**[Start of transcript]**

**Interviewer:** Alright, we’re recording. I will be asking you questions about your perspectives about your child's transition to adulthood in relation to his sensory sensitivities and interests. And I’ll be doing something a semi-structured interview, which means I have a set of planned questions. But then I will be adapting my questions to follow our conversation based upon what you say so it actually makes sense for you. Do you have any questions before we begin?

**Interviewee:** Nope!

**Interviewer:** Okay, awesome. And if there are any questions that make you uncomfortable or you don’t want to answer them, that’s totally okay.

**Interviewee:** Okay.

**Interviewer:** Awesome, alright. Could you start off by telling me about your child’s sensory sensitivities and interests, please?

**Interviewee:** So, Justin’s sensitivities I learned today **[both laughing]** are he definitely has auditory, very, very acute hearing, so, actually the questionnaire I filled out, one of the things, they had asked one question which was, *“do you manage your attention by trying to shut out sensory stuff,”* and what I learned from that was that he can’t. So, I said, *“Let’s say I was talking to your brother in the hallway, would you go shut the door so you couldn’t hear us?”* And he said, *“It wouldn’t matter, I would still be able to hear you.”* And our house is an old house, so when you shut the door I can’t hear, but apparently he can. He said, *“No, it wouldn’t dampen it out enough.”* So he has very, very sensitive hearing. And I have memories from when he was a baby. We lived a block from the railroad tracks and I have memories of being near the railroad tracks and the train coming and him literally going into freeze mode. He would do one of those baby reflexes and then just freeze, and he would just be frozen for a while, because it was so overwhelming even though I was covering his ears and trying to help. So, anyway. He’s always been very sensitive to sound, but I think I didn’t realize that it’s still as big an issue as it is.

**Interviewer:** Is it all sounds? Is it particular frequencies or particular volumes, or like particular qualities of sound?

**Interviewee:** Well, one of the things I learned today is that, when he was a baby, speech was not special, and so all sounds were very distracting to him. But, what I learned today is that now speech is special to him, for sure. So, all those years of speech therapy actually did something, yay. **[both laughing]**

**Interviewer:** Good! That’s important.

**Interviewee:** So, speech is very distracting for him and he said that he listens to music to block other sounds out, like it’s not enough to just wear earplugs, or whatever, like, it has to be something else **[00:03:00]** that is playing that actually he can attend to that instead of the other stuff. He does like music a lot and he listens to it almost all the time. And I’m trying to think, to answer your question, uh, I don’t know that there are specific sounds that bother him. Here, here’s a specific sound that bothers him, his brother’s voice. **[Interviewer laughing]** I would love to say that’s not true, but it’s just true. So, I think that’s the one thing I can say for sure really bugs him.

**Interviewer:** And what type of music does he like, or helps him block out distressing sounds?

**Interviewee:** He listens mostly to videogame background music, that’s his favorite kind of music, though it’s instrumental, usually, but it’s definitely got kind of a driving, you know, get excited kind of music.

**Interviewer:** That was a great segue to my next question, so my next question is how does he manage and cope with these sensitivities? So, you just talked about using music to block other things out. What else does he do?

**Interviewee:** Oh, I wanted to go through some other senses...

**Interviewer:** Oh, yes, please...

**Interviewee:** Can we do that? Because we just talked about auditory. But, he’s super sensitive taste, he has an incredibly limited diet, which we’ll get into in the second question. But yeah, now, I say that, that’s gotten a lot better, a lot better. He used to really just eat, I called it the beige diet. But now he’s got some things he likes. He started as an adult really enjoying hot, spicy food, like he really loves spicy salsa. He has always enjoyed like sour, really sour things, so he’s got some interesting taste stuff going on. That’s one thing that’s gotten a lot better as he’s gotten older.

**Interviewer:** And this is Justin?

**Interviewee:** Yeah, mm-hmm. And so, let’s see, so, sight, taste, smell, he said he wasn’t sensitive to smell, and I agree with that. Visual stimuli, he does not like bright lights, so bright sunshine is not his favorite thing. He’s not particularly sensitive to any colors or anything like that, and motion doesn’t bother him, seeing motion doesn’t bother him too much. So, there’s that. Proprioception, he does bang into things a lot, just to kind of get his body awareness. He’s definitely clumsy, he has developmental coordination disorder. And so he bangs into things to kind of keep his body aware **[00:06:00]** of where he is. So, he is clumsy, I mean, he just is. And so that’s one way he kind of wakes his body up. So, there’s that one. Vestibular, he said he was afraid of heights and he definitely does not enjoy spinning or anything that involves stimulating your vestibular system. That’s definitely a problem for him. He likes deep touch a lot, so like a big bearhug or rubbing his back, he really likes that. I think that’s enough senses.

**Interviewer:** I have a couple follow-up questions, actually, if that’s okay.

**Interviewee:** Alright.

**Interviewer:** You talked about a beige diet. What did that look like for him?

**Interviewee:** Pasta, rice, chicken nuggets, peanut butter sandwiches, I’m trying to think. He does like jelly, so he liked jelly on his sandwich, and he would eat broccoli now and again, I could get him to eat broccoli. What else? Waffles and pancakes. I mean, really, truly, beige food, you say it, he will like it. He likes pizza, he likes pizza, and he actually likes pepperoni pizza, and he likes the spicy pepperonis, and the tomato sauce on that, he likes. He’s always liked spaghetti and meat sauce, which is not beige, but he does like the meat sauce, a lot, he likes my meat sauce. **[laughing]** Yeah, so that’s what I mean by the beige diet, foods that are beige.

**Interviewer:** Yeah, absolutely. And then you talked about not liking bright lights. Is he able to articulate what he doesn’t like about bright lights?

**Interviewee:** It just makes him want to shut his eyes. He definitely does the sneeze thing when he walks out the door, so that definitely is a thing for him. Oh, are you talking about enteroception, at all?

**Interviewer:** I don’t think I know what that is. What is that?

**Interviewee:** Oh, it’s one of the senses. So, that has to do with your awareness of internal bodily sensations.

**Interviewer:** Oh, okay, and that’s different from proprioception.

**Interviewee:** Yeah, so proprioception is like how your joints, how you are oriented and how your body positions. This is about things like, you know, my stomach hurts because I’m hungry, or, you know, my heart’s beating fast, or just awareness of your body’s physiological state, that is terrible for him, it is really terrible. So, he has a lot of gastrointestinal distress, but it’s like he doesn’t notice it until it becomes a horrible problem and then it’s a horrible problem. **[00:09:00]** So, yeah, I did want to mention that, too.

**Interviewer:** Yeah, thank you for sharing that. Going back to the proprioception, so you talked about he like bumps into things on purpose so he kind of knows where he is in space, does he like bump certain parts of his body and are there certain circumstances where that happens more often or less often?

**Interviewee:** Alright, so here are some things he will do, and I’m not sure this one is proprioception, but he has very low core strength, and it’s very common in DCD, so, anyway, but he kind of slumps over when he’s sitting and so if he’s sitting next to me, he’ll kind of slump onto me, which is very sweet, and I used to think, oh look, he’s leaning on me, isn’t that sweet, and then I realized I was holding him up. **[both laughing]** So, it’s definitely like a coping strategy. But yeah, so he prefers to lie in his bed to do his schoolwork and stuff, so he’ll prop himself up with a bunch of pillows in bed so that it just holds him up. Going down the stairs, it’s very common for him to kind of bang back and forth between the wall and the railing, like, just kind of boom, boom, boom, boom, down the stairs. Banging different parts of his body, I’m trying to think about the answer to that. I think it’s mostly his shoulders, it’s mostly his shoulders, now that you’re saying that, I’ve never thought about it before, so I think that’s right. So, it’s mostly his shoulders. And you know, when he was little, I had a trampoline set up on the back porch and I would just make him go jump on it to wake himself up, like, every morning he’s come down, I’d be like, *“Go jump 100 times, then you can come in and eat breakfast.”* But it just organized his body, he needed that kind of pounding action. And he takes walks, like if he’s taking a break, he likes taking a walk around the neighborhood, and I really think that’s again about, just, you know, moving and banging his feet around, or whatever.

**Interviewer:** Yeah, absolutely. So, it’s a good segue to my second question which was very premature, but how does he manage and cope and handle all of these sensitivities and preferences?

**Interviewee:** Yeah, so the auditory stuff, I’d say his primary coping mechanism is to avoid and he does get pretty shut down if he can’t avoid. He does not like going to concerts, he does not like going to a festival, I have not taken him to like a festival for a really, really long time. So, he avoids that actively. And then like I said, **[00:12:00]** he does listen to music to kind of block out sounds when he’s not able to avoid it. He totally avoids large parties and stuff, where it can get really loud. And that has social ramifications, right? So, that’s how he manages the auditory. The proprioception, we talked about him banging down the stairs and walking, and things like that, that’s definitely what he does. I have to tell you, for the enteroception stuff, he’s actually working with his therapist right now on a curriculum designed to develop his enteroceptive awareness, which is actually, I have to say, of all the bazillion interventions we’ve done, it has been pretty amazingly helpful.

**Interviewer:** Oh yeah? How so?

**Interviewee:** Well, so, he’s very anxious, but he’s one of these flat affect kids, and so he presents to the outside as very, very calm. My favorite story about that was, it’s actually about auditory stuff. There was a college fair at his high school and I wanted him to go this college fair, and that day in high school they had a steel drum band concert, they had this amazing steel drum band, they were incredible, but it’s super loud, and he had gone to it, and he was just rattled, I don’t know how else to describe it. He came home and he was just like, I guess he was kind of in freeze mode, like he was just -- like that. And so we’re eating dinner and I said, *“Okay, we’re going to have to go to this college fair,”* and two of the colleges he’s applying to were at the fair, so I really wanted him to talk to them and get more information about the college, and he’s sitting with that deer in the headlights thing, and I said, *“You have to eat, like, we gotta go.”* And he finally looked at me and he said, *“I can’t, I can’t go, I just can’t go.”* And I said, *“Justin, we don’t have a choice, like, there’s not another college fair, we gotta figure this out.”* And he said, *“Mom, I am telling you that what you see on the outside is not what I am feeling on the inside.”* And so for that particular thing what I ended up doing is I took him to the high school, he sat outside, I found the college tables that he was going to, I would get him, we’d go in, he would visit, and then he would go back outside. And then I go, so, I basically did the starfish thing so he could manage the sound, it was crazy loud.

**Interviewer:** I’m sure it was.

**Interviewee:** Yeah, so anyway, I mean, that’s a story, but that kind of gives you a sense of how overwhelming the sound can be for him and how much it shuts you down. And so we’ve tried to be very creative over the years **[00:15:00]** about solving problems around that so it doesn’t limit his opportunities.

**Interviewer:** Absolutely.

**Interviewee:** So, those are some sound things. The taste stuff, I have to tell you that for a while when he was little, I really tried to expose him to different foods and his pediatrician finally told me I had to stop and just get calories into him, because he was underweight, he was very underweight, and this actually happened with both my kids. So, you know, it’s just one of those challenges of parenting a kid with a very sensitive palate, you know, anyway, so, his brother is way more sensitive than he is, so he was more flexible than his brother was. He will eat fruit. Grapes are not beige, but he likes grapes, he likes apples. The food I basically just totally cater to it, I just gave up. Like I said, when he became a teenager, he definitely, his palate started expanded because I was always like, eh, just take one bite of this thing, you know, then eventually, you know, at 17, he was actually like, *“Oh, I actually really like that.”* **[both laughing]**

**Interviewer:** It worked!

**Interviewee:** Yep, so that’s another one, and yeah, we talked about the proprioception. The enteroception he’s actually learning to attend to those. The vision, the bright stuff, sunglasses and a hat when we walk outside.

**Interviewer:** Totally.

**Interviewee:** He doesn’t mind a little light, he doesn’t want to live in the dark, I actually had this friend I worked with who wanted to be in a cave, he literally, he didn’t want an office with windows, he would his halogen light turned up really low, and that was all the light he could stand. Justin is definitely not in that category, so he likes a little light, but just really bright light is hard.

**Interviewer:** You talked about therapy helping him with enteroception. What type of therapy is that? OT?

**Interviewee:** Well, actually the curriculum is by a woman named Kelly Mahler, and she developed a curriculum for enteroception. She is an occupational therapist, so she’s got these really nice exercises for developing that. His therapist is actually a PhD psychologist, but he has been using the OT curriculum to work Justin through it.

**Interviewer:** Gotcha, mm-hmm. Have other therapies throughout his life helped him cope with sensitivities at all? Or other interventions?

**Interviewee:** That is such a good question. He did do listening therapy, what was it called, Integrated Listening Systems **[00:18:00]** Therapeutic Listening program, I think that’s what it was officially called. And that program we actually gave to him because we were told it would help with attention, and it did, it really helped, it was incredible, and the funny part is it did nothing for his brother, whatsoever. But it was super helpful for Justin. What I don’t know is whether it did something with his auditory processing because he does have definitely some auditory processing stuff going on and so I don’t know the answer to that. But he did find it easier to pay attention after doing that intervention and we will do little touch ups with it.

**Interviewer:** So, it helped with attention, not necessarily just with auditory processing.

**Interviewee:** Yeah, see, what I don’t know is if it helped with the auditory and therefore it’s easier to pay attention, I just don’t know the answer.

**Interviewer:** Yeah, absolutely. So, you’ve talked a lot about how his taste sensitivities were much stronger when he was younger. How else, and how more specifically have his sensitivities changed over time?

**Interviewee:** Alright, so I did talk about the taste set, which, definitely his palate is really expanding, which, thank heaven, **[both laughing]** I was pretty worried about the long-term health consequences of that. The auditory stuff, honestly, we just adapted. Now, I had heard things like, you know, you don’t want to wear noise-reducing headphones all the time, you don’t want to wear filters all the time, because it makes you more sensitive. So, what I would do is I would have those available for him if he needed them, but we didn’t have him wearing them all the time. And I don’t know if that was good, or not. But, what I can say, just sitting here thinking about whether that’s gotten better, I don’t think that one has gotten better, I think it’s still overwhelming for him. But, we have just so adapted to it and just tried to respect it, so yeah, I don’t think that one has gotten less sensitive over time. Now, as far as the proprioception, I do feel he’s getting better. He worked with a woman who was both an OT and a PT, so she had both training, and he worked with her...

**Interviewer:** Great combo...

**Interviewee:** ...for many years. Yeah, she was so fabulous, on so many levels, she was great for him. **[00:21:00]** I would say that he was more reluctant to engage in physical activity, but through his work with her he definitely has gotten, I mean, to give you an idea, when he was in high school he actually got an award, now this is a very clumsy child, he’s super clumsy, **[laughing]** but he got an award for most improved in PE because he just has such a great attitude. He just perseveres and just keeps working at it, and he really works hard to keep himself moving around. I think he’s aware there are health consequences of not moving and getting exercise, and so he works to try to do that, but he is so clumsy that it’s hard for him. So, really his preferred form of activity is walking. So, he does a lot of walking, and you know, that’s mostly what he does. So, anyway, I would say, I do feel he is more coordinated now, for sure, than he was when he was a kid. His handwriting is better, so yeah, I mean, you know, and honestly, that has just been a long, really, a long process of a lot of therapy to help him get to where he is now. But, you know, if you were to see him, you would think he would be kind of shlumpy, that’s how I would describe, like he just kind of shlumps around, you know, but he’s within the normal range of hanging out, you wouldn’t notice anything different.

**Interviewer:** Absolutely, yeah. And you talked about how his enteroception has also improved over time.

**Interviewee:** Just recently, though, because that work, literally, his therapist has been doing that maybe for three months now and usually with most of these therapies, progress is so slow and so incremental, this one has been much more shocking. So that listening therapy I mentioned was shocking, and this one has been shocking.

**Interviewer:** And then, so thinking about the improvements or the changes that you’ve seen in him over time, do you think any of those changes are related to any independence that he has gained also over time?

**Interviewee:** One of the things we’ve emphasized a lot is self-advocacy skills, so being aware of what is up for you and then advocating appropriately for that. And I do think that his ability to do that has gotten better, and therefore he is more functional. So, for example, I **[00:24:00]** told that story in high school, like the fact that he was able to tell me, *“I can’t do this,”* I have many memories from elementary school of us trying to do to a fun day at the elementary school and him just totally shutting down and me not understanding what was going on and trying to force him to do stuff, **[laughing]** mistakes we make as parents, and so his ability to advocate for himself has really improved, and I think that has helped him become more functional. Now, the coordination piece that I talked about, getting better, and the eating getting better, I do think that’s going to help him, I definitely think being able to go out to a restaurant and eat something on the menu is definitely a social thing, and the fact that he’s a little more flexible about that now is definitely helpful. And being less clumsy does help you navigate the environment more effectively. **[both laughing]**

**Interviewer:** Yeah, so you talked about how if sound is overwhelming he kind of shuts down. Do his other sensitivities cause or increase anxiety for him?

**Interviewee:** The vestibular stuff, so the heights, that can definitely cause him to freeze. The auditory is the big one. And you know, the taste stuff, so I mentioned I’m always asking him to just take one bite of a new thing. And so if it’s really bad, he will literally spit it out **[laughing]** he’ll just be like, “No, I’m not eating that. But, you know, I would never do that to him in public, only in our house. So, I do think his flexibility with eating is better. So, yeah, yeah, I think it’s the advocacy piece that is helping him functioning better, to be honest with you.

**Interviewer:** Yeah, absolutely. For the anxiety he experiences with auditory situations and then vestibular situations, what does that look like for him?

**Interviewee:** Freeze.

**Interviewer:** Freeze?

**Interviewee:** It literally, he looks like a deer in the headlights.

**Interviewer:** Yeah, got you. How does he cope with that or manage that?

**Interviewee:** Actually, this enteroception thing is part of learning to manage that. It honestly took me many years to realize how anxious he was, I’m sorry to say how long it took me. I think he was 17 when I finally understood that the freeze was not compliance. So, all his teachers were always like, *“well, he’s never a problem in the classroom,”* and they always thought he was such a well-behaved child. **[00:27:00]** I had him in a social skills intervention program called PEERS, so he was doing the PEERS thing, and it’s a manualized approach to social skills, and there comes a period in it where you as the student have to start reaching out and connecting to people you don’t know yet. So, you’re trying to practice making new friends. And he panicked so badly that we could not complete the intervention, like he got stuck there, and that was when I realized how disabling his anxiety was, and it was super disabling, I had not understood until that point how bad it was. So, we got him on medication, we had to put him on medication, because we started realizing freeze is actually what’s going on here. And so he does take medicine for anxiety, but that enteroception, so things that happen to him when he gets anxious are heart rate increase, he gets gastrointestinal things, so his stomach clenches, and so on, and he wasn’t aware of that. So, what’s happened is as he’s becoming aware of those things, now he’s been trying to do CBG, cognitive behavior therapy, for all these years, and it just never worked because he didn’t know that he was feeling anxious. And so now he’s like, *“Oh, my heart rate’s up, I must be feeling anxious, therefore I can now use my coping strategy,”* so that’s kind of where we are right now, and I think we’re wallowing around in that right now. **[laughing]**

**Interviewer:** Well, it’s hard to realize you’re anxious, it’s not comfortable.

**Interviewee:** Yeah, and just interpreting, how do you interpret, because he did have very significant language problems so when he was first diagnosed with language issues, he was below the 1st percentile, so his language skills were really poor, and he’s now at the 75th percentile. But he does have some weird language issues. He had a very bad, it was called esophageal, a fungal infection in his esophagus, and he couldn’t eat, and he lost 20 pounds in three weeks, it was bad. And the doctors would ask him, *“Are you feeling nauseous?”* And he would say, *“What is nauseous?”* And we would say *“it makes you feel like want to throw up.”* Well, if he ate anything because his throat was so irritated, he would throw it up, so he was like, *“Yes, I’m nauseous,”* but he wasn’t nauseous. So, just understanding how to interpret all those different feelings, we don’t think about we learned it, but for him it’s hard to learn those things. He’s learning about them now.

**Interviewer:** That’s a good segue, my next question. So, you talked about **[00:30:00]** how you are now realizing how anxious he was and now he’s on medication for anxiety, but how has his anxiety changed benchmark qualitatively or quantitatively over time?

**Interviewee:** I actually think he’s more anxious, he’s gotten more anxious over the years. And the reason I say that is I actually recently found a video of him from when he was in third grade and he was doing a magic show for his school, and I’m not kidding you, I looked at that video and I was like I don’t even know who that little boy is anymore, because he just looks so self-confident and he was really happy. He’s definitely more withdrawn now, and there’s just no two ways about it, and I think that comes from repeated exposure to situations where he didn’t feel understood. So, I think it’s probably worse now than it was when he was in the third grade. Now, I would say it’s better now than it was a year-and-a-half ago, and that’s because we got him into very intensive therapy, which actually helps.

**Interviewer:** And would you say that increase in anxiety from when he was that young is related to his sensory sensitivities or just kind of the social components of not being understood?

**Interviewee:** I think it’s all of the above.

**Interviewer:** Yeah, really, absolutely. And then thinking about his future a bit, what are your goals or hopes for him in regards to his sensory sensitivities?

**Interviewee:** I hope he can find a job where it’s quiet **[both laughing]** and he super smart, so one of the things about him, he’s a twice exceptional kid, so he’s super smart, but he does get overwhelmed really easily, so I do worry, I really worry about that and how that will play out in a work environment. I keep thinking, his passion in life is computer programming so I strongly suspect he will be a software engineer. The way they work is in these giant cube farms and I keep thinking the that may be really bad for him, but if he can listen to his music, he’ll be totally fine. I think that in terms of job and career, I think he’ll be good. In terms of relationships, something we haven’t talked about is light touch versus deep touch, I forgot to bring that up.

**Interviewer:** That’s okay, we’re here now.

**Interviewee:** He is pretty sensitive to light touch, it does not feel good to him, **[00:33:00]** whereas he loves a deep hug. That has obvious impacts on your ability to be close with somebody. Because he’s so self-aware and able to communicate, I think he would be pretty clear with other people. So, when my parents come to visit, then he does not enjoy a hug from grandma and grandpa which is hard, but they understand who he is and they’re fine with it. So, I worry about long-term relationship with somebody. He has announced that he is asexual, that he just doesn’t care about having a relationship. I do wonder if that’s partly because of his sensory challenges.

**Interviewer:** Mm-hmm, like, because he thinks they’re hard? What do you mean by you think it’s because of his sensory?

**Interviewee:** I think that navigating being close physically with somebody would be really, really tough for him.

**Interviewer:** Mm-hmm, absolutely. And back to the light touch, has he always been sensitive to light touch?

**Interviewee:** Yeah, yeah, always, since he was a little baby. And that one, we did OT for that one, like the Wilbarger Brushing Protocol which did nothing for him, nothing helped with that light touch sensitivity really, and it’s just always been part of who he is.

**Interviewer:** Does that make him anxious or just uncomfortable?

**Interviewee:** I would say just uncomfortable.

**Interviewer:** Yeah, mm-hmm, gotcha. So, moving on to our next chunk of questions, and obviously you can go back, this is all circular, it doesn’t matter if you want to add something else, don’t worry about it. As he’s grown up and aged a bit, how has your and his community reacted to his sensory sensitivities?

**Interviewee:** We’re very lucky, we’ve lived in the same house his whole life. So, our neighborhood definitely knows him and people report back to me, you know, *“Oh, I saw Justin walking to the corner grocery store,”* whatever. When he was younger, I did have neighbors, this is embarrassing, like in retrospect, realizing what was going on, I feel really bad about it, but it is what it is. So, when he was a baby, remember I mentioned how people say he’s very compliant, and I think he was actually in a freeze state a lot of time, **[laughing]** so, our neighbors always thought he was disconnected, because he does have autism and he’s definitely distant, like you feel that distance with him. So, they reacted to the distance. I don’t think they really every noticed the different sensitivities, and part of that is because those, I could see when those were a problem **[00:36:00]** and we would just exit. It just got the point where I was like, you know, a friend of mine, actually, thank heaven for her, she said, *“This isn’t fun for him, like it’s fun for you to go to the carnival, but it’s not fun for your son, so why are you doing that to him?”* And I was like, that’s a really good point, we should do things that are fun for him. And so, if I want to go to a carnival, we would get a babysitter and we would go to the carnival and not torture him. So, yeah, anyway, I don’t know if that answers your question.

**Interviewer:** That’s an answer, absolutely. Was the community more or less accepting when he was younger? Or differently accepting?

**Interviewee:** I actually think they’re more accepting now.

**Interviewer:** Yeah? How so?

**Interviewee:** Well, with have a diagnosis now, so they know, he’s on the spectrum, and they’re just like, okay, that’s who he is. When he was little, there was a lot of *“why is your kid weird?”* Right? So there was a lot of that. And then once we started understanding what was going on, there has been a lot less judgment about that.

**Interviewer:** Mm-hmm, absolutely. And were different aspects of your community and his community more or less accepting?

**Interviewee:** Yeah, absolutely. We totally lost friends over his issues. I’ll give you an example, and I do think this is a sensory thing. When he was 2-1/2, our friend called us up and said, we had our babies at the same time, so his son was also 2-1/2, he said, *“We’re taking our baby Alex to go see Chicken Run*”, which was this Wallace and Gromit movie, a totally fun movie. I was like, *“You’re taking your 2-1/2-year-old to a movie?”* I couldn’t even fathom this idea, and he said, *“Yeah, we do it all the time.”* And I was like, *“You do?”* And so then I thought, oh, I’ve been over-protecting my kid, I should take him to this movie, so I took him, he lasted about 20 minutes, and I had to take him out, because he just couldn’t handle it. That was such a stark contrast to how his friend Alex was able to handle and enjoy the movie, and my son just could not handle it. So, that’s an example of his sensory issues definitely got in the way of his social, navigating the social world, because he just couldn’t do things that other kids thought were perfectly normal things to do. And that issue, by that way, has persisted. So, we watch all movies at home, we don’t go into the theater, or we go to sensory-friendly performances, so that’s how we do that. But, you know, it does an impact on what social activities he can do with other people. **[00:39:00]**

**Interviewer:** Yeah, absolutely. And what about family versus school, maybe friends?

**Interviewee:** We’ve been super fortunate that our family has been ultra-supportive and amazing. I’ll tell you this other story with my other son, I won’t tell you now about Justin. But there have been a few glitches, but for the most part our family has just been unbelievably supportive, I mean, really, really wonderful, and I know that’s not true of many people, so I’m very grateful for that. Our friends have for the most part been really wonderful. I did lose some friends, I had a friend who just told me my children were bad, and I was just like, they’re not bad, this is a baby. She said my baby was bad.

**Interviewer:** Babies aren’t bad.

**Interviewee:** Exactly, well, she didn’t have any children so she didn’t know. But I did have to just stop doing things with her because I couldn’t handle the judgment.

**Interviewer:** Understandably so.

**Interviewee:** When he was growing up, I did have some really bad interactions with strangers in stores and things like that, really terrible, people telling me how to parent my kid and being very judgmental and me just saying fine, I’m leaving, I can’t cope with this. Strangers I think are less accepting, and they just don’t know and they have to give you their opinion about things sometimes, **[both laughing]** unfortunately, so, yeah, I’d say for the most part our community has just been wonderful, really, really wonder.

**Interviewer:** That’s so lovely, that’s awesome to hear.

**Interviewee:** And I know that’s not most people’s experience, I’m super, super grateful for it.

**Interviewer:** Yeah, for sure. And then again think ahead to the future, what are your hopes for how his community will react in the future?

**Interviewee:** Well, you know one thing that has been nice about these last 20 years is that our societal awareness of neurological differences in general I think is much higher than it was when he was little, and so I do think that many people are more accepting and more aware of what things might look like, but there are some notable exceptions to that and things that worry me are things like interactions with the police, and that’s not sensory, that’s probably emotional. I could see some of the stuff that happens to kids with disabilities and bad interactions with the police happening to him because he **[00:42:00]** freezes, and that freeze response can look like noncompliance, and I don’t know what to do about that, so I worry about that. But I would say that because he’s such a good self-advocate, I think he’ll find his tribe, or find his place in the world and be fine. He’s got good self-confidence, he definitely has a good sense, he thinks he’s competent, he thinks he’s capable and he works towards his goals and he achieves them.

**Interviewer:** That’s awesome, that goes a long way.

**Interviewee:** I always say, he’s got grit, I mean, that kid, he really does have amazing, amazing perseverance. He’s really incredible that way.

**Interviewer:** That’s great to hear.

**Interviewee:** And when you hear what I say about my other son, you’ll know I wouldn’t necessarily say that about all my kids. **[both laughing]**

**Interviewer:** Well, I’m excited to hear about your other son later. So, shifting gears again, in the transition to adulthood, where do you see Justin?

**Interviewee:** We’re working on that, I mean, it’s his goal to get into his own apartment and to have a job. I’m a mom, right? So, I want him to live near me. We have this little apartment building that’s near us, so I’d love for him to go live in that apartment, but I don’t know if that’s what he wants. He definitely wants to live independently and have a job. It’s funny, he’s not, so, this is in one of the questionnaires. He does not literally have one friend, he does not have any friends, and I’m really worried about that, because we actually don’t live near our families. We are outside of Washington DC, they are all in New Mexico and Texas, so they’re very far away. And so it’s not like when we go, there’s going to be family that he can just keep hanging out with. So, I do worry about that with him. But he is also, he just doesn’t care, he’s pretty happy just doing his thing. What I tell him is that friends are helpful when you get in a pickle, because they can help you through that, but they can also be fun to hang around with, and he has had friends in the past, he’s not good about initiating any kind of friend activities. So, I do worry about that, but I don’t think it’s the sensory stuff, I just think that’s part **[00:45:00]** of his social stuff.

**Interviewer:** Totally. And also thinking about adulthood and adulthood milestones, he is able to care for himself physically?

**Interviewee:** Yeah, yeah, and honestly, this therapist has been just phenomenal with this. He showers daily, brushes his teeth, he can fix meals, he does his own laundry, so yeah, he does a good job caring for himself and doing the basics. He pays rent now, it’s not huge, it’s certainly what an apartment would cost, but part of what I’m hoping to teach him is just this idea of paying regularly on things. He’s very responsible about it, he’s very responsible. He pays his share of the utilities, so, you know, I think he’s going to be okay, I really do.

**Interviewer:** Yeah, absolutely, sounds like it. What do you think will help him achieve more independence than he already has now?

**Interviewee:** I think this carefully scaffolded approach, we’re basically just upping the demands very gradually over time and like with anything you’re learning, there’s backsliding and then you recover, and he’s just learning. So, I don’t know if that was a sensory thing, I’m trying to keep my scope limited to sensory stuff, but he did go off to college and lived in a dorm, and actually that was hard and I think sensory was definitely part of it, because, you know dorms, they’re loud, and that was hard for him. He actually ended up coming up, we had to pull him out, and honestly it was a medical withdrawal because he was having so much anxiety that he was having actually these gastrointestinal problems, so we thought he might have Crohn’s disease. It was really severe, and so we just brought him home, and it turned out that it was all anxiety. So, what we learned from that is you can’t just throw him in a dorm seven hours away, and expect him to go be successful. So, he’s at home taking college classes from home, and we’re just gradually stepping up those demands and not just throwing him into the deep end of the pool. I always tell him, *“You’re my starter model, so I get to make a lot of mistakes on you.”* **[both laughing]**

**Interviewer:** Absolutely. So, you said it was hard on him, what about that was hard besides the noise?

**Interviewee:** Well, he has major executive functioning challenges, and that was super, super had for him. So, he just has major executive functioning challenges, so being organized, he would get very overwhelmed by large projects, **[00:48:00]** despite a mountain of help from the school, the school was amazing, he was actually in what was called a spectrum support program, they were incredible, incredible. They met with him three times a week, helped him break things down, there was a grad student in speech language pathology, so they have lots of training on executive functioning, they were amazing. But when he gets overwhelmed he shuts down, you’ve heard that, and then he freezes, he can’t make himself do what he needs to do, the work just keeps piling on. He got overwhelmed, and after two kidney stones and multiple trips to the hospital, the gastrointestinal stuff, we were just like, we can’t do this.

**Interviewer:** No, totally. And so what type of scaffolding have you currently done and what do you see being continually being scaffolded up for him?

**Interviewee:** So, he’s living at home right now. Actually, I do think the first step would be for him to move to a place maybe in the neighborhood where he could have his own place, but if something happens, we can be there in two minutes. So, that’s one piece. His therapist has been, I can’t tell you enough great things about this fabulous therapist, but he works with Justin to figure out what Justin’s goals are, and then they just work on them. I will tell you, honestly, I have stepped completely back. What I say to Justin is, *“I’m here to support you, I’m here to help you do what you need to do, but this is your life, and you’ve got to figure this out.”* And so I’m basically the cheerleading squad in the background. So, I’m not doing a lot, his therapist and he are doing a lot. We coordinate about what I’m supposed to do to support him with stuff, but Justin has to ask me for help. So, I’m trying not to force my opinions about what should be happening on him, and just let him work his way through it, coordinating with his therapist.

**Interviewer:** Yeah, absolutely. And what else do you think will help him move into adulthood? Are there particular therapies or intervention that you’re hoping he will be able to get later on to help him keep on moving forward?

**Interviewee:** So, he’s 22 and he’s eligible for services from the Developmental Disabilities Administration here in Maryland and what we’re hiring for him is an executive functioning coach who will help him with some of these executive functioning issues. And so it’s my hope, we did that for years, honestly, we had four years of executive functioning coaching before he went off to college, he got it while he was at college, **[00:51:00]** I honestly think that’s a skill that’s a tough one to remediate.

**Interviewer:** It is hard.

**Interviewee:** It’s really hard, and it’s not that he’s not working at it, but boy, stuff just doesn’t stick, it’s truly a disability. So, if he can maintain, I do think at this point it’s literally an accommodation, like he needs somebody to support him. Maybe later, something clicks in his brain and he’s able to start doing that, but right now I do think that’s his biggest obstacle, and so that’s the kind of support we’re trying to get for him.

**Interviewer:** Gotcha, that makes sense. And so now putting these two things more explicitly together, sensory sensitivities and this transition to adulthood, how do they intersect for him?

**Interviewee:** Here’s an example, when you lived in an apartment usually there are the noises of the other people in the other units, and that’s part of apartment living, right? So, I could imagine that being a challenge for him. We’ll see, I mean, I’ll advise him, things like make sure you live on the top floor, you know, try to get a corner unit, if you can, things like that, so that hopefully that will help with the sound stuff. So, that’s definitely one. I think the types of jobs that he could take are definitely limited by those issues. I think they do interact. The thing is, he’s very good about he if can’t handle something, he’s just like, I really can’t handle this right now, he’s very good about saying that, and as long as his dad and I are around, we can help him brainstorm solutions. And if he has a good therapist and things like that, then he can work with them. So those are things I think, that’s the part where not having a friend really worries me, because if he had friends, you know, that’s what friends do, they help you figure your way through tough situations.

**Interviewer:** Absolutely. And then would you say his sensitivities interests are an obstacle, a vehicle, or a bit of both for him in terms of gaining more independence?

**Interviewee:** You know, you’ve been saying “interests” and I’ve been ignoring that this whole interview, and that’s bad of me, because, I wanted to mention to things that he does. So, we have cats and he adores our cats, and they are definitely a special interest of his, I know he really loves our cats and he talks about them all the time. And that can get in the way **[00:54:00]** of normal conversation because he wants to talk about the cats all the time. So, I did want to mention that. He has two other areas of passion and these are huge strengths for him, also. One is computer programming that I mentioned, he loves, loves, loves computer programming. He loves solving hard problems and just the thrill of getting something to work, he just really enjoys that. My husband also does programming for is work, and he and my husband can totally geek out on discussing programming stuff. I’m also hoping that if he gets a job, his co-workers will be people he can geek out about these things with. So, that’s a thing. He also has a special interest in politics and history, that makes him very, you can have really good conversations with him about current events or historical things, and so I actually think that interest will serve him very well just in terms of being able to talk to people, if he can get off the cat topic and go onto that one, he’ll be good, unless meets somebody who loves cats as much as him, then he’ll be good.

**Interviewer:** People love cats, I’m sure he could find some people like that.

**Interviewee:** He actually had some neighbors who the husband has told us he’s on the spectrum, and they are way into our cats. They always walk past our yard and the cats come to greet them, the cats love them. That couple, I love that couple, they’re so cute. But you know, to answer your question, I do think it’s about finding your tribe. So, finding people who share those interests and then just being with those people, I think that is really going to be the thing that helps him be successful, is to find his tribe and be with his tribe. And the good thing about his social cluelessness is he really doesn’t have a desire to try to be with people that he doesn’t connect with. He’s just like, yeah, they don’t like me, they’re never going to like me, whatever.

**Interviewer:** That’s a strength, though.

**Interviewee:** Very useful for him. I’ve seen other kids who desperately want to connect with other kids and struggle to, and for them it’s hard, it’s really hard. He is not that kid.

**Interviewer:** Yeah, for sure. And then focusing more on the sensitivities, are those an obstacle, a vehicle, or both for him?

**Interviewee:** The auditory sensitivity very definitely is. I would say the light sensitivity would keep him from, ooh, so, beaches are not good, beaches are not good, and I’ll tell you there are many reasons; bright sunlight, **[00:57:00]** loud crashing waves, and the sand, it’s just a perfect storm, a sensory nightmare, and we do live in Maryland and so we’re on the coast, and so going to the beach is definitely something that people do socially here. So, I think it’s going to these social events, so, going to concerts, that’s out, going to movies, probably out, going to the beach, right out. So, there are a lot of activities that he’s just not going to be able to participate in, and it does have social repercussions, absolutely.

**Interviewer:** Mm-hmm, for sure. You left me good segues. So, what do you anticipate as being challenging for him as he does gain more independence in relation to his sensitivities?

**Interviewee:** I think for the most part he’ll just effectively self-advocate and not put himself in situations that are bad. But the one thing I worry about is you’ve heard me say, I’m always kind of pushing him just a little bit and I won’t be there, I’m not going to be there forever to push him out of his comfort zone, and I worry that he’ll get closed in because of that.

**Interviewer:** Mm-hmm, absolutely. And thinking again about how these two things intersect, what do you think will help him?

**Interviewee:** I do think the therapy he’s doing right now, so, learning to cope with his anxiety and push through it, so instead of shutting down or just avoiding the situation entirely, if he can say, okay, this is going to be hard, but I’m going to go ahead and try and do this thing, I think getting better strategies for managing his anxiety will be probably the most helpful thing for that.

**Interviewer:** Mm-hmm, for sure, and then do you feel like there are any gaps in the available services or interventions for him?

**Interviewee: [laughing]** Why do you ask?

**Interviewer:** A philosophical question, tell me everything.

**Interviewee:** Oh no, you don’t want to hear that. One of the things that’s super hard when your kid becomes an adult is that insurance stops paying for especially sensory-related things. So, things they think kids should be dealing with. And that by the way goes for speech language therapy, as well, it’s much harder to get that reimbursed. So, I can get his therapist to be reimbursed for him right now, I could probably get OT reimbursed, just because various functional things having to do with **[01:00:00]** occupational functionality, so I think I could probably argue that one. We’re very good at arguing with our insurance company. But when he turns 26 he’s going to be on his own for that, and we’re scared about that, frankly, and we are working on seeing if because of his disability he can stay on my husband’s insurance. But if we are not advocating for his insurance, I can guarantee you he won’t, because it requires a lot of executive functioning. So, my guess is he would just stop doing all the therapies. I have a lot of worries around that and I am working to try to get those supports in place, but it is a very, very different world for adults than it is for kids up to the age of 21. Very different. And honestly, there is a cliff that happens somewhere in teenage years, just getting insurance to pay for therapies. But availability of therapies for older kids, most therapists either work with young kids or they work with adults, but they don’t really work with young adults. And so there is just availability issues that are a challenge. I think the executive functioning coaching, the fact that DDA is willing to help with that, is good, and I think working with his therapist is really good. I don’t know that there would be right now a lot more I would do for him. So, you know, who knows what the future holds.

**Interviewer:** And then again, thinking about his sensitivities, how did they impact your goals, hopes and expectations for him as he now is at adulthood.

**Interviewee:** Because they’re a huge deal, I had to get real about what he could and could not handle, and not put him in situations that shut him down. And so, I mean, I’ve talked about that earlier in the interview. As far as career and adulthood go, I think the social and the career impacts are really around accommodating and the way that limits you. I truly do think things like loud restaurants are actually an Americans With Disabilities Act issue. I think there should be quiet areas in restaurants so people can go out. It is very, very limiting, that fun equals loud.

**Interviewer:** Yeah, my grandparents are hard of hearing and we have to ask for a quiet corner, because they can hear us.

**Interviewee:** Yeah, exactly, exactly.

**Interviewer:** It’s a widespread thing. **[01:03:00]**

**Interviewee:** Yeah, yeah, exactly. My dad has tinnitus and so he can’t go to these loud restaurants because it just sets his ears ringing, and it’s terrible.

**Interviewer:** Yeah, absolutely, I’m sure it’s really frustrating for him.

**Interviewee:** It is, it is.

**Interviewer:** And so kind of moving on to our last chunk of questions, we’re almost there.

**Interviewee:** I actually just remember something that’s hugely relevant.

**Interviewer:** Yeah.

**Interviewee:** Justin actually has mild hearing loss in one of his ears and I do think that also makes it harder for him to process sound, because of going into one ear versus the other ear is different. So, I just wanted to mention that, because I do think that’s part of what’s going on with him.

**Interviewer:** Has he always had that? Or did something like an ear infection...

**Interviewee:** We don’t know. It took us a long time to get him diagnosed because, what happened, **[laughing]** this is gross, he had a lot of ear wax, we would make an appointment and then they would be like, *“Oh man, there’s a lot of ear wax,”* and so we’d work on clearing it out, and then we’d have another appointment, and maybe that worked or didn’t, it honestly took us about three years to get a diagnosis for him because of the ear wax issue. **[both laughing]**

**Interviewer:** That’s not that gross, I was expecting way worse, don’t worry. Just wax, just lipids.

**Interviewee:** But yeah, he got that diagnosis, I think he was 12 or 13 when he got that diagnosis.

**Interviewer:** So young.

**Interviewee:** Yeah, so it’s been around, and I don’t think, I say he never had an ear infection, but I don’t know because he would never have reported it because of his lack of enteroception.

**Interviewer:** And that’s just in one ear you said?

**Interviewee:** Yeah, it’s his left ear.

**Interviewer:** Mm-hmm, gotcha. Cool, thank you for sharing that. And it’s totally okay if you remember things, also, we can go out of order, it doesn’t matter.

**Interviewee:** Definitely a sensory issue.

**Interviewer:** Yeah, for sure. And so kind of like, more of like an overarching set of questions, but as a caregiver, as a mom, as a parent of someone with ASD and sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** To me, for Justin?

**Interviewer:** For Justin.

**Interviewee:** I think it means being able to live the life that makes him feel happy, whatever that is, that’s kind of it.

**Interviewer:** And has that changed over time at all?

**Interviewee:** No, I’ve always had that goal in mind, it has always been my top priority for him to have a satisfying life that he feels good about. I will say that my conception of what that might involve as changed over time. **[01:06:00]**

**Interviewer:** How has that changed?

**Interviewee:** When he was younger, pre-diagnosis, I think I had the idea that it would look like my life looks, so a wide circle of friends, a family, a partner, all these things. I’m very active in our community, and as you heard, we have a wide circle of friends in our neighborhood, and so I assumed that those were the things that would make him happy. And you know, one of the things we’ve really struggled with is that people keep telling us that having friends is a big predictor of mental health outcomes. So this is one reason like elderly people as their friends die, they start getting depressed and their health declines. So, there’s all this research on the importance of having a social network. And every time some says that to me, I say has anyone done that research on people with autism? And the answer is no, as far as I can tell, but if you can find it, I would love to read about it.

**Interviewer:** Well, I was going to say, I’ll send you an email about it. But, do you know what INSAR is?

**Interviewee:** I’ve heard of INSAR, the conference?

**Interviewer:** Yeah, yeah, and they have a summer institute where they do six lecture series, and this season was all about development and young adulthood, even into later adulthood, and there was one lecture by Cathy Lord that talks about that, I think. So, I’ll send you all the info.

**Interviewee:** Yes, that’s awesome.

**Interviewer:** It was super good. I think you have to be a member to watch the recorded ones, but I’m sure you could figure it out, I’ll send you all the information, I think you’ll find it really interesting.

**Interviewee:** Yeah, that sounds great. You know, at a minimum, I could write her and ask her if she has a paper to share with me, or something like that, so that would be great. Great, so do you know what the answer is?

**Interviewer:** I think the answer was it has a similar outcome, but I think probably to your point is like are you asking if people want friends. I think that’s probably the bigger thing. If you don’t want friends, maybe it doesn’t impact your mental health.

**Interviewee:** Right, right, right. Yes, my younger son is very social and really wants friends, and I can see that it has an impact on him, and he’s autistic. So, if you include both of my kids in the same cohort, you would get, you know, they’d probably balance each other out. But with Justin, he really just doesn’t seem to care. But again, I’ve misinterpreted his flat response before, so I’m not totally sure of my answers here. He’s very clear about it. When he was first diagnosed, John Elder Robison’s book, Look Me In The Eye, had just come out and I read it **[01:09:00]** and at the end of the book he’s like, *“Parents, if you have a kid like me, here’s what you can do.”* So, I gave it to Justin and one of the things he waxes poetic about for a page is the importance of social skills intervention. And by this time we had tried seven bazillion social skills interventions with him. I showed him this page and I said, *“I want you to read this.”* And he read it, and I said, *“Does it bother you that you have very few friends?”* and he said, *“No, I’m happy.”* And I said, *“Okay, so now you know that if it bothers you, I can get help for you.”* He has never asked for that help.

**Interviewer:** Some people don’t really love other people.

**Interviewee:** He likes them fine, he just doesn’t need them. I don’t know if that makes sense.

**Interviewer:** Absolutely, absolutely. It’s all degrees of variation. And so what do you see specifically happening in his future?

**Interviewee:** I honestly think what’s likely for him is that he will live in an apartment or small house by himself and have a job that he likes, and that will be is life, and he will be very happy with it.

**Interviewer:** Real happiness, if you can achieve that, that’s good. You talked about how you had to recalibrate a bit of your expectations. What role did his sensory sensitivities have in that recalibration?

**Interviewee:** Well, the thing I was saying about the kinds of social activities that he could participate in, they had a big impact. And so when friends would invite him to large conventions, he’s got all these nerdy friends who like various CONs, Comicon is big here in DC, and so he would go, but he couldn’t, like there this gang of guys that would go from thing to thing, and he would stuff like they would go into the room and he would just hang out in the hallway while they all went in and did the thing. If he was really into the thing, then he would go in and just deal with it. But he definitely couldn’t be with the gang in same way, because they could tolerate a lot more sensory stuff than he could. It has always, always been an issue for him, so it does have big social repercussions. The other thing I will mention, as far as jobs go I just realized, things like air travel with the motion sickness and fear of heights, that definitely, like taking a job where you’re traveling a lot, he would not do that. That’s a sensory thing **[01:12:00]** that would drive getting a job that does not involve travel.

**Interviewer:** Yeah, absolutely. So, that’s actually it for all of my formal questions. Is there anything else that you would like to add?

**Interviewee:** They’re great questions and I certainly gammered on a bit.

**Interviewer:** No, gammering is great, that’s why we’re doing it.

**Interviewee:** Because I’m coding it all. Yeah, no, you’ve done a nice job, the open-ended questions are nice because they kind of cue me to think of different things.

**Interviewer:** Thank you, glad you thought so, awesome. So yeah, this is it. When do you want me to consent you for your other son?

**Interviewee:** We would do it right now if you want, is that okay?

**Interviewer:** Give me a minute, I need to make codes and stuff.

**Interviewee:** Okay, I have a thing at 4:15, so if you can’t do that, then don’t worry.

**Interviewer:** Yeah, let’s not do that, just because it will take a few minutes to do all the codes and stuff, so when is another good time for you?

**Interviewee:** That one didn’t take very long, right?

**Interviewer:** On average it’s 20 minutes, I think for us it was 19.

**Interviewee:** What does your Friday between 12:30 and 2:30 look like?

**Interviewer:** As in tomorrow?

**Interviewee:** Yes, that would be tomorrow, wouldn’t it.

**Interviewer:** Unfortunately, I’m basically booked from 11:00 to 4:30 tomorrow.

**Interviewee:** 4:30, now, is that at the end of your workday?

**Interviewer:** It will have to be the end of my workday because I have to go my boyfriend’s dad’s birthday party.

**Interviewee:** Oh, exciting. Alright, so let me look at the next week.

**Interviewer:** Yeah, if that’s okay with you.

**Interviewee:** Yeah, it’s fine. Tuesday between 3 and 4.

**Interviewer:** Okay, can we do 3?

**Interviewee:** I do have a client from 2 to 3, and he tends to finish right on time, he’s autistic. He finishes right on time. So I think that will be fine, but if I’m a little late, you will know why.

**Interviewer:** No, that’s totally fine, I have something at 4, but that’s okay, I can plan and set up so I can go straight into the next thing, great.

**Interviewee:** Okay, that’s fine.

**Interviewer:** So, 3 on Tuesday the 28th, and then I’ll get all the codes ready and then you’ll do the forms, and then we’ll find a time for the interview and all my questions.

**Interviewee:** Yes, it will feel so familiar, like deja vu, except you will be so surprised at how different they are.

**Interviewer:** Every interview is so different and it’s so interesting, because it’s the same script effectively.

**Interviewee:** Yeah, I can imagine. I don’t know if I mentioned to you, but I’m actually friends with Carol Stock Kranowitz, she wrote The Out-of-Sync Child. **[01:15:00]**

**Interviewer:** Let me write that down.

**Interviewee:** For sensory stuff, that book is the bible. Where is it, here we go, so this is her book, The Out-of-Sync Child, and she’s really great. But yeah, this book, she actually was a nursery school teacher and she learned about sensory issues from an OT who was working at the school and she was like, parents need to know about this, and she wrote this book. So, then she wrote this follow-up book.

**Interviewer:** Oh, that’s great.

**Interviewee:** For your study this would be great because what she did is interviewed all these people on what they were doing as adults with their sensory stuff. And here, I don’t know if you can see.

**Interviewer:** Oh, is that your son?

**Interviewee:** That’s my son! He wrote two vignettes for her, here’s the other one. Getting Older Helped.

**Interviewer:** Oh, that’s great. I’ll have to look it up.

**Interviewee:** Yeah, this book, it’s a lovely read. She’s so lovely, she just has a really nice way of putting things. She’s very relatable. But she interviewed all these adults about their sensory issues about what had gotten better and what hadn’t. So, when you were talking, you were asking these questions, I was thinking about that book.

**Interviewer:** Awesome, perfect. So, my reading list which is, you know, that high...

**Interviewee:** I know, if I showed you my pile over there. Alright, well, I will see you on Tuesday.

**Interviewer:** Yes, and I will send you an email with the correct passwords and all that stuff, and I will also send you a gift card for doing all this with me.

**Interviewee:** Yay, okay.

**Interviewer:** Thank you so much for your time and your insight, it’s so great to talk to you.

**Interviewee:** Yeah, likewise, I’m very excited about your study, I think it’s really important.

**Interviewer:** I think so, too.

**Interviewee:** It’s really, really important, so I’m very excited about it.

**Interviewer:** Yeah, me too, I’ll be sure to share all the results whenever they come, whenever we’re done coding, which, you know, takes a while.

**Interviewee:** It does, it does, alright.

**Interviewer:** Awesome, well have a great day and enjoy your client later.

**Interviewee:** Thank you, I will

**Interviewer:** Bye.

**Interviewee:** Bye.

**[End of transcript]**