**[Start of transcript]**

**Interviewer:** Ok we are recording and again I will be asking your perspective about your child’s sensory sensitivities in relation to his transition to adulthood and we’ll be doing again a semi-structured interview, where I have my questions in my script, but I’ll be adapting them so they follow our conversation and make sense for us.

**Interviewee:** Ok.

**Interviewer:** And again, like before, if there’s anything that makes you uncomfortable you don’t have to answer it and you’re welcome to bring things up that came up earlier.

**Interviewee:** Ok.

**Interviewer:** Any questions?

**Interviewee:** No.

**Interviewer:** [00:00:33] Ok, awesome, and talking about Devlin today, could you please start off by telling me about his sensory sensitivities and sensory interests?

**Interviewee:** [00:00:43] So he … I think most of his sensory sensitivities are more auditory as well, but a little bit … he has a lot of anxiety and some of it is around like, that he can’t necessarily filter sounds, so sometimes something sounds like weird or scary and he has a hard time kind of like separating sounds, if that makes sense?

**Interviewer:** No, totally.

**Interviewee:** So sometimes he’ll hear something and it will sound kind of weird or scary. He’s gotten a lot better with it because we’ve been talking about it and I’ve, you know, we’ve told him to come and ask us if he hears something like … you know, like for example my neighbor, downstairs neighbor, used to play music kind of loud and you’d hear the base. He didn’t know what it was and he would say like, you know, “*I’m hearing things and I think I’m crazy and it’s really scary and it sounds like a monster*,” and, you know, and I had … we finally figured it out. Like, he came to us and I was like, “*Is it that noise right there?*” and I said, “*That’s the music playing*,” you know, like when you can only hear the base when the music is really loud in another apartment. You know, but like things like that have given him a lot of anxiety. But I think he, I think it’s a lot better now because, like I said, he’s learning to like ask questions and we explain that sometimes something can sound weird if you don’t know what it is.

**Interviewer:** [00:02:18] Yeah. And is it … you just talked about music, what other sounds are hard for him to understand and cause that type of anxiety?

**Interviewee:** If he can hear like other people’s voices, like sometimes, you know, when the windows are open you can hear people talking outside, or we have another building that’s kind of close to us so in the summer like, you know, they have parties, or they’re outside, or the windows are open and there are people talking, and music and stuff like that. So like voices and music that’s kind of, you know, that’s distant, that he can’t quite make out as music or talking.

**Interviewer:** [00:02:58] Totally. And then I think on the form a while ago you indicated also, like he likes to stomp and also likes the kind of like deep-pressure touch situation?

**Interviewee:** Yeah, yeah. So he definitely has a lot of kind of tactile stuff going on where he … yeah, he needs that kind of input, like he, he stomps his feet a lot on the floor. He actually stomps so much that a doctor recently was looking at something else on his foot and he was like, “*Does he play some kind of sport or … ?*” And he said, “*I’ve never seen such like callusing on like the ball of someone’s foot*.” Because I mean he likes to walk on tiptoe and I mean he stomps really loud [*laughs*]. But, so yeah, that’s another thing, like that kind of deep-pressure stuff, so it can’t really be good for him and it’s not so good for our ears [*laughs*].

**Interviewer:** [*laughs*] Yeah, and does he seek out that deep-pressure sensation through other actions?

**Interviewee:** [00:04:02] I’m trying to think … he … I don’t think so. He doesn’t seem to really like, you know, like wrap up in blankets or anything excessive like that. I think it’s mainly, I think it’s mainly that kind of input on his joints that’s … that, yeah. But he also knows, like – well this will probably come up later – but he kind of knows like, he won’t do that when he’s at school or when he’s outside, but he does it at home.

**Interviewer:** Absolutely. And then, does he have other sensory sensitivities or like sensory interests that he seeks out?

**Interviewee:** [00:04:43] … No, not really, those are kind of the main two things with him.

**Interviewer:** Nothing with like vision, taste, or touch? Oh, taste or smell, sorry.

**Interviewee:** No, he’s definitely a sensory seeker, like he’s more, like all of my kids are, they’re like more on the side of like exploring different tastes. Like he likes all different kinds of food, you know, very curious to try things, like you know, different tastes and textures. So, yeah, so he’s more of a sensory seeker as well.

**Interviewer:** Awesome. And have his sensory interests or sensory sensitivities, have they changed over time?

**Interviewee:** [00:05:38] Yeah, when he was smaller he was actually, he was one of these kids who was obsessed with things that spin, like wheels. He loved cars, like it was mainly like toy cars, all manner of toy cars, anything that had wheels, he’d like lay down and watch the wheels. So he, yeah, he had more – I don’t know if that was really a sensitivity, but it was kind of like, you know, like blocking out other sights and that was kind of soothing for him to see that.

**Interviewer:** Yeah. When did that stop? Oh, sorry.

**Interviewee:** Oh, that’s ok. He was pretty small actually when he stopped doing that, like he probably kinda stopped doing that when he was, probably like six or seven, maybe a little younger.

**Interviewer:** And then what about that anxiety you described about sounds that he doesn’t totally understand, has that always been a consistent thing for him?

**Interviewee:** [00:06:33] You know, I think so, but he wasn’t really talking about it as much as he has been like in the past like five years or so. So I think he just had these like anxieties but now he knows, like he’ll just come to us and say, you know, even if he says something like, you know, “*I heard something that sounded like demons or something*,” we can kind of like go, “*Oh, well what did it sound like, what* …” You know, I’ll say, “*Let me know when you hear it*,” and then I’ll say, “*Oh, ok, well you know what that is, that’s people talking outside*,”or other things, so it’s helping him because he’s, I guess he feels comfortable enough to come to us and say, you know, “*This is scary*” or “*What is this*?” I think he wasn’t really doing it before and things seemed more scary to him.

**Interviewer:** Yeah, that makes sense.

**Interviewee:** Yeah, but now he can kind of go, “*Ok, well that’s kind of just* …” you know.

**Interviewer:** Totally. And then that deep-pressure input from stomping, has that always been like an interest to him?

**Interviewee:** [00:07:39] Yeah. I think, I would say it’s gotten more intense over the past few years. I’m trying to think of … Yeah, I think, well, it’s become, you know, what, I … it could just be that I notice it more because we’ve lived in apartments for the past couple of years so I’ve been really like, oh god, you know, like what are the neighbors going to think, you know, they probably have like plaster falling on their heads [*laughs*]. You know, and this apartment, it’s a little bit less stressful because we have two floors so I tell him like, “*You have to be on the top floor*,” and even then it’s probably shaking the foundations [*laughs*].

**Interviewer:** [*laughs*]. That’s ok, houses are meant to be used right? [*laughs*]

**Interviewee:** Yeah [*laughs*].

**Interviewer:** And these changes that you’ve noticed, do you think they’re related to any independence that he’s gained over time?

**Interviewee:** [00:08:36] … I think it’s kind of like reverse, I think he … not reverse, but I think he, once he started realizing that he could like ask us and that there was probably, you know, a logical explanation that I think that has kind of given him more like confidence and more independence because he feels more able to talk about it, whereas before I think he was just like, “*Ok, like I think I’m nuts*,” like, you know. “*I don’t know what these sounds are*.” And he knows like we’re not going to laugh at him or say, you know, “*Oh that’s ridiculous*.” We’re like, “*Oh, okay, what’s that? Let’s figure out what that is*.” You know, so I think that’s kind of helped him, you know, grow up a bit and become more mature, you know, as he’s understanding that he can advocate for himself and he can ask for help.

**Interviewer:** Totally. And then, when he is in a scenario when he hears something he doesn’t understand, you said it caused anxiety, what does that anxiety look like for him?

**Interviewee:** [00:09:50] So sometimes, you know, sometimes he would like say things, like, you know, “*I think I’m crazy*” or “*I think there’s demons*,” and it would really bother him and he would be like kind of, he’d be kind of scared about it and … you know, and it started with him saying like, “*You know, I think something is really really wrong with me*.” And I would say, “*Well, why do you say that?*” Like, you know, but I think over time he’s realizing like, and I explain to him too, I say like, you know, “*Sometimes, being autistic means that you, your senses are a little bit different, like, you know, some people notice things a lot more or a lot less, or some people have trouble like deciphering sounds, sometimes like all sounds kinda come at you at the same level and it’s overwhelming, or you can’t, you know, it’s hard to decipher*.”

**Interviewer:** Totally.

**Interviewee:** And I think it kind of, like because I can also kind of relate to that because I have similar like auditory stuff, like I can’t be in crowded places because I just can’t filter [*laughs*]. But … so I can definitely relate. But he has trouble with filtering, you know, and it sounds like just all manner of noise and he can’t make out, “*Oh, those are just people talking*.” But he’s, I think now he can, like he’s kind of getting the know-how to go, “*Ok, there’s more than likely a logical explanation for this*,” you know. And so now he’ll actually like come and ask, like, you know, he’ll say, “*Oh, what is that sound? Oh, is that people talking?*” So, you know, he’s starting to be kind of able to go, “*Ok, that weird sound is just people talking outside, you know, with music playing*,” or somebody’s car stereo like four blocks away but it’s really loud [*laughs*].

**Interviewer:** So it sounds like he kind of manages his anxieties by like talking to you and asking and trying to figure it out?

**Interviewee:** [00:11:57]. Yeah, yeah, and he’s been doing that a lot more. Like he was, he really was struggling with it a few years ago and he was actually getting, he was actually talking to a licensed social worker at his pediatrician’s office and he kind of, he kind of like gave him a lot of tools to like manage the anxiety and we talked a lot about like his sensory stuff and how that was giving him anxiety and so I think between being able to realize that, you know, there’s a logical explanation for most sounds and we can even figure out what most sounds are that we’re hearing outside, and having some kind of like coping skills for when he *is* feeling anxious, I think the combination of the two has really helped him with that, so …

**Interviewer:** Yeah, and were those the tools that the social worker provided?

**Interviewee:** [00:12:47] I think he mainly … I think a lot of the stuff they worked on was like just breathing and focusing and … some of it was kind of like thinking logically though, like, ok, that there’s probably not demons outside [*laughs*]. It sounds weird but there probably, you know, there’s probably, just think about the different sounds you’re going to hear in your neighborhood and there, you know, there’s a lot of people, there’s a house close to us on either side that have lots of apartments and people, you know, listen to music, and in the summertime they’re having cookouts and they’re outside and, you know. So there’s a lot of sounds around here [*laughs*].

**Interviewer:** And when he was younger did he also get anxious by these noises he didn’t understand?

**Interviewee:** [00:13:38] I think he did but he wasn’t really able to talk about it, so he would just get really, he was kind of nervous and anxious and also like, his older sister was also kind of overbearing and a bit of a bully to him when he was little, so I think there was also that because she was like always around and he was afraid, “*Oh she’s going to make fun of me or* …” you know, and so … and now it’s a little bit easier, like the living situation that we’re in is a little bit easier for him to kind of like come and seek us out. Like, you know, I’ll be cooking and he’ll come into the kitchen, sit down and talk to me and ask me stuff, or like he’ll ask my husband to come upstairs and talk to him. So he has more, more space, which is good, and he’s able to, well to distance himself from her a bit, which has given him a lot of confidence too. So I think it’s easier for him to come to us and ask us questions.

**Interviewer:** That’s great.

**Interviewee:** Yeah.

**Interviewer:** And then if he isn’t able to do that stomping to get that like deep-pressure input, does that cause or increase anxiety?

**Interviewee:** [00:14:57] I guess it does, I hadn’t really … I hadn’t really thought about it much, but yeah, like if has to sit somewhere for a long time, or, you know, go on a long car ride – which we’re doing a lot these days [*laughs*], which the kids are really over by now [*laughs*] – when he has to sit somewhere, I think that really, I mean a lot of people for different reasons don’t like to have to sit somewhere for like three hours straight, myself included, but yeah, I think … Yeah, I think it probably does, you know, if he can take like a break and go upstairs and like pace back and forth and kind of stomp and get that input, that really kind of … what’s the word I’m looking for, that kind of sets him straight or helps him kind of be able to stabilize himself, yeah.

**Interviewer:** And has that always been the case where not having the opportunity to get that input causes anxiety?

**Interviewee:** [00:16:04] Yeah, I think so, I think so. And I think, yeah, because I think part of why he’s, he’s adapting better too is that he’s able to do that more freely without … he has the space to do it, he has his own room, his sister’s on a different floor, you know, and we don’t really tell him to stop unless it’s like at night and we’re all trying to sleep. So I think, you know, most like 99 percent of the time I just let him do it because it really, it really helps him.

**Interviewer:** Totally. And like in general, how does your son like cope with, or manage, or like handle his sensitivities and his sensory needs?

**Interviewee:** [00:16:54] I would say, I would say that he, like he, you know, like the talking about it and, you know, and trying to, and realizing that he, you know, that he can get help trying to figure out what something is to make it not be scary. And he also, he loves music, so I think that helps to, like he, being able to listen to music in his room and kind of tune stuff out really helps.

**Interviewer:** Totally. Does he, when he’s out, not in his room, will he wear like earbuds or headphones to have that music to tune everything out as well?

**Interviewee:** [00:17:35] Yeah, yeah. Like when he and his dad used to take the train places, the subway, he would have like earbuds so he could just kind of sit and listen to music on his phone, and his phone helps too I think, you know, because he can like watch videos or … and social media is also helpful to him because like some of his friends from school are there, so I think it’s comforting that he’s interacting with them even though everybody’s still kind of quarantined. And it’s hard because he graduated, he graduated last month, so he can’t really, he can’t go back to online classes, because I think that would really help him too, like he’s missing that social piece [*inaudible* …] So I think, yeah, I think stuff like that, oh yeah, that’s where I am, sorry, branching off …

**Interviewer:** No worries.

**Interviewee:** Yeah, but he … having, you know, like access to social media or music when he’s out is, it definitely helps him kind of deal with the outside world. And he does like, I mean he also does like to go out and people watch and interreact with people, like he’s *extremely* social. So I think that distracts him too, like if he, if he is able to go and hang out with people or just people watching, he, it’s, you know, it’s been, he hasn’t really gotten to go out like he was before, because, you know, everything has to be remote now, but he copes pretty well in, you know, in public and in social situations. But I think, yeah, having that little distraction when he needs it is …

**Interviewer:** Totally. And has he ever received, besides the social worker, has he ever received specific therapies or interventions to help him with his sensory needs?

**Interviewee:** [00:19:36] No, I mean he had OT [occupational therapy] in school, so he did have access to OT, pretty much all throughout school. I think in high school he had, he did, I can’t remember what the service delivery model was in high school … I think his last few years of high school I think he just really had like a consult like once a month, but like in school, like once they see that a kid is showing that, you know, looking like they don’t need something, they very often like scale back on it and sometimes it’s like, he’s doing *well* because he has the *service* [*laughs*]. But with him he’s able to kind of … it doesn’t interfere with his, you know, like with his ability to like do schoolwork or work or whatever.

**Interviewer:** Do you think the OT *did* help him when he *was* receiving it?

**Interviewee:** [00:20:43] Yeah, he was receiving it … he got it in, I think through middle school and then in high school, I think that’s one of the things that they very often kind of taper off, or they’ll have like one session a month and then like a consult with a teacher. Whereas when they’re younger, I think, they have like, usually they have OT like once a week, you know, OT and speech once a week and then like a spot group when they combine speech and OT. But I don’t … I have so many like IEPs [individualized education plans], so I’m trying to remember like …

**Interviewer:** Oh, no worries! [*laughs*]

**Interviewee:** I think, yeah, they had kind of stopped most OT services by the time he was in high school. You know, because he wasn’t really demonstrating like a huge need for those services.

**Interviewer:** Yeah. And what were they, when he was receiving it, what were they helping him with, with the sound filtering, with the deep-pressure input?

**Interviewee:** [00:21:43] I think a lot of it was like the input stuff and they had … they have a pretty good OT room at the LEA [local education agency] where he was going, so I think just going into the OT room and like swinging and getting input from different like OT equipment was helping and I think … I’m trying to remember … I don’t think he got like, he didn’t have really … I don’t think they had to do like a whole lot with him, I think one of the main things with him was like going to the OT room and getting some like input from the swings and stuff like that. He also really loves the sensation of like swinging and stuff like that too. So yeah, I don’t … yeah, so that’s, I think that’s pretty much like the extent of the stuff they did with him.

**Interviewer:** Yeah, that makes sense, thank you. And then thinking a bit more broadly, what are your goals or hopes for your son, in terms of his sensory needs?

**Interviewee:** [00:22:50] I think he’s, I mean I pretty much think he’s there, like, I think you know, being able to … have someone that he can, you know, if something freaks him out he can ask them about, or … you know, just being able to advocate for himself like if something feels too overwhelming, to say, you know, “*I need a break*,” or “*I need to go somewhere quiet for a minute*,” or “*I need my headphones*,” or … and he’s pretty much … I mean he’s pretty much there, like he, you know, having the ability to ask about things that he, now he realizes … having the knowledge that, “*Ok, things that sound, sounds that are weird to me are not like me going nuts, it’s that I can’t filter so I’m hearing like this weird cacophony*,” like, you know. But being able to, knowing that, and going like, “*Ok, well now I know that, so I can kind of ask for help*,” or say what, you know, ask what that is or kind of try to break it down a little bit. You know, sometimes he can kinda do that too, like kind of break it down if there’s a whole bunch of noise, but he can say, “*Oh ok, well that’s, you know, talking, music, a siren*,” you know.

**Interviewer:** Absolutely. And then moving on to our next chunk of questions, as your son has grown up and aged a bit, how has his and your community reacted to his sensory needs?

**Interviewee:** [00:24:28] I don’t know that it’s really been much of a thing because he doesn’t, he doesn’t really show that when he’s out. Like when he’s at school, like I think he takes … he would need like breaks to walk around a little bit or, you know, that kind of thing, but there was nothing … I don’t think there was … yeah, I don’t think it really, I don’t think a lot of people really *see* a lot of the stuff that he struggles with.

**Interviewer:** Totally. This might be not so applicable then, but when your son was younger, was his and your community more or less accepting of him and his needs?

**Interviewee:** … I think most people were pretty, that worked with him or that knew him in any capacity, were always pretty accepting of him because he’s got, he’s got like a really great disposition and he’s really outgoing and friendly and like everybody loves him. So … yeah, I mean I mostly think … yeah, I mostly think people have been pretty accepting.

**Interviewer:** And that hasn’t changed with age you don’t think?

**Interviewee:** [00:25:55] No.

**Interviewer:** That’s great.

**Interviewee:** Yeah.

**Interviewer:** That’s great. Again, this may not be so applicable for you and your family, but were there or have there been particular spaces or places that have been more or less understanding of him?

**Interviewee:** I’m trying to think if we’ve ever really had … I don’t think we’ve really had any issues with that. I mean, you know, sometimes people stare if they see somebody stimming or whatever, but I’ve never had, I’ve never really had an incidence where I felt like he wasn’t accepted or …

**Interviewer:** Yeah, and you felt like his school was accepting of him and his needs as well?

**Interviewee:** [00:26:38] Yeah, yeah, I mean we’ve had like, I’ve … over the years I’ve butted heads with a lot of professionals about people wanting to, people like discouraging like stimming or anything that’s like harmless – again, I think I brought that up with my daughter too but – but aside from that, because, you know, like I don’t think everything needs to be pathologized, it’s just somebody being autistic, they’re not hurting anybody, you know? But other than that, I really … yeah, I don’t really think there’s been, in terms of like people being accepting of him.

**Interviewer:** Yeah, that’s great then.

**Interviewee:** Yeah, he’s, like his teacher, everyone who’s ever worked with him like loves him, they’re always sad when he like graduates or moves on to another grade [*laughs*]. I’ve had teachers literally like crying in meetings, like “*I’m going to miss him, I can’t believe he’s like going to another school*” [*laughs*].

**Interviewer:** I think it’s good to have that, where people care so deeply about your son! [*laughs*]

**Interviewee:** Yeah [*laughs*].

**Interviewer:** That’s great. And then, again, thinking a bit more broadly, what hopes or worries do you have for how his and your community will continue to react to his needs?

**Interviewee:** [00:28:04] I hope it, you know, I hope it kind of stays the same. You know, I think, I think it will, I mean he makes friends wherever he goes and people just like take to him right away, which is good, so I think overall … and he doesn’t show a lot of the stuff that kind of makes him anxious. Like he’ll talk about things when he comes home if something made him really anxious, so it’s not like it’s something that a lot of people might not even be aware, like if he, you know, if he was anxious about some kind of sensory input that was, you know, that was bothering him or whatever.

**Interviewer:** Yeah.

**Interviewee:** So, but in terms of, you know, in terms of people being comfortable and accepting of him, I think, you know, I hope that continues [*laughs*].

**Interviewer:** Yeah, absolutely.

**Interviewee:** [*inaudible …*] and he’s really starting to, you know, do better with feeling like he can ask for help when he needs it.

**Interviewer:** That’s great, that’s so important.

**Interviewee:** Yeah.

**Interviewer:** And then in the like transition to adulthood, where do you see your son?

**Interviewee:** [00:29:21] I mean he’s … he’s definitely matured a lot and I think, you know, he’s got, in terms of transitioning to, you know, we don’t know exactly yet what his service model is going to look like or what kind of opportunities are there, but I think that, you know, he could do well. He could work, he could access different community things with no problem, like different services or service models or job training or anything like that. I think he’s, I think he’s ready. You know, he hasn’t really done much yet because we’re kind of in the middle of the transition from the agency, the DDS [Department of Developmental Services], and putting services in place and getting services started but knowing that we’re going to be moving with him in like three weeks or so. But yeah, I think he’s come as far as he can *right now* and he’s definitely like ready for what’s next.

**Interviewer:** That’s great. And then in terms of like his current stage of independence, what are some things that he is able to do by himself and what are some things he needs continued support with or needs to keep on working on?

**Interviewee:** [00:30:57] So he definitely needs help with … he needs help with like cleaning up after himself and making that sure he puts his stuff away. Like he can *do* all these things but he needs like reminders.

**Interviewer:** Totally.

**Interviewee:** He was doing a little bit of travel training and I think he could, I think he could travel to some places independently, but he can be a little spacey at times [*laughs*], but I think that’s, I think that’s something he could definitely, he could definitely reach that goal at some point.

**Interviewer:** How is he with like taking care of his body physically on a regular basis?

**Interviewee:** He needs a lot of reminders [*laughs*].

**Interviewer:** Is he able to do it with like, reminders aside, can he physically take care of himself?

**Interviewee:** [00:31:47] Yeah, yeah.

**Interviewer:** What about like preparing meals or simple meals?

**Interviewee:** He can, he doesn’t have to much because a lot of the time I just do the food prep, but I think he’s actually interested in learning how to cook, so that’s something that I think I’ll work on with him because …

**Interviewer:** That’s great.

**Interviewee:** Yeah, I think the more … he can actually, I think he can do a lot more than he’s doing, but he just needs like the support and the prompts and the, you know, the know-how.

**Interviewer:** Yeah, absolutely, the experience.

**Interviewee:** Yeah.

**Interviewer:** Maybe before COVID, but was he able to go shopping with you to help buy groceries for things that like he and your household need?

**Interviewee:** Yeah, yeah he actually loves shopping [*laughs*].

**Interviewer:** That’s fun! And then what about like money management, does he understand money? Is he able to manage it?

**Interviewee:** With some help. We were actually, that’s one of the things he’s kind of been working on with regard to that, like he’s working on counting money and knowing, you know, like how much should it cost or how much should I bring for this thing. Because sometimes, like he would cash his checks, like he was working through school and he’d have like a bunch of cash, and I’d say, “*Oh, you know, bring a little money if you want to buy yourself a snack or whatever*,” and he’d just like shove some bills in his wallet. And I’d be like, “*Well how much did you bring?*” And he’d be like, “*I don’t know*,” and it could be like five twenties or it could be like a bunch of singles, and I’d say like, “*Well, no, you should think about* …” So, you know, we’re kind of working on that, like, you know, let’s put a, like maybe you should put a cap on it and say, “*Ok, I’m going to bring thirty dollars because I don’t want to spend more than thirty dollars*,” or, you know, or something like that, and know what you have and what things cost, and you know.

 **Interviewer:** Absolutely. You just mentioned … oh, sorry go ahead.

**Interviewee:** Oh it’s just, you know, having him look at how much something costs like in the store, because sometimes he’ll just be like, “*That looks good, that looks good, that looks good*,” and I’m like, “*Dude, you’re about to spend like sixty dollars on snacks at CPS*,” you know [*laughs*].

**Interviewer:** It adds up there! [*laughs*]

**Interviewee:** Yeah, maybe not all at once, you know! [*laughs*].

**Interviewer:** [*laughs*] Absolutely. You just mentioned he had a job through school, what was his job?

**Interviewee:** So he was doing custodial work and then last year he was working at the Disc Program, which is, BPS [Boston Public Schools] was doing this, they had a project where they were taking all of the old school records that were like boxed at like, you know, the turn of the century, like [*laughs*] decades and decades, and inputting them, so they’re making all records digital. So the [*inaudible* …] program actually has this program where they have people like scanning documents and then entering them manually. So yeah, he was doing that. They had a bunch of different types of jobs so it was pretty cool that he got a little bit of training in different areas.

**Interviewer:** Totally.

**Interviewee:** Yeah, so he really liked it and they get paid, so.

**Interviewer:** Even better! [*laughs*]

**Interviewee:** Paid work is good!

**Interviewer:** For sure. Does he want another job like that? Not like that, but does he want another job in the future?

**Interviewee:** [00:35:24] Yeah, he’s actually very interested in working, which is pretty cool.

**Interviewer:** That is great.

**Interviewee:** Yeah.

**Interviewer:** And does he ever express interest in wanting to live independently from you and your household?

**Interviewee:** He’s talked about it before but mostly … mostly like at times if he was kind of like bored or a little bit stressed, he’d be like, “*Oh, you know, yeah, sometimes I want to get my own apartment*,” and I’m like, “*Yeah, maybe you could do that one day*.” But for the most part he’s kind of like, he likes living with us, so … which is good.

**Interviewer:** Absolutely.

**Interviewee:** We always make sure that he, you know, now, you know, we’ve lived in kind of small spaces before and this place we’ve been in for like five years is pretty big so he’s finally, I think it’s really helpful for him. Like he has his own room, he has plenty of space in the house, and so that’s really good. And the new house is the same, he has like a lot of space upstairs, so he’s pretty excited [*laughs*].

**Interviewer:** That’s amazing. And you talked a lot about his friends, does he manage his social life to some extent?

**Interviewee:** [00:36:36] Yeah, I mean mostly, currently mostly on social media because everybody’s still in quarantine still.

**Interviewer:** Yeah [*laughs*].

**Interviewee:** But yeah, his schoolfriends are on social media and he talks with them and kind of keeps up with what they’re doing, and so yeah, I was telling him like, “*You have to make sure you get their emails too and you guys can like talk on Google chat or like Zoom or whatever and just stay in touch*,” because he does have a pretty good like network of friends that … I know he’s going to miss them and, you know, he misses going to school. And they’re actually, they haven’t graduated just yet so I see them when my son Aiden is at school, and they’re like, “*Where’s Devlin?*” [*laughs*]. But yeah, he does stay in touch with them, which is good.

**Interviewer:** That’s wonderful.

**Interviewee:** Yeah.

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

**Interviewee:** [00:37:39] I think so, you know, again with the right kind of support of course, but … yeah I definitely think so. And I think it helps him, the more … he’s kind of anxious about doing things himself, but the more you give him like a gentle push and say like, “*I know you can do this*,” you know, that kind of support really helps him to, I mean I think it helps a lot of people, but with him especially, like a lot of the time he won’t want to try something or he’ll be nervous about it and I’ll be like, “*No, you are totally capable of doing this*,” and he’ll say, “*Oh, ok, well I guess I am.*” He’ll catch on pretty quick when he’s kind of gently nudged into it [*laughs*].

**Interviewer:** Other than this gentle push, what else do you think will help him transition more into adulthood and into independence?

**Interviewee:** Good question … I think … I don’t know, I think really just having people who, support people who like really build his confidence … and like, you know, respect his sensory needs or respect his, you know, the stuff that he kind of, the supports that he needs. In terms of … I also think things like visual schedules are helpful to him, so stuff like that would be helpful, like I think in an employment situation, in a living situation, visual schedules are definitely helpful, or step by step, like or having a checklist, like here’s what you do today so you don’t need someone else [*laughs*]. You know, like here’s a checklist of stuff you have to do, you know, you get up, you brush your teeth, you know, you have breakfast, you get dressed, you know … take the empty bottles of soda and water bottles out of your room [*laughs*], tidy up, you know, stuff like that. Like having a checklist for things that he does on the regular, like here’s how to make a sandwich, having some kind of visual schedule, not schedule, but visual step-by-step instructions is helpful. So that’s definitely something that’s good for him because I think he is definitely more of a visual learner.

**Interviewer:** For sure. Do you think there are any services or interventions that could help transition him more into adulthood?

**Interviewee:** [00:40:33] … I would say … I would say probably support staff. I don’t really think – I think I mentioned before that I’m not real crazy about ABA [applied behavior analysis] in general – but I think some things that … yeah, I think some things that are helpful, you know, making sure he’s able to meet his sensory needs and being able to have supports, like the visual schedules and having maybe people who kind of know how to do that, but which … but I don’t, yeah, there’s no specific like … I don’t think there’s any intervention that would help. Yeah, I think really just like any really good support person would be good, would be adequate for him to kind of be successful.

**Interviewer:** And now putting these two things together – his sensory needs and his transition to adulthood – how do they intersect for your son?

**Interviewee:** [00:41:42] … I had trouble with this before too …

**Interviewer:** They may not intersect and that is totally ok.

**Interviewee:** I’m trying to …

**Interviewer:** I can rephrase the question if it helps?

**Interviewee:** Yeah, if you could.

**Interviewer:** Sure, no problem. I guess another way to think about it is how do his sensory needs impact his transition to adulthood, if at all?

**Interviewee:** [00:42:19] I don’t … I don’t really think they do beyond, you know, the ability to ask for help when needed, because I think that the main issue that he had with sensory stuff was the anxiety it was causing him because he was, you know, like he was like scared of everything. You know, it was like, “*What is that weird noise that I’m hearing?*” But beyond that I don’t really … I don’t really think it does. You know, and it’s like I said before, as long as people who work with him are supportive in that way with understanding that, you know, sometimes he needs to like get physical input, you know, by stomping around, and that he needs understanding and help to just explain, you know, to help him understand that he’s not imagining things, you know. But I think he really, yeah, I don’t think, I think beyond that I don’t really think it will really impact that.

**Interviewer:** Yeah, that’s great then. And then do you think his sensitivities and his sensory needs, do you think they are an obstacle, a vehicle, neither, or both towards his independence?

**Interviewee:** [00:43:50] I’d say neither really.

**Interviewer:** Again because you don’t think they really impact his transition?

**Interviewee:** Yeah, yeah. I guess as I said before, I think he, I think a lot of the hurdles that he had around his sensory needs he’s kind of already overcome.

**Interviewer:** Yeah, do you think they *were* an obstacle in the past?

**Interviewee:** Just in the sense that there were things that he didn’t understand, you know, but now having an understanding of it it’s like, “*Oh, ok, you know, it just is what it is and I can get help when I need it*,” you know.

**Interviewer:** Yeah, that makes sense. And then this may not be so relevant given what you’ve just said in the last few questions, but what do you anticipate as being challenging for your son, as he does gain more independence in regards to his sensory needs?

**Interviewee:** [00:44:46] Yeah, I don’t think, I don’t think anything really.

**Interviewer:** Yeah? Awesome. Again, this may not be relevant, do you think there’s anything that could help him in this intersection?

**Interviewee:** No, nothing beyond what I mentioned with support people and … [*laughs*]

**Interviewer:** Totally. And then do you think there are gaps in the available services and supports for kids like your son in this intersection?

**Interviewee:** … Not … no, I don’t think so, not really.

**Interviewer:** What about, oh sorry, go ahead.

**Interviewee:** [00:45:34] Yeah, no, just, no I … I don’t think so with him, no.

**Interviewer:** What about maybe broadly, outside of this intersection?

**Interviewee:** In terms, the gaps in services in terms of just …

**Interviewer:** Yeah, you know, for people like your son.

**Interviewee:** It’s hard to … it’s hard to know for sure. I mean it seems … I don’t think so. I don’t, I’m not, as far as I know I don’t really think so, but I don’t know for sure, like I don’t know. I kind of know some of the stuff that’s out there, but I don’t really … with him I haven’t really navigated services yet. Like with my daughter I had trouble because of the different agencies, etc. But with him, you know, his needs are a little bit more … less complicated I would say.

**Interviewer:** Got you, no that makes total sense. I think I know your answer, but how have your son’s sensory needs impacted your goals, hopes, and expectations for him as he navigates adulthood?

**Interviewee:** [00:46:55] … I think I said, I think overall, I think, you know, because he’s … you know, he’s so much more able to advocate for himself, I think, you know, things look pretty … good overall for him. Yeah, I don’t think, I don’t see that being an issue. And I think, yeah, I mean I think, I think the progress he’s made has, over the past couple of years, has been really encouraging to me, because I can see that he’s really making big gains in having a better understanding of himself and how to ask for what he needs and, you know, without feeling, without feeling, you know, like he’s weird or there’s something wrong with him. So I think, yeah, I mean I think overall it’s … I think yeah overall he’s … I’ve completely lost my train of thought, but anyway …

**Interviewer:** That’s ok [*laughs*], that’s ok. Thank you, we’re going to move on to our last chunk of questions, we’re almost done. We’re flying through it today. As a parent, as a caregiver, as a mom of someone with autism and some sensory needs, what does transitioning to adulthood mean to you?

**Interviewee:** [00:48:27] Self-advocacy, learning how to … learning how to adult in whatever to the best of his ability and being able to have the supports that he needs and kind of reaching as much, yeah reaching as much independence as he can, but without, without being pushed into things that he’s really not ready for. You know, and kind of getting all the help along the way that he needs. But I think, yeah, I think that would make sense.

**Interviewer:** Yeah. Has this perspective changed over time at all?

**Interviewee:** Yeah, I mean I was, you know, when … when your child is growing up, you know, when they’re small and then when they’re … you know, you always kind of wonder like what is his future going to look like? What is he going to be able to do, is he going to be really helpless? And that’s, that’s … helpless isn’t … but what I mean is, you know, you kind of fear and then you kind of go, “*Oh, ok*,” when you start seeing. Because a lot of people act like autistic kids are basically going to stay children forever and they *don’t*. They just, you know, what they, the way they grow up, the way they change, the way they mature looks different to someone who’s not autistic, but they do grow, they do mature, they do surprise you with how much, how much, how many skills and how much knowledge they gain. So it’s … so yeah, it’s definitely changed over time because, you know, because I was more fearful when they were young and now they’re growing up I’m like, well, they do, they’re probably going to always need support and that’s not a bad thing and, you know, it’s just a matter of making sure, to the best of your ability, that they always have the best support available. Because that’s really key. The key isn’t … you can’t always say, “*I want my kid to never need supports*,” because a lot of them probably always will. You know, and being afraid of that isn’t helpful, but going ok, well what kind of supports, you know, making sure they have the right kinds of supports and having just the right, where they’re not, the right balance, where they’re not being treated like infants, but they’re also not being like pushed into things or made to feel bad for things they need help with.

**Interviewer:** Absolutely, it sounds like it’s like finding that right balance for them.

**Interviewee:** Yeah, yeah big time.

**Interviewer:** Awesome, thank you. And then what do you see happening in your son’s future?

**Interviewee:** [00:51:31] I think he could, I mean I think he’ll always need support, but I think he could definitely live semi-independently. I think he could definitely work if he wanted to and he’ll always have friends, you know, like he always, people just love him. So he’s, you know, I feel good in that way because people always want to help him and people really tend to like him. And I think, you know, he definitely has a lot of friendships. I think he could have a girlfriend someday if he wanted to [*inaudible* …]

**Interviewer:** I’m sorry what did you say?

**Interviewee:** Yeah, I think, I think that would actually be really nice for him if at some point he like met somebody and had a romantic relationship. I think that would be nice for him.

**Interviewer:** Absolutely. You said you see him maybe living like semi-independently. Do you mean like in a group home, do you mean taking on more responsibilities in your home?

**Interviewee:** [00:52:39] Well as with my other kids, like, you know, as long as I’m alive they’re fine to live with me. Like if he ever wanted to at some point like move into an apartment I think he would need somebody living with him, like maybe an adult foster care kind of situation. I mean he could live in a group home too. I don’t know if he’d like that as much, I guess it depends on the home, but a lot of them are not so great. But I think, I definitely think, you know, if at some point he wanted to move out or whatever he could definitely have an apartment with a caregiver. And he doesn’t need like, you know, round the clock, intense, you know, care. He just needs someone to make sure, you know, help him kind of like make sure he cleans up, make sure he’s safe, you know, make sure he gets home safely, etc. So, yeah, I think, you know, he could definitely do those things. And he can live at home as long as he wants to.

**Interviewer:** That’s nice. And then final question, again I think I know what you might say, but how have your son’s sensory needs impacted this perspective you just articulated?

**Interviewee:** [00:53:56] [*inaudible …*] I’m sorry can you ask that again?

**Interviewer:** Oh no, I’m happy to ask it again. How have your son’s sensory needs impacted this perspective you just articulated, in terms of what it means to transition to adulthood?

**Interviewee:** … I think … I think … yeah, I think … I think they’ve pretty much … sorry.

**Interviewer:** No it’s ok, is everything alright?

**Interviewee:** Yeah, I was trying to hear what my other son was doing in the hallway. I think he … how have they impacted … I think … I think pretty much, I mean, a lot of the stuff I already covered, but he’s … I’m trying to answer, sorry.

**Interviewer:** No, it’s ok. It’s totally ok.

**Interviewee:** I think … I would say … that’s hard to answer, I mean it’s not hard to answer, I feel like a lot of it was already covered so I’m trying to formulate like how I would answer that specific thing … with his … wait a minute, one second.

**Interviewer:** No worries, you’re fine.

**Interviewee:** [*Leaves the room to see what’s going on in the hallway …*] Sorry.

**Interviewer:** [00:56:33] No don’t worry, it’s totally fine. It’s also ok if they haven’t impacted your perspective.

**Interviewee:** I think … I’m trying to think … I think … I don’t know. I feel like I’ve just always like been kind of like observing and not really, I haven’t had … some of my perspective with regard to like his sensory needs, I don’t think I was really thinking a lot about them, it was just like this is what’s happening now, this is, you know, how he’s kind of changed and developed, how can I help him kind of better process things or access any like supports that he needs. But yeah, I don’t really know that it impacted my perspective all that much.

**Interviewer:** That’s ok. Thank you.

**Interviewee:** Sorry.

**Interviewer:** No, don’t be sorry at all, it’s kind of a, it’s a tricky question I’m finding. I find people don’t know how to answer it so you’re *not* alone by any means.

**Interviewee:** Oh, and two of my kids were like, it sounded like there was an altercation out there so I was like, “*Ok, what’s going on?*” [*laughs*]

**Interviewer:** [*laughs*] Is everything alright? [*laughs*]

**Interviewee:** Yeah [*laughs*].

**Interviewer:** Well I’m glad to hear that. Well that’s actually it for all of my formal questions. Would you like to add anything else?

**Interviewee:** No, I think we’ve pretty much covered, you know, covered everything and I will, I’ll fill out the surveys like I did the other time. I’ll get on those so you’ll have them like before the [*inaudible …*]

**Interviewer:** No worries, take your time. And does Wednesday at 3 o’clock still work for you for your other son?

**Interviewee:** I think so. I might, I was going to, I was waiting to hear back, I might have to go out that day, but I will, I’ll definitely know by tomorrow morning or so, so if we have to move it. I was waiting to hear back and I was hoping I’d hear something by now, but …

**Interviewer:** Not a problem, just send me a text or email me, whatever’s easiest for you. Just let me know, I can be flexible.

**Interviewee:** Ok, I appreciate it, thank you.

**Interviewer:** No thank you. You are going above and beyond to help us so much and your life seems like you have lots going on right so we so appreciate it.

**Interviewee:** Well thank you.

**Interviewer:** Awesome, well I hope you have a nice night and hopefully you can catch some sunlight before the sun goes down. [*laughs*]

**Interviewee:** Yeah, I know, daylight saving is like all of a sudden, it’s like wow it’s 5 o’clock and it’s like nighttime.

**Interviewer:** Yeah, it’s not even 5 o’clock yet.

**Interviewee:** I know, yeah pretty soon it will be like the next couple of weeks it will be like getting dark at 4. That’s so weird to me.

**Interviewer:** I know, it always happens this kind of year unfortunately.

**Interviewee:** I remember like my kids were in afterschool a few years ago and it was like I’d be picking them up at 5 and it had been dark for an hour and I was like, “*This is so weird, like picking them up at night*.”

**Interviewer:** Yeah, I was at an afterschool program when I was a kid too and the whole wall was windows and you could see when it went dark and then you were still there.

**Interviewee:** Yeah, I was like, this is weird, I’m supposed to be home right now.

**Interviewer:** But again, truly thank you so much for your time and help, we couldn’t do this without you.

**Interviewee:** Thank you.

**Interviewer:** And whenever you have a chance to fill out the surveys, after that I’ll send you another gift card as another thank you.

**Interviewee:** Oh great, thank you.

**Interviewer:** Awesome, well I’ll let you go, but I will see you maybe Wednesday, maybe later in the week, we’ll figure it out.

**Interviewee:** Ok great, thank you, yeah I’ll let you know, I should know by tomorrow anyway, one way or another.

**Interviewer:** Ok.

**Interviewee:** Ok, thank you.

**Interviewer:** I’ll see you soon.

**Interviewee:** Ok, see you soon, have a good night.

**Interviewer:** Bye.

**Interviewee:** Bye.

**[End of transcript]**