, what about friends or a social life?

**Interviewee:** They have a buddy club at his school.

**Interviewer:** Yeah.

**Interviewee:** So he does have peers, but I would not say any of them are friends per se. But he has a lot of people … like, if I go out in public with Ian, I mean, they’re all going to say hello to him.

**Interviewer:** Yeah.

**Interviewee:** I mean, there are people that come up to us. And they’re like, “*I know Ian from such and such*” or what have you. You know, he participates in the Special Olympics and things like that, so he has all these peer buddies, but I would not refer to them as being friends.

**Interviewer:** Yeah.

**Interviewee:** Just … but I think a lot of that is his communication … he … and his own, you know … he … I don’t think he understands how to be a friend, you know. Like, he’s not going to play a game or something like that with them.

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

**Interviewee:** I do—only because I see that he has made improvements, even in the last few months, as what he’s able to do and I see how happy it makes him, you know, because when he’ll go, like, to the Salvation Army, or, you know, there’s times where his therapist has just taken him to McDonald’s, to go and order his food … Now, he needs help with that, because I can understand what he says, but a lot of other people can’t understand him. But he does have a device where he can type it out and it’ll say it for him, you know, and he enjoys that, you know, he likes being seen as a [49:00] big boy and being able to do things.

**Interviewer:** Yeah. Can you give an example of improvements that he’s made in the past couple months?

**Interviewee:** Well, Covid wise has kind of messed up.

**Interviewer:** Yeah.

**Interviewee:** But if we take those Covid months out …

**Interviewer:** Of course, of course.

**Interviewee:** … in the time preceding that—Oh, my goodness!—he was going out probably twice a week with his therapist. One of the things that they had been working on too was to increase his safety skills, as far as being able to walk, you know, like, in the parking lot or down the street. They’ll take him to our local town area and work with him on walking in the sidewalk without stepping off of it and looking in traffic and things like that, so. And I think he enjoys it, being able to go and to do these things without someone holding his hand like he’s, you know, a toddler.

**Interviewer:** Yeah.

**Interviewee:** You know, so it’s just little things like that, that we’ve noticed and he likes doing it. Like, he likes walking the trash can out to the curb, you know, which is something that still makes me a little nervous because I worry he’s going to, you know, step into the street, but that’s something that he’s doing and, you know, and he feels independent as **[inaudible at 50:14]**. Like I said, it’s my own anxiety that’s probably holding him back a little bit, just because I worry about him getting hurt.

**Interviewer:** Yeah, I mean, every parent worries about that, I think, you know, from what I’m hearing, you know. I’m not a parent, but … And then, what do you think will help move him more into adulthood, into more independence?

**Interviewee:** I think giving him more responsibilities, letting him … It’s probably me in some ways … giving him more freedom to do things and to actually do those things independently, you know, even if it’s just shopping and letting him be an aisle away from me. Right now, I’m not willing to do those things, I’m just nervous, but probably me allowing him to have more independence.

**Interviewer:** Yeah.

**Interviewee:** And he’s probably … will do just fine. I’m just nervous.

**Interviewer:** That’s OK. Are there particular services or interventions that you think could also help him along in this process?

**Interviewee:** I think, over the years, we’ve probably had just about every intervention that is out there. And his ABA team, they are doing a wonderful job right now.

**Interviewer:** That’s good.

**Interviewee:** Because they … the team we have just now, we just switched agencies about a year ago and they’ve been wonderful about truly working with us on a plan, because they say, you know, he’s the oldest child they have, because he’s 17 and when you think of ABA, you don’t think of a 17-year-old.

**Interviewer:** Yeah, yeah.

**Interviewee:** So they’ve kind of tailor-made a plan for him to help increase his independence.

**Interviewer:** That’s great.

**Interviewee:** And **[52:00]** what he’s able to do in the home and in the community … they’ve kind of made it their personal mission, to kind of help him have more independence in the community in particular.

**Interviewer:** That’s awesome. That’s really wonderful. And now, putting these two things together—his sensory sensitivities and sensory interests and his transition to adulthood—how do they intersect for your son?

**Interviewee:** I think him being able to be more tolerant of things. He also needs to be, I don’t know, more careful. He likes that sensory input of ... he’s just active and bouncy and he still needs to learn not to do those things in the public. You know, when I think … that’s hard, you know, that you can jump and run maybe at home, but you’re not able to jump and run out there. Because, you know, he is a sensory seeker, you know.

**Interviewer:** Yeah, yeah.

**Interviewee:** So he wants all of this input and it’s like, “*That’s not OK.*”It’s not appropriate to do that, because, again, some of it could be misconstrued about you, you know, running into someone and them thinking something.

**Interviewer:** Yeah.

**Interviewee:** But I think there are things that that he can do, like the headphones, because there’s a lot of people who walk around with headphones these days …

**Interviewer:** Absolutely.

**Interviewee:** … or little earbuds in their ears and people don’t even know it. I work with some people that somehow manage to have the little earbuds in all day and I’m not sure they’re supposed to actually have those in, but they do it. And so … and somehow they get away with it, but whatever. So there might be hope for Ian to be able to do something and have his little earbuds in and not be so obtrusive and be allowed to be in a job-type setting, so …

**Interviewer:** Oh yeah.

**Interviewee:** So basically, that, I think, that would give him the independence and the safety that he would need to be more successful.

**Interviewer:** Yeah, that’s great. Thank you. And would you say his sensory sensitivities and sensory interests are an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** I see them as barriers. I really do.

**Interviewer:** Could you explain a little bit more of why you feel that way?

**Interviewee:** I think his sensory seeking is unsafe …

**Interviewer:** Yeah.

**Interviewee:** … in many settings. And he doesn’t see it as unsafe. Safety, obviously, is a big concern, but that’s where …

**Interviewer:** Yeah.

**Interviewee:** You know, like, in a parking lot, you have to walk. You can’t just be running and, you know, you actually have to look at where you’re going, that kind of thing. And, as independent adults, sometimes there’s going to be things going on in the environment that we’re going to find aversive, you know, like the fire drill, you know, because those are … I mean, they’re awful, you know, and I teach children with autism, they’re awful. I just get them all covering their ears, but it’s life, you know, and there’s going to be things going on that we’re just going to have to deal with. We may not get the advance notice that something’s going to happen, and when that event happens, we’re just going to have to deal with it. Even if we don’t have our headphones on, even if we didn’t know it was coming, we’re still going to have to deal with it.

**Interviewer:** Yeah.

**Interviewee:** And **[55:00]** I think that’s hard for him.

**Interviewer:** Absolutely. Thank you. Segue, again, that was ... you seem to have answered my next question, but I’m going to have to ask it. What do you anticipate as being challenging for your son, as he does continue to gain more independence in regards to his sensory sensitivities and sensory interests?

**Interviewee:** Again, the safety … so that’s probably always my primary concern. And then to deal with the events as they come up, even without the advance notice, I think, those surprise ones are going to get him. You know, let’s say, if he’s working in the grocery store and the big truck comes in and they’re unloading and it’s loud and noisy, you know, you just have to deal with it, you can’t scream and run because something loud is happening.

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

**Interviewee:** And so, I think a lot of it is the exposure. That’s what we’ve seen as being most successful with him is to have the limited, repeated exposure to things that he finds aversive. And so some of that as he is more independent and we see what his interests are and what is available to him, you know, gradually getting him used to it, because even if it’s working in the furniture shop, I’m sure they use tools …

**Interviewer:** Yeah.

**Interviewee:** … you know, so gradually getting him used to what those sounds are. Taking him there, and letting him see them, you know, and to get the safety lectures because, you know, obviously, if you’re using tools, you have to be safe and …

**Interviewer:** Totally

**Interviewee:** equipment, you know, even if it’s just putting him in the safety glasses at home and the setting is familiar to him. But that’s what we’ve seen as being the most … the thing that works best for him, is to have the limited exposure and build that exposure up over time.

**Interviewer:** Absolutely. You’ve given me all these great segues. It’s awesome. Are there other services or interventions that you think could help him besides just, like, you know, exposure that you just talked about?

**Interviewee:** If there are, I don’t know. I know we, because of his age, we are already in contact with voc rehab so they are already … he hasn’t started services with them yet, because he’s 17 and still in school, but he’s already on their waitlist, and they will be doing job training with him and exposing him **[58:00]** to different career paths that might work for him. So and as his mom, I don’t know …

**Interviewer:** Yeah.

**Interviewee:** He has already shown me many, many, many times that he’s more capable than I even know that he is. So I’m kind of putting a lot of faith into voc rehab. There’s also some private agencies that do work with them. Here, I think locally we’ve got Easterseals, that are … that do certain job training as well. So I don’t know what else is available. That’s kind of new to us too …

**Interviewer:** Yeah.

**Interviewee:** … the whole transition to adulthood. And we’ve just now gotten to the point, like, at his IEP meetings, where we’re talking about those transitions and getting the community to come in. His last IEP … was when he was 16 … and unfortunately, it was cancelled because of COVID. So it was all virtual.

**Interviewer:** Yeah.

**Interviewee:** So these community resources were unable to come in and meet with us, but I know they’re there.

**Interviewer:** Yeah.

**Interviewee:** I just don’t know what all they are yet.

**Interviewer:** Yeah, yeah.

**Interviewee:** But I know that they will be working with him to provide some more services for him as well.

**Interviewer:** Got you. Do you feel like there are gaps in the available services for your son or kids like your son?

**Interviewee:** Yes. I feel like most of them are geared towards people with less needs.

**Interviewer:** Yeah.

**Interviewee:** And my child … it’s very difficult with someone with the communication delay that he has, is … There’s not much for that, you know, because we do so much for individuals with disabilities, as long as they’re able to speak and …

**Interviewer:** Yeah.

**Interviewee:** … you know, there’s so much they can do, but when you don’t have that voice, I think people automatically assume that you are incapable of doing things.

**Interviewer:** Yeah, yeah.

**Interviewee:** Because he doesn’t talk that much. So I … he’s not categorized as non-verbal because he does speak, but he doesn’t speak in sentences really. And he certainly is not going to sit there and have the ability to have a conversation. So he’s not going to be able to go to a job interview, and have that give and take, because it’s just not something that he’s capable of. And again, that doesn’t mean that he’s not capable of doing the job.

**Interviewer:** Yes.

**Interviewee:** But he wouldn’t get the job because he can’t get through the interview process.So I think that, for individuals like that it’s … they are still probably underserved and underrepresented in the population. Because I think a lot of these services are geared towards people with a physical disability or who, you know, maybe are mildly intellectually disabled, you know, so they’re still very capable, though what ... they may not be able to go to college.

**Interviewer:** Yeah.

**Interviewee:** But again, it’s the very hidden **[1:01:00]** for them, so.

**Interviewer:** Absolutely. Thank you for sharing that. Sorry, I’m yawning. I’m very interested, it’s very ...

**Interviewee:** It’s quite all right.

**Interviewer:** And then, kind of taking, like, a broader approach and a broader thought process: how have your son’s sensory sensitivities and sensory interests impacted your goals, hopes and expectations for him in terms of how he can navigate adulthood?

**Interviewee:** Oh, goodness, that’s hard, because I don’t know … we see them sometimes as being so limited, you know, they limit what he is able to do because there’s such a hindrance …

**Interviewer:** Yeah.

**Interviewee:** … but I don’t know … There’s things that I think he’s probably interested in, but I don’t know if there’s things that he would be tolerant of, you know. Like, he enjoys, you know, like, big trucks …

**Interviewer:** Yeah.

**Interviewee:** … so I don’t know. And he enjoys air conditioners. I know, there’s strange things like that, but I don’t know how tolerant he would be to even be, like, an assistant or, you know, something,

**Interviewer:** Yeah.

**Interviewee:** You know, because even those crews … like a HVAC repair, they still have people that’s got to clean up things, you know, but I don’t know how much he is going to be able to participate in that.

**Interviewer:** Yeah.

**Interviewee:** You know, both with the sensory seeking … to be able to be still in a job. And then with the things that he finds aversive, you know, being able to respond to that appropriately.

**Interviewer:** Yeah, absolutely. We didn’t really talk about sensory seeking in the beginning—has he always been a very sensory seeking type of person?

**Interviewee:** Yes. Yes, he is. He is loud and he is always moving.

**Interviewer:** So we’re going into our final chunk of questions. It’s very short, thus we’re almost done. As a caregiver, as a parent, as a mom of someone who has ASD, but also has some sensory sensitivities and some sensory interests, what does transition to adulthood mean to you?

**Interviewee:** It’s scary.

**Interviewer:** Yeah.

**Interviewee:** The whole process is terrifying to me. And it’s so scary that I almost can’t even picture it, if that makes sense.

**Interviewer:** Yeah, absolutely.

**Interviewee:** Because I’m just so worried about it and how he is going to navigate in the world and be accepted in the world as an adult who has a disability. And with the safety concerns, and with his inappropriate responses to things that are, you know, seemingly normal, to a typically developing person, you know, how he responds, it’s not **[1:04:00]** OK. And yes, I just have a lot of fears there. And so it almost blocks out. Right now, the farthest I can get is seeing him receiving those services through voc rehab or another private agency to help him learn some job skills. I’m not sure if I, as his mom, can see him being able to work. I don’t even know …

**Interviewer:** Yeah.

**Interviewee:** … at this point. So that’s where I am right now. It’s just, “*OK. This is the next step*.” And I don’t know about the next step. I just can’t at this point.

**Interviewer:** Yes.

**Interviewee:** And I probably should but I …

**Interviewer:** You’re doing your best.

**Interviewee:** It’s just … yeah, it’s unnerving. It is.

**Interviewer:** I can imagine so. And has this always been the case, like, this perspective that you just articulated?

**Interviewee:** Probably not. I … as he ages, some of the things that … some of the skills that we hoped that he would develop, such as the ability to communicate more effectively, we kind of hoped that he would always get there, you know that one day, magically, he’d wake up, you know … We’ve got all these therapies in place for him and so one day, he’s going to be able to do these things. And it’s become rather clear that it’s not going to happen. I mean, we never give up hope, but odds of it happening at this point are pretty slim. So, you know, I guess we’re still coming to terms with the full nature of his disability as he goes into adulthood.

**Interviewer:** Yeah.

**Interviewee:** Losing those services that we have now, mainly because they don’t exist for people once they’ve reached the age of 21 … There’s been some recent events that have happened—not with him, other than the grocery store incident … And then we hear of young people with autism who have not had good experience with police officers. And, you know, those are terrifying, you know, because, you know, we never want to think of those things happening, but it’s very real. So there’s all these anxieties that have come. And they’re new, because I didn’t know at any point that I would have to worry about my child being accused of sexually assaulting someone because he bumped into them in the grocery store, and that they … if he were there by himself, if they would have called the police and how he would have responded to that. I mean, that’s terrifying. So yes, as he gets older, I probably am more scared than if he ... when he was younger.

**Interviewer:** Yeah, no, that makes that makes complete sense. Sorry to hear that. It must be scary to feel ...

**Interviewee:** It’s OK. It is.

**Interviewer: [crosstalk at 1:06:47]** It’s scary to feel scared.

**Interviewee:** Yeah, it is. But yeah, that’s kind of our reality. And that’s … the grocery store incident was just a few months ago, you know, right before Covid hit, you know, **[1:07:00]** and so, you know, coming to terms with that and that safety aspect. So yeah, that’s something I didn’t know I’d have to even worry about. For now, it’s there.

**Interviewer:** But maybe now you can make some good tools, so that way you don’t worry about it.

**Interviewee:** Hopefully, so. Yes, that’s something actually we’re working with with private therapists is … we’re working on, you know, how to walk with people and how to say, “*Excuse me*.”

**Interviewer:** Yeah.

**Interviewee:** So yeah, hopefully, we’re making some preparations for it.

**Interviewer:** Yes, I’m sure you are. And then, what do you see specifically happening in your son’s future?

**Interviewee:** What I see now is receiving those services once he is no longer able to attend school. But receiving those services through voc rehab or through a private agency to get some job skills. Hopefully, we are able to get him some kind of meaningful employment. I don’t know what that looks like yet. He might … he does like the grocery store, so maybe he’ll be able to bag groceries or something like that. So ideally, he’ll get some kind of job. Right now I think he wants to work at the barn. And by ‘work,’ that could be volunteer.

**Interviewer:** Yeah.

**Interviewee:** I mean, he doesn’t need to get paid for it, but something that he would enjoy going to do every day. If the barn will have him, of course, but … And right now, I can only see him living with me. I can’t see the group home yet and or true independent living at this point. It might get there at some point. But, you know, we’ve already kind of dropped hints not only to his twin brother, but I have an older son who is 24. And, you know, we’ve already had the discussion, if something were to happen to me and his dad that, you know, we have those long term plans in place for him.

**Interviewer:** Do you think you ...?

**Interviewee:** I do believe something to ...

**Interviewer:** You’re freezing on my end. Can you hear me? Hi! Can you hear me?

**Interviewee:** I can.

**Interviewer:** Hi! We’re back. Great. I don’t know what happened.

**Interviewee:** I’m not sure either.

**Interviewer:** That’s OK. This is life. The last thing I heard you say was “*putting in place long term plans*.”

**Interviewee:** Yes, no, that’s where … that’s exactly where I’d stopped actually, with long-term plans for if something were to happen, including I have asked my older son—I haven’t had the conversation with his twin brother yet, because I feel he’s too young—but the request to please not to just **[1:10:00]** put him in some center.

**Interviewer:** Yeah, absolutely. So, one final question: how have your son’s sensory sensitivities and sensory interests impacted this perspective you just articulated about, you know, how unnerving this transition is, things like that?

**Interviewee:** It’s probably the primary issue … well, the lack of his ability to communicate, obviously, but then, this is obviously the biggest safety issue for me, you know, because it’s not appropriate for an adult to react to something aversive and scream and start hitting himself. It’s the kind of thing that they’re going to call the police about, you know, and, of course, the safety issue, as well, because, I mean, I’ve literally seen him run in a parking lot. And, you know, it’s like “*Oh!*” you know. It’s scary, you know, so those things … Yeah. It’s a big impact. It really is. Because it’s hindering me allowing him to be more independent and, of course, it’s impacting his own ability to be independent as well.

**Interviewer:** Yeah, absolutely. So that was … that’s all I have for formal questions. Would you like to add anything else?

**Interviewee:** I can’t think of anything to add. I think I’ve already given you stuff you didn’t ask for, so.

**Interviewer:** No. It was all so wonderful and so helpful. Thank you.

**Interviewee:** That’s awesome.

**Interviewer:** No, but really, thank you. We appreciate your time and you sharing your experiences and you sharing your perspective. It’s so so valuable. Really, thank you.

**Interviewee:** My pleasure, anything to help because I know how important this all is.

**Interviewer:** It is, yeah. Do you know anyone else who might want to participate in the study by any chance?

**Interviewee:** I may have some … What is your age range—because I know some young adults as well, but I don’t know if they’re too old?

**Interviewer:** Yeah, no, great question. We’re looking for 16 to just under 26, so, like, 25 and 11 months.

**Interviewee:** OK, then yes, I probably could, if you would like me to share your information with them, I would be happy to do that.

**Interviewer:** That would be lovely. Could I ... want me … do you want me to send you anything? What would make this easiest for you?

**Interviewee:** Well, if you just send me an email, I’ll be happy to send them some messages.

**Interviewer:** We ...

**Interviewee:** But yes, I’ve got some people who have young adults still at home and we’re, you know … they’re the people we look up to “*This is us next*.” So yeah, I’d be happy to share.

**Interviewer:** Thank you, that would be so wonderful. So this is it for me. As soon as this video renders, I will send you a thank you gift card, as compensation for your time and your effort and your weekend also.

**Interviewee:** Well, my pleasure. If you need anything else, we’d be more than happy to help.

**Interviewer:** Thank you. And likewise, if you ever have questions for me or need anything, please let me know. **[1:13:00]** I’m happy to help however I can.

**Interviewee:** Perfect. Thank you.

**Interviewer:** Awesome. Hope you have a really nice rest of your weekend and good luck teaching next week.

**Interviewee:** Thank you very much. I appreciate that.

**Interviewer:** You’re welcome. All right. Talk to you soon.

**Interviewee:** All right. Bye.

**Interviewer:** Bye.

**[End of interview]**