**[Start of transcript]**

**Interviewer:** We are recording and like before I will be asking you questions about your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities and sensory interests and this will be a semi-structured interview, which means I have my planned questions but I’ll be adapting them to fit our conversation and what we talk about.

**Interviewee:** Ok.

**Interviewer:** Perfect. And again, if there’s anything that makes you uncomfortable you don’t have to answer it. If you don’t know an answer that’s perfectly ok too and you’re welcome to bring up later anything that we talked about earlier. It doesn’t have to be linear.

**Interviewee:** Ok.

**Interviewer:** Any questions?

**Interviewee:** No.

**Interviewer:** Ok. You’re a pro. So could you please start off by telling me about Aiden’s sensory sensitivities and sensory interests?

**Interviewee:** [00:00:50] Yeah, so he’s, he is pretty much more of an auditory learner, which is different from all the other kids. So he … he does … so he’s not really sensitive to most sounds in the way that my other kids are, but he … he does sometimes like to make his own sounds – meaning make vocalizations or listen to music really loud to drown out other sounds so he’s kind of in charge of what the sounds are. But he also does better with spoken explanations, spoken schedules, as opposed to visuals, because he really, he grasps things really easily in that regard. And he is very much a deep-pressure/sensory seeker. Probably more than, more than my other kids in some ways, like he seeks out deep pressure, he … yeah, he likes to wrap up in a blanket, he likes to wear clothing that’s kind of, not tight, but that’s, you know, that’s kind of very fitted, you know, like jeans or tank tops that are, so he can kind of feel that pressure on his body. I’m trying to think … and he does, he does have like visual stims as well, like that, you know, he likes to play with things and watch things like out of the corner of his eye, like strings or his hands. And … he eats a lot, he’s a very adventurous eater, including things that are *not* food [*laughs*]. He’s a huge sensory seeker in that way that we have to really keep a close eye on him because … his … yeah, his sensory seeking is not limited to food. So yeah, those are pretty much his sensory-seeking activities and sensitivities.

**Interviewer:** [00:03:10] Awesome. I’m going to ask a few follow-up questions if that’s ok?

**Interviewee:** Sure.

**Interviewer:** So when talking about sound, you mentioned [*coughs*], excuse me, you said that he will sometimes listen to music to drown out other sounds, what does he try to drown out when he does that?

**Interviewee:** Talking, his siblings – he has siblings who are also listening to music in close proximity – so he will sometimes like turn his TV on really loud and his iPad so that he can kind of surround himself with sounds that he chose. I think that’s basically what it is, it’s not usually like there’s something upsetting going on or something that’s stressing him out, it’s just that he kind of wants to control what he’s listening to 100 percent.

**Interviewer:** Got you. And then for that deep-pressure input you talked about, does he also stomp like your other kids, to kind of feel that pressure in his joints and his body?

**Interviewee:** [00:04:13] Does he stop?

**Interviewer:** Stomp, like with his feet.

**Interviewee:** Oh stomp, I though you said stop [*laughs*].

**Interviewer:** No, no, sorry.

**Interviewee:** [*laughs*] Not … oh I didn’t hear you … the audio’s not quite as great as the computer. A little bit but not quite as much. It’s definitely not as much of a thing with him. I mean he does it occasionally but nowhere near to that extent that they do, yeah.

**Interviewer:** Got you. And does he also like seek out like hugs from you and your partner or like his other siblings?

**Interviewee:** Yeah, yeah. He does, he really likes hugs and, so he, or he sometimes like will – he doesn’t do it as much now that he’s bigger – but he used to like bring me a blanket because he wanted me to like wrap him up in it and like really give him deep pressure and like squeeze him.

**Interviewer:** Yeah, got you. And then you talked about visual stimulation like with things out of the corner of his eye, is it just hands and his string or is it other objects that he likes to do that with as well?

**Interviewee:** [00:05:17] Usually it’s like string-like objects, like it could be, he could grab a phone cord or … you know, rope or string or anything that’s kind of string-like.

**Interviewer:** Got you.

**Interviewee:** And he also likes shoelaces, he also likes, he does sometimes also mouth things that he, you know, like he’ll have, sometimes like I buy him extra shoelaces that are specifically just for him to like stim with or chew on rather than, you know, taking someone’s shoelaces out of their shoes [*laughs*]. So he … he, yeah, so those are all kind of ways that he like engages with stuff and the way he stims.

**Interviewer:** And then when you were talking about food you mentioned that sometimes he will try to eat things or like have like oral stimulation from things that are not food. What nonfood objects does he seek out?

**Interviewee:** [00:06:15] Pretty much everything [*laughs*].

**Interviewer:** Ok.

**Interviewee:** You know, if he’s outside he would like pick up a blade of grass or a leaf and like eat it. He’s … we’ve called Poison Control numerous times [*laughs*] and obviously we have to lock up medications really well and cleaning supplies and stuff like that, because he wants to taste *everything*. Like he would, you know, he would drink, like he would drink cleaner or put it in his mouth to taste it. He is, you know, again if we were outside, a stick or, he would put it in his mouth or … Toys, so we get him a lot of toys, there are a lot of stim toys that are for like intense chewing and I try to get him a lot of those. He *mostly* likes those, but maybe it’s not as fun if they’re made for that [*laughs*].

**Interviewer:** Absolutely.

**Interviewee:** He also does things with food too, like he’ll, he’ll dip something in food, you know, like a stim toy, which is fine, I try to encourage that as opposed to like, you know, a wash cloth or a shoelace because that’s kind of gross [*laughs*]. But I’ve definitely learned to, I’ve calmed down a lot because I used to go like, “*Oh my god what is he eating?*” But now I’m like, “*Well it’s not toxic and it wasn’t on the ground outside so* …” [*laughs*].

**Interviewer:** [*laughs*] Absolutely.

**Interviewee:** Over the years … most definitely … I’ve become desensitized a little bit [*laughs*]. So over the years I’m just like, “*Oh, ok* …” [*laughs*].

**Interviewer:** Yeah.

**Interviewee:** He’s not going to die or choke on it or be poisoned, it’s not been, you know, he didn’t pick it up off the street [*laughs*].

**Interviewer:** [*laughs*] Absolutely. And then does your son have any sensitivities or interests regarding smell?

**Interviewee:** [00:08:17] He does like to smell things but not … it’s not like, I don’t think that’s one of his more intense sensory-seeking things, but he does like to sometimes smell things, like he’ll pick up food and smell it or if an item … he used to do it more when he was smaller, like he would pick up like random things and part of it, he’d smell it, he’d taste it. He isn’t doing that quite as much as he used to, but he definitely used to do that more.

**Interviewer:** And was it like all things or like particular things?

**Interviewee:** I think it was all things but then, I’m trying to remember, I know there were some things that he liked the smell of more and he would like, you know, like certain, I think chocolate was one of them, like he would like, he would kind of taste it but he would, you know, also like smell it a lot instead of, or he’d like eat it, he’d take a bite and then smell it. And I’m trying to think if there were other things … I think in that case it was mostly food that he seemed to like the smell of.

**Interviewer:** Yeah, got you. And then in general, you’ve kind of alluded to this, but how does Aiden or how do you help him like manage these preferences and sensitivities?

**Interviewee:** [00:09:40] Mainly by, mainly by just kind of trying to encourage him to do things that are safe, you know, like chewing on things that are meant to be chewed on or that are safe to chew on. Stuff like that, I mean because the main thing, you know my main concern is obviously like the danger, danger and hygiene too, like I have to keep an eye on him outside if he drops a string he’s playing with, I have to like take it from him until I can wash it because he would like put it in his mouth again. So things like that can be … you know, I have to keep an eye on stuff like that.

**Interviewer:** Yeah, totally.

**Interviewee:** And it’s hard for him, like sometimes he’ll kind of know not to do it and I’ll explain to him like, you know, you can get really sick if you put something in your mouth that fell on the ground outside because there’s things that we can’t see and it can make you sick. And he kind of understands that but he has a hard time with controlling his impulses. Like, you know, he’s like, “*Ok I dropped it, I picked it up, I’m playing with it, it goes back in my mouth, right?*” Like, he won’t think about it.

**Interviewer:** Totally.

**Interviewee:** So, yeah.

**Interviewer:** And then for the sounds, does he ever use headphones to help kind of control his like auditory environment?

**Interviewee:** [00:11:01] He won’t wear headphones. He doesn’t like the, there are certain … certain kinds of clothing and things on his body that he *doesn’t* like and that’s one of the things, he won’t wear things over his ears. You know, he won’t wear hats or gloves or anything. So yeah, he actually, he won’t wear headphones.

**Interviewer:** Got you. What about in the winter when it’s really cold? Will he wear a hat or gloves?

**Interviewee:** No. He just takes them off and throws them. So yeah, a lot of times, I was … I would like drive him to school and go thank goodness I’m driving you and you’re not waiting outside for a bus because [*laughs*], you know, after like going through like, you know, five dollar-store hats in a week just so I could feel better about him wearing a hat, I was just like this isn’t working. He won’t leave a hood or a hat on. So he doesn’t, he doesn’t like things on his head or his hands.

**Interviewer:** Got you. I don’t really like hats either, so I understand [*laughs*].

**Interviewee:** Yeah, I don’t usually wear them either [*laughs*].

**Interviewer:** And has your son ever received any specific interventions or therapies to help him with his sensory needs?

**Interviewee:** [00:12:20] Yeah just OT [occupational therapy] again, you know, and just kind of finding things that kind of help him self-regulate. Like stuff, you know, stuff that he can chew on, stuff that he can, you know, manipulate with his hands that, you know, kind of the same stuff as I’m doing because like the main, you know, the main thing is kind of making sure he doesn’t, you know, do anything dangerous.

**Interviewer:** Yeah, totally. Do you think this OT helped him?

**Interviewee:** I think a bit. I mean it’s, you know, it’s challenging to kind of find things that he really likes, that he’s willing to accept as a substitute for something that he really wants to stim with. But he also, he, I think he also got a lot out of the movement stuff, like, you know, using the swings and stuff like that. Because he really likes, he really likes, he does like motion a lot, like he likes being in the car, he *loves*, *loves* swings, and now it’s a challenge to find him a swing, places that have swing sets because he’s like six foot three [*laughs*].

**Interviewer:** Wow! That’s tall!

**Interviewee:** Yeah! [*laughs*] So now I have to try and find *really* big … some of them are big enough to support an adult but … [*laughs*].

**Interviewer:** It’s really challenging. And then in general, how have his like sensory sensitivities or sensory preferences changed as he’s gotten older?

**Interviewee:** [00:14:06] I would say … I would say they haven’t changed a whole lot. He’s just … he’s a little bit … he does certain things a little bit less, like he knows that, I don’t know if it’s because, part of it is because he has a better understanding of what’s dangerous and what isn’t. And I really thing that’s what it really comes down to, is that, you know, because there have been a few times where he actually, like he’s had to, he’s actually gone to the ER [emergency room] a couple of times and he doesn’t really … *mind* that for the most part, but like he thinks that’s like an adventure, but I’ve explained to him like, you know, “*You could really really get sick or you could die from eating something you’re not supposed to, like if you got into something really toxic*.” So he, he does, he does understand when I explain things like that to him. But, you know, you have to keep doing it because his impulses and his compulsion make it hard for him to like, “*Oh my god I have to taste that*,” you know, and he’s not really thinking about, “*Oh, what is that, is that a cleaning supply*?” So we’ve kind of … so I think he’s getting, he’s starting to get a better understanding of safety in general and he understands things like, he understands that cars are dangerous, if you’re crossing the street you have to look out for cars, you know, whereas when he was younger, he would, for example, he would like bolt out of somewhere and just run into the street without looking, and now he has an understanding of like, “*Oh, you know, wait a minute*” [*laughs*]. So he, yeah, so I think a lot of it has to do with his understanding of danger.

**Interviewer:** And so, will he try to eat, will he eat fewer dangerous items now, as opposed, is that what you’re saying, or does he understand more now when they are dangerous?

**Interviewee:** [00:16:19] A little bit of both. And then also, another piece to that kind of I think is also of course we’re, you know, we’re having to adapt, we’re, you know, we’re making sure we keep things away from him that are dangerous. Luckily now that he’s as tall as he is, he’s less, he gets into less, because, oh my gosh, if he was as tall as he is when he was doing the stuff that he was doing when he was little I don’t know what we’d do [*laughs*]. So luckily he’s gained some maturity around that and we, you know, we’re overly, I’m overly [*inaudible* … ] I try to, I just basically switched to cleaning supplies that are entirely nontoxic so if he did get some I wouldn’t have to, you know, call Poison Control, and just kind of keeping things locked up. So I think it’s a combination, but I think, he *has* matured, and I think part of like somebody maturing in those ways, like when they, with him especially, like understanding, part of it is *removing* things that he has a hard time with his impulses, like removing the things so he’s not experiencing it and then when those things are kind of removed it kind of helps him to cope. Like I kind of have to meet him halfway and not just expect him to, you know, necessarily understand, “*Ok, you know, I shouldn’t drink bleach*,” you know [*laughs*].

**Interviewer:** Absolutely, absolutely.

**Interviewee:** So yeah, so I just think all of those factors kind of work together, like having, like us being careful and keeping things away from him has helped him. Once he can feel successful, like, “*Ok, I’m not doing that anymore*,” because, you know, “*I’m not seeing the stuff but I’m not getting, you know, people aren’t panicking because I’m not drinking weird stuff anymore*,” then he kind of understands, “*Ok*.” If that makes sense.

**Interviewer:** I think so, thank you. What about smells though, you said that he doesn’t tend to smell things as much? Has that changed?

**Interviewee:** [00:18:34] Yeah, it seems like he just, yeah it wasn’t super pronounced like his other sensory interests, like it never was, but I did notice him doing it more when he was younger and just kind of not doing it as much.

**Interviewer:** Got you. And then these changes that you just described, do you think they’re related to any independence that he’s gained over time?

**Interviewee:** [00:18:57] … *Possibly*, I think, yeah, like I think maybe like what I was talking about a few minutes ago was … where he’s gained independence, you know, because the things that he, that he has a hard time controlling his impulses around are kind of removed, so he’s not constantly surrounded by things that make him want to, to … do whatever those things are and therefore, you know, he … so when he’s not *forced* every day to like control his impulses I think it helps in general with the big picture of impulse control.

**Interviewer:** Totally. Yeah, absolutely. And then when your son is in a scenario where either he isn’t able to do the sensory things that he needs to do or he’s, yeah, so if he’s ever in a situation where he’s not able to do the sensory actions that he needs to do, does that cause or increase anxiety for him?

**Interviewee:** [00:20:01] … It can to some extent but I don’t think in a huge way because for the most part, for the most part at home we don’t restrict anything that he does as long as it’s not dangerous or, you know, dangerous or, you know, doesn’t hurt or bother anybody else. And he does kind of have an understanding of, like when he’s, when we go outside he’s more, he stims and we allow it, but he’s a little bit more low-key and kind of paying attention to his surroundings, so I think … yeah I think so. I think he… yeah, I think he’s … yeah, so I think that’s kind of helped him in that regard, yeah.

**Interviewer:** And that small amount of anxiety, what does that look like for him when he does experience it?

**Interviewee:** Sometimes he, he’ll, he gets a little bit tense or he, very often when he’s feeling super anxious he wants to bolt. So we have to like, you know, make sure he doesn’t take off running or … or sometimes he’ll kind of like tense up or like squeeze one of our hands or bite his hand, which he hasn’t been doing that much of lately, really at all. But yeah, a lot of the time if he gets *really* upset he’ll sometimes like grab my arm or grab my husband’s arm kind of hard and we have to tell him like, “*That hurts!*” He’s not really, he’s not trying to hurt us but he’s just trying to like show us that he’s like frustrated or that he’s trying to contain himself and hold himself together kind of.

**Interviewer:** Yeah.

**Interviewee:** So that’s usually a [*inaudible …*], you know, that we need to like take him some place quiet or kind of separate him a little bit and let him, you know, go off by himself or, you know, with one of us making sure he’s ok, but, you know, kind of distance himself a little bit from whatever the situation is that’s causing it, that’s stressing him out.

**Interviewer:** And has that changed over time? Like has he always experienced a little bit of anxiety when he wasn’t able to do the sensory things he needed to do?

**Interviewee:** [00:22:45] Yeah, but I think … I think over time, you know, I think he’s kind of matured about it because he’s become less anxious in certain situations like at school or whatever. And I’ve talked to them as well like and said, you know, there are certain things I think he should be *allowed* to do. I think when he was smaller a lot of the therapists and ABA [applied behavior analysis] people who worked with him at the school were very much like, you know, “*Quiet hands*,” and that really stressed him out like it would any autistic kids, because they need to stim in order to … they can, a person can stim and actually have an *easier* time listening, whereas people would act like, “*Oh, well he’s not paying attention if he’s looking at a string or flicking fingers or something and not looking directly at me, oh he can’t be listening*.” And that would cause him a lotmore stress and anxiety, you know, when people are trying to make him not stim. And as he got bigger I think, it seems like a lot of the people he was around were less, they seemed like they got a little bit, people seemed like they got a little bit less rigid with that. You know, there are still some people who work with autistic kids, that are like, you know, “*Quiet hands, don’t* …”, you know, if they’re walking down the hallway and they’re stimming, they’re like, you know, “*Oh, put your hands in your pockets*.” That kind of thing was *really really* distressing to him when he was little and … and I think as he got older, or maybe he just lucked out and got some better staff working with him. But he also got a one-to-one, which helped as well because he was bolting a lot and his one-to-one when he’s really having a hard time can like walk him out of the classroom for a bit and give him a break. They had a, the school he was at actually built a sensory room, which was pretty cool because it was kind of designed for that, like for kids to go where they feel really overwhelmed or when they’re, you know, with like crash pads and stuff they can jump on and [*laughs*] stuff like that. So yeah, having breaks like that definitely helped and being able to, you know, have sensory breaks and kind of get away from the situation if he needed to. So yeah, yeah. So I think a lot of that has to do with how he’s calmer now, but he still, he hasn’t, he’s not, I mean he’s changed a bit because he’s older, but I mean he still does a lot of that stuff and he’s not, you know, made to feel bad for it.

**Interviewer:** Totally. And then thinking a little bit towards the future and a little bit like more generally, what goals or hopes do you have for your son in terms of his sensory needs and sensory preferences?

**Interviewee:** [00:25:51] I mean kind of the same as I was saying, like having him be able to do things that make him, to regulate his body, knowing how to advocate for himself and also knowing, but knowing how to not bother other people, you know, doing things that are more acceptable – and when I say acceptable, I mean, you know, things that don’t bother anybody – if he’s … so I want him to kind of be able to be himself and just kind of have that understanding of … you know, what’s ok and what isn’t in terms of – and again, I think I bought this up with my other kids, but how to advocate for himself to like, “*What I’m doing is ok, the way my body moves is ok, there’s nothing wrong with me*.” But also kind of being aware that ok, you know, some things could be, could bother other people, but the only time it’s not ok is like if you’re literally, you know, like if you’re making a lot of noise or, you know, something like that. But otherwise, you know, otherwise it’s all good and that, you know, the way he moves his body is not wrong or he’s not damaged or … [*laughs*]

**Interviewer:** Totally.

**Interviewee:** You know, because I feel like a lot of, a lot of what they, what kids hear when they’re, like what my kids were hearing when they were younger – and I mean it still depends on the people who work with them – but, you know, it was that you need to make your body look more “normal” and not stim and not do these things and kind of pathologizing all these behaviors, like sensory-seeking behaviors, when really I mean it can just be *channeled*. It’s the only thing, you know, as long as they can coexist with other people, it’s fine.

**Interviewer:** Absolutely. Thank you for sharing that. And moving on to our next chunk of questions again, so thinking about community, as your son has grown up and aged, how has his and your community reacted to his sensory needs? Which you’ve kind of alluded to already, but …

**Interviewee:** [00:28:13] Yeah, yeah. I don’t really … think … I mean he goes out and people, you know, well he goes to school, but he also, you know, just going out and interacting with people he works with or going out into the community. I think people are kind of used to seeing autistic people now and it’s not, it’s not as … I think as a whole, I mean people always will look at people and people … but I think as a whole it’s becoming more acceptable and I think it’s because there weren’t as many autistic or otherwise disabled people going out into the community and just doing things as there are now. Like there’s a lot more services that are aimed at that, you know, if it’s like keep your autistic kid at home because you’re, I don’t know, ashamed of them or whatever. Like a lot of people use to just kind of, you know, have their kid stay at home all the time or put them somewhere, which I don’t understand how anyone can if you have a choice but … So I think people are kind of more used to seeing that now because I’ve seen people kind of like look if one of my kids makes a noise, if Aiden makes a noise or something, and then they’re just kind of like, “*Oh ok*,” you know, and they … There’s not as many people who kind of like stare or who make remarks, so I feel like as a whole, you know, experiences in the community, I think people have been pretty accepting, yeah.

**Interviewer:** That’s great.

**Interviewee:** You know, I occasionally get people, you know, saying things like, “*Oh, you know, I don’t know how you do it*,” and it’s just like, you have kids you take care of them, like whatever they need you do it to the best of your ability. Like, you know, how do I not do it? [*laughs*]

**Interviewer:** It’s what you sign up for by being a parent [*laughs*].

**Interviewee:** Yeah [*laughs*]. Like I can’t *not* [*laughs*]. I mean I could, but, you know, that’s not really … [*laughs*]

**Interviewer:** Yeah [*laughs*]. I understand. Again, you kind of already answered this so I apologize if it’s a little repetitive, but was the community more or less accepting or accommodating when Aiden was younger?

**Interviewee:** [00:30:40] I think people … I think people were pretty accepting when he was younger to like when, you know, when we would go places or … yeah, I think … I think people were pretty much, you know, I sometimes explain things because when he was younger he was really, he was also really active and made a lot more noise and, you know, people would kind of stop and look because he would be like running all over the place. And sometimes I’d explain that he was autistic and people were pretty understanding in general I think.

**Interviewer:** Wonderful. I’m glad you’ve had mostly positive experiences.

**Interviewee:** Yeah [*laughs*]. I know, some of the things I’ve heard from other parents, I’m like “*Oh my god*.”

**Interviewer:** Yeah, indeed. So you talked a lot about like kind of general people in the community, were there other spaces and places that were more or less accepting, like maybe school, family, other community groups that you might be a part of?

**Interviewee:** [00:31:52] No I think pretty much … you know, pretty much everyone was … the only, like when he was younger my grandmother a few times said things, you know, she was an older person but she was, she a couple of time said like, “*Oh, well, you know, he’s going to have be in an institution, you’re not going to be able to manage him*.” And I was like, “*Over my dead body!*” [*laughs*] I mean people don’t do that anymore anyway, but even if they did I wouldn’t. But for the most part yeah, just people that we were around were … and I think a lot of it has to do with, with … with like the way we were reacting to it or somebody, you know, would kind of say something. You know, I got more people saying things like, you know, “*Oh, you’re so wonderful for, you know, caring for your kid*,” I guess, or things like that, or like, “*Oh, I don’t know how you do it*,” or “*I’m so sorry that* …” You know, like a few times like, “*Oh, I’m so sorry that your kid’s autistic*,” and I was like, “*Why are you sorry? He doesn’t have leukemia, like, you know, he doesn’t have like a terrible disease*.”

**Interviewer:** Yeah, it’s not a terminal thing [*laughs*].

**Interviewee:** Yeah [*laughs*]. So I think for the most part people are pretty decent and accepting now. I occasionally get those people who say things like that and I tend to shut them down pretty quick because, like …

**Interviewer:** Yeah, absolutely. Thank you for sharing that.

**Interviewee:** I think they, you know, they mean well but it’s, it’s, “*No, and don’t say things in front of my kid*,” that, you know, they think don’t understand because they don’t speak [*laughs*], you know, or act like, “*Oh I’m so sorry about your kid*.” I’m like, “*Why? My kids are awesome!*” [*laughs*]

**Interviewer:** Yeah, absolutely. Thank you for sharing that. And then thinking a little bit more broadly, what hope or worries do you have for how the community will continue to react to Aiden’s sensory needs as he gets older?

**Interviewee:** [00:34:11] Well one, one worry that I have, but I think he’s … like I said because he’s maturing it’s got better, but one thing that I’ve been worried about a lot is that people are less understanding if they see somebody who’s big, who’s not like a cute little kid, not that he’s not a handsome young man, but, you know, when somebody looks like a cute little kid, is a cute little kid and they’re doing stuff, it’s different, but sometimes if like, for example, if for some reason, I don’t know, he got away from us and he was outside and a police officer saw him and he couldn’t comply because, you know, he doesn’t know that they’re, you know, barking commands at him. Or if they see him going in somewhere that he’s not supposed to, like I don’t know walking into someone’s yard and they think like, “*Oh there’s a six-foot-three guy in somebody’s yard*,” you know what I mean, they might not be as, somebody might react too quickly, like, “*Oh there’s somebody in my yard, shoot ’em*,” you know, or a cop throws him on the ground and, you know, because he doesn’t, he walks into somebody’s yard, for example, or something like that, and then they come and tell him to stop and he doesn’t stop or he runs because he’s scared. You know, things like that, and there have been a lot of things like that with autistic people. So it’s a little, that kind of thing is kind of scary, where people might not, might see him and not knowthat he’s autistic and just think that, you know, he’s doing something weird or he, you know. So that kind of thing bothers me, that scares me, you know, and worries me.

**Interviewer:** Absolutely, thank you for sharing that. You are not the first parent to express that worry, so for better or for worse you are not alone in feeling like that.

**Interviewee:** Yeah, I think a lot of us are, you know, it’s something you have to worry about when they grow up and they start looking like adults.

**Interviewer:** Absolutely. We’re going to move on to our next chunk of questions again. So in the like transition to adulthood, where do you see Aiden?

**Interviewee:** [00:36:26] Well he’s, I mean he’s still in school, although it’s remote right now, but I think he’s … I think he’s making a lot of good progress and, you know, it will always depend on who his support people are, but he’s … Yeah he’s making good progress. He gets, you know, he gets some services so he’s getting the experience of getting to go out into the community and do things and I think that’s really helping him in general with kind of knowing how to act where and that sort of thing. So yeah, I think, I mean it’s hard to say now like once, as he, once he’s transitioning out of school like what things will look like, or … you know, it’s a little hard to say like what outlook I think we have. I mean I think as always it depends entirely on like support people and what kind of, you know, what kind of supports we have, like who’s around him. And it’s easier, like it’s, the good thing is since he does live at home and since we’ll be helping him, you know, coordinate services and stuff, like with his input, but we can kind of ensure as long as we’re alive and he’s living with us, we can kind of ensure that, you know, that the programs or services that he gets will kind of meet his needs. Anyway, I’m kind of babbling …

**Interviewer:** That’s ok.

**Interviewee:** He’s, but yeah he’s, I feel like he’s definitely making progress. He’s in high school and he’s, things are of course weird right now because, you know, he hasn’t been in school since March, so we’re doing remote learning. But overall, you know, he’s growing up, he’s making progress, and he’s maturing in ways and gaining, gaining a lot of understanding of himself and how to kind of, he’s kind of learning how to advocate for himself a bit and having his like different communication, his ways of communicating be honored and I think is helping him a lot as well. You know, like he types, he gestures, he bring us to things, he shows us things, so … yeah, I don’t know if that really answers the question.

**Interviewer:** No that’s great. I’m going to ask some follow-up ones so that was great, thank you. Could you talk a little a bit about like his like stage of independence, like what are things he’s able to do independently and what are some things that he needs some support with right now?

**Interviewee:** [00:39:35] He pretty much needs support with everything. You know, he has a PCA [personal care assistant] who comes and helps him with like dressing and showering and stuff. He does use the bathroom pretty much independently now, which is good. And … he can do a lot of things that we, like, he needs somebody with him just to kind of make sure he’s ok and he’s safe, but he’s able to do things like, for example, if his, his support worker takes him to the store, or my husband takes him to the store, he can walk in and they just kind of hang back a little while he picks out the stuff that he wants, so he can kind of do that and he knows to bring it up to the cash register, he knows he’s supposed to give them some green paper [*laughs*] and like to wait for change. So those are things he can, I mean I’m not … he needs a support person there to make sure that he’s safe, but he pretty much can do those, like he knows what to do and he can pretty much handle those things himself.

**Interviewer:** Yeah, totally. Is he able to … Oh, I’m sorry, go ahead please.

**Interviewee:** Oh no it’s ok.

**Interviewer:** Sorry. Is he able to with support like maybe like make his bed, or like help take care of his physical environment?

**Interviewee:** [00:41:10] Yeah, with, if he has prompting he can do that, if he has … like he’s been like wiping up spills, or if I ask him to like wipe the table he’ll do it, or throw, you know scrape his plate in the garbage, he will do it if he’s asked to. He doesn’t like, he doesn’t tend to do it on his own but he’ll do it if he’s asked.

**Interviewer:** Got you. What about like food or like simple meals, is he able to with support kind of prepare things for himself?

**Interviewee:** Not really no. He comes in, like he’ll go into the kitchen and show us the things that he wants. Like if he said, you know, “*I want* …” he’ll like point to the bread and point to the peanut butter and point to the jelly and the toaster if he wants, you know, if he wants it toasted. He’ll like tell us all the stuff that he wants and he kind of knows how to do that, but he doesn’t really make it himself.

**Interviewer:** Got you. And then through the school program that he’s in, have they helped him with like any job skills or things like that?

**Interviewee:** [00:42:21] To be honest they haven’t really been doing much of that with him, because something, actually one of the things I wasn’t really happy with, they were doing things like having him sort things and it’s just like … that’s just such a, what is that skill for? [*laughs*] And I think, you know, I’m hoping that, I don’t know what they have at the school he’s going to go to when he does go back to school, but I’m hoping they have more things like that, because he could definitely learn. Like the other kids were, he went to the same high school as his brother and, you know, Devlin and some of the kids were doing like learning car detailing and custodial work and it’s like Aiden could do that, I mean he needs support but, you know, I think it would be nice for him to learn how to do that. So even with support, even if he can’t do it independently enough to do it, you know, to do it as a job, it would still, you know, those skills can be carried over into other areas and, you know, I think it would kind of boost his self-confidence as well to be able to, you know, to complete those tasks.

**Interviewer:** For sure. And then in the scenario you described, him going to a store, knowing how to bring things to a counter and give money, does he understand money beyond that kind of like mechanical, like that logistical process?

**Interviewee:** [00:43:50] I’m not sure how much he really understands about money except that it’s something, like he kind of understands that it’s something you trade for items and that you need it to go to a store to get items. I’m not sure like how, how much he really understands about that, but he seems to have an idea, he does seem to have an idea about how much things cost. Like sometimes if we say, “*Ok, you have ten dollars*,” he’ll get, if we actually tell him, “*Ok, we’re working with this amount of money right now*,” he will very often like know to, he’ll get like a lot fewer things and usually it will come to under ten dollars. Like he seems to kind of understand that so …

**Interviewer:** That’s awesome.

**Interviewee:** Yeah, so he has some understanding and he has some understanding of like math and how much, you know, “*Do I have enough to buy this?*” and “*Oh this is what I’m working with and I know these items are, these three items would come to less than ten dollars*,” you know.

**Interviewer:** Absolutely. And then does he have friends through his school or maybe even not through his school?

**Interviewee:** [00:45:08] No, he doesn’t really, he seems to prefer interacting with adults. You know, like he likes to hang out with his teachers, he likes his one-to-one, and he doesn’t really seek to hang out with other kids, sometimes his brother, but other like classmates and stuff he doesn’t really seem to have much of an interest in.

**Interviewer:** Got you.

**Interviewee:** [*inaudible …*]

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

**Interviewee:** I think so, yeah. I mean I think he’ll, I think he’ll always need support but oh definitely, I definitely think given more opportunities that he will, yeah.

**Interviewer:** Yeah and what do you think will help move him into this increased independence?

**Interviewee:** [00:46:03] Having people, you know, having support people who kind of … explain things to him and guide him through step by step and then say, “*Ok, you do it*” [*laughs*]. That’s the kind of thing that seems to help him along. And his, like his one-to-one … is … you know, a lot of the time it kind of worked out that he has this kind of super-laid-back personality and he would just kind of be like, “*No, you do it*,” you know, “*You can do that*.” And Aiden would be like, “*Oh, ok*,” and then he’d do it, you know, like [*laughs*], he’d be kind of like … so having people that are like, “*You can do that, do it*,” you know, “*Give this a try*.” Explain it to him and walk it, and if he has trouble with it of course you might have to go back a few steps, but that’s really, that’s kind of really the best way to … I think with, having people that know how to do that will be kind of the key to him being more independent.

**Interviewer:** Totally. Other than these support people who are like giving, you know, like gentle pushes, with scaffolding, do you think that there are other services or interventions that could help him?

**Interviewee:** [00:47:23] Again … I still think OT could address sensory needs and some skills like fine-motor skills and things like that. I don’t think, I think that and just, you know, having supportive staff, I think that’s kind of, out of the things that I know about, I think those are the main things that would help him, yeah.

**Interviewer:** Yeah, wonderful, thank you. And now putting these two things together – his sensory preferences, sensory needs, and his transition to adulthood – how do they intersect for Aiden?

**Interviewee:** [00:48:09] … This is the one I always get stuck on [*laughs*].

**Interviewer:** I can rephrase it, do you want me to rephrase it again?

**Interviewee:** Yeah, for some reason I, this one really throws me.

**Interviewer:** It’s ok, no, that’s totally fine, totally fine. How do Aiden’s sensory needs or sensory sensitivities, how do they impact his transition to adulthood and transition to independence?

**Interviewee:** I think … I think that his impulsiveness could make certain situations kind of difficult for him and … sometimes it’s a little bit hard for him to … sometimes it’s a little bit hard for him to kind of stay focused on things so I think, you know, because he gets distracted by things. I think … but I think a lot of it has to do with … with the people that he’s around, because if he, I think it could have, I think if he feels, if his sensory needs feel restricted he has a much tougher time and therefore makes less progress. But if his sensory needs are met and he’s allowed to meet those needs safely, that he, he, you know, that he’ll be a lot more successful, like he feels more accepted. Like I’ve noticed that with remote learning, with being at home all the time, even though he’s bored and I think he misses some aspects of going to school, I’ve noticed a lot less destructive and self-injuring behavior, which is … so I think, you know, certain situations stress him out a lot, so it’s … but if he kind of feels like he can meet his sensory needs and even though we’re, you know, we do have to place restrictions for safety reasons on certain things, overall kind of feeling accepted and being allowed to do whatever he needs to do to self-regulate, I thing that’s everything. I think that kind of … I that’s kind of the key to his success, I think that’s kind of the way he … I think that’s what will impact … the way he, you know, his ability to transition to whatever he has to do, you know, whatever program or situation he’s in or takes up. But he’s in general a lot calmer and therefore more able to function better.

**Interviewer:** Absolutely. I’m going to ask two follow-up questions if that’s ok. That was a really wonderful answer. Do you, do you think that he uses, like he engages in these sensory-seeking behaviors when he is stressed and that’s kind of the way that he kind of like manages that stress?

**Interviewee:** [00:51:48] Yeah, but it’s also, it’s a combination really. Like when he is using, he also uses them just to kind of regulate himself and some of it, a lot of it’s just very calming and self-regulating. But when he’s under a lot of stress I notice a lot more impulsivity … like he does, you know, he’ll grab things and put them in his mouth or he gets this compulsion like he has to grab certain things that he knows he’s not supposed to or he gets more destructive, like he likes to tear things up. Like a year ago he was tearing up his clothes, like on the regular, like I had to buy him all new clothes because he was like ripping up all of his shirts and he had like a wound on his hand near his thumb at all times because he was like biting his hand. And I think, yeah so I think … I think they’re a little bit of both but I think things can get kind of – sorry that’s a notification on my screen it’s driving me crazy – but yeah I think … so I think they can be both, but I think mostly they’re calming if he’s allowed, you know, in general. But yeah, he definitely gets, they can definitely be, they can definitely lean toward like destructive or dangerous if he’s under a lot of stress also.

**Interviewer:** Got you, no that makes sense, thank you. And then in the beginning of your answer you said that sometimes his impulsivity can make things difficult for him, what do you mean by difficult?

**Interviewee:** [00:53:55] I think because he knows, like he knows that he’s not supposed to do certain things and on some level he might know that it’s like destructive or dangerous … and so, you know, it kind of becomes like a cycle I guess.

**Interviewer:** Yeah, that makes sense, thank you. And then would you consider his like sensory needs and sensory sensitivities an obstacle, a vehicle, neither, or both towards his independence?

**Interviewee:** With him I’d say both, a bit of both. You know, depending on … I think kind of depending on how accepting people are around him and how much he’s allowed to do the things that he needs to do versus kind of the stress he feels when he feels that he’s like limited or that people are, you know, not allowing him to do the things that he needs to do. If he’s allowed to do what he needs to do to kind of regulate himself, within, you know, within reason, and he’s kind of, for the most part to help ensure his success, keeping things away from him that are unsafe or that are, or that you really don’t want him to get into, once he, when he has that balance of like, you know, he’s accepted for who he is, he’s allowed to do what he wants, and the things that are really hard for him and that he kind of knows he shouldn’t be doing are sort out of reach, he feels successful and then he’s kind of able to focus and learn more. But if he’s in an environment where people are discouraging that or telling him not to do certain things, combined with, you know, “*Well these things are within his reach so I think you’re just going to have to learn how to control yourself*,” which, you know, it’s easier to learn how to control yourself when the things aren’t in your face all the time that you’re not supposed to be getting to. But I think, I think it can be a little bit of both and … you know, again depending a lot on the people that he works with and interacts with.

**Interviewer:** Totally, thank you. And then relatedly, what do you anticipate as being challenging for him as he continues to gain some independence in regards to his sensory needs?

**Interviewee:** [00:56:40] I mean I think sometimes his sensory seeking can be an obstacle because it’s very distracting to him, so that could definitely be, that could definitely be a challenge for him, you know, and having the things in place that I’ve been, that I’ve talked about endlessly [*laughs*].

**Interviewer:** That’s ok.

**Interviewee:** Having that kind of support system/environment is really needed to kind of ensure his success, but I think the, you know, I think his sensory-seeking behavior can definitely be a problem or an obstacle at times for him as well because it’s hard for him to … sometimes it can go from calming to at times like, especially if he’s under stress, to like he can’t focus because he really has to, you know, engage with things in certain ways, like either, you know, sensory, intense sensory seeking, or like kind of panicking or running off to escape a situation, or … so yeah, that’s definitely, those are definitely challenges.

**Interviewer:** You talked a lot about like community and the people who like are working with him directly. Other than those things, is there anything else that you think could help him in this intersection?

**Interviewee:** [00:58:20] … I … nothing I can think of really … except I mean, I guess his environment as well, like, you know, the … places where he, like actual places where he is allowed to go and allowed to access and stuff like that, I guess that would be something that would help him. I don’t really … and having, you know, being surrounded by, having actual *things* that help him meet his sensory needs safely.

**Interviewer:** So like the safer stim toys, so like the safer stim toys instead of unsafe food or nonfood items, is that what you mean?

**Interviewee:** Yeah, just having access to a full range of things that are safe for him to interact with, however he wants to, biting it or …

**Interviewer:** Totally. And then, again, this might not be relevant, but are there any services or interventions that you think could help him in this intersection?

**Interviewee:** [00:59:43] Not really besides, I mean, like maybe besides like OT … because they can, sometimes they can, they actually help with certain skills if there was a particular skill he wanted like for work, combined with like a sensory diet to help him stay self-regulated, and helping him kind of identifying those things, like, “*Ok these* …” that’s like really key as well, like, “*These things really help me, these items, you know, really help me to kind of stay focused and calm, and certain things are calming and self-regulating and certain things, certain stims, for example, might not be appropriate for here but when I go home* …” Like, you know, if he had some kind of job or something and he wanted like a string or something he could like squeeze or bite a little bit – but when he goes home he can like, you know, run around more, and you know what I mean, and kind of be less inhibited or whatever but kind of understanding that, you know, “*Certain things are better for certain places and this is, you know, this is what I can do here*.” And kind of, sometimes you kind of have to make a compromise with yourself and other people, you know, like you might, you know, you can’t do all the things that you might do at home when you’re just comfortable when you get home from work, but when you’re at work you like, “*Ok I have to behave a certain way, I have to, you know, I don’t know, I have to, I can’t be in my pajamas, I can’t, you know* …” [*laughs*].

**Interviewer:** Exactly, exactly [*laughs*], for everyone it’s like public versus private behavior [*laughs*].

**Interviewee:** Right, right [*laughs*]. Yeah and it’s really no different, you know, with autistic people transitioning to adulthood and kind of understanding, you know, like I don’t want them to feel like, “*Oh, I can’t be my authentic, autistic self in public*,” but there has to be like a balance, like, you know, you can’t be walking around shoving shoelaces in your mouth, you know. But if you have some at home and you really need to do that when you get home, ok, you know [*laughs*].

**Interviewer:** Absolutely.

**Interviewee:** But it would be like, you know, things like that, it’s kind of, there’s just a different version for everyone, but, you know [*laughs*].

**Interviewer:** Absolutely.

**Interviewee:** It’s not really much different.

**Interviewer:** Not at all.

**Interviewee:** [*inaudible* …]

**Interviewer:** Yeah … and then, sorry?

**Interviewee:** Oh, it’s the same concept [*laughs*].

**Interviewer:** Yes, exactly. And then, for kids like Aiden, do you think there are any gaps in the available services or interventions?

**Interviewee:** [01:02:43] Again it’s a little hard to know with, like with adult services, because I haven’t, I don’t have the full like range of experience with that yet, but just autism specific, I do … like we’re lucky that he’s also in the DESE [Department of Elementary and Secondary Education] program through DDS [Department of Developmental Services] so he gets some at-home services. I *would* say, I guess one thing I guess is that with something like that where you can have a direct support worker, you don’t have to have somebody who’s ABA, so you can kind of pick someone who, you know, like if you have to have, some things like the Autism Waiver Program for younger kids you have to have somebody who has ABA training, so you kind of have to use ABA even if you’re not that, you know, you’re not in favor of a lot of things that they do. But with this you have more flexibility to kind of work on specific things. Because the whole idea is to kind of keep, to make it so that people with certain disabilities can like … don’t have to go into a group home but can live in a community more easily, so that’s a lot of the goal, and we’re super lucky and I know a lot of people, it’s not, you know, I think there’s a wait list for it, and I think that this could help so many people having that kind of service where, you know, you design a specific plan, you know, it’s kind of like a mini-IEP [individualized education plan] kind of thing, where you say, “*Ok, these are some goals that we need to work on*,” they’re very specific, and you can hire anyone that your kid, that you know, that you choose. You know, so if you have somebody, even a friend or family member that your kid really likes and that works well with your child, you can hire them. So I think having that flexibility instead of like, you know, it *has* to be a very specific intervention and you have to pick somebody from some agency that you don’t know, so you don’t know how well they work with you child and, you know. So we’re lucky that we have this but I wish more people were able to have access to services like this. Like everyone should be able to get this.

**Interviewer:** Absolutely.

**Interviewee:** So yeah, I think, yeah to answer that I guess there are gaps and we’re very lucky that we’ve had, you know, both of my, two of my younger kids are on this program.

**Interviewer:** That’s awesome.

**Interviewee:** Yeah and it’s just by luck I guess because it’s a wait list, not a wait list, it’s kind of like a lottery I guess, but somehow we lucked out.

**Interviewer:** So it really is luck then! [*laughs*]

**Interviewee:** Right [*laughs*].

**Interviewer:** Well I’m glad you’re able to have those supports for your family, that’s wonderful.

**Interviewee:** Thank you yeah, they are good. I wish, like I said, I think things like this would really help, you know, having somebody, being able to have people that, of your choosing to work with you child and go out into the community. I mean that would be such a great thing for like everybody and probably cheaper than ABA too.

**Interviewer:** Yeah, totally. That’s wonderful. And then thinking a little bit more broadly … sorry did I cut you off? Were you going to say more?

**Interviewee:** [01:06:34] No, I was just going to say, so I think one of the gaps was like not having a choice, like if you want help for your kid to help them with certain skills it *has* to be ABA because insurance will cover that, but a program like this, it doesn’t necessarily have to be.

**Interviewer:** Awesome, no thank you. I’m sorry I cut you off, that was important.

**Interviewee:** Oh no, that’s ok.

**Interviewer:** Anything else before I ask my next question? I don’t want to cut you off again [*laughs*].

**Interviewee:** Oh, no, no [*laughs*].

**Interviewer:** Ok, thank you. And then thinking broadly, how have your son’s sensory needs impacted your goals, hopes, and expectations for him as he navigates adulthood?

**Interviewee:** [01:07:25] It’s funny, I don’t know that I’ve really given it a lot of thought, just because … he’s … he’s always been who he is so I’ve always just been kind of thinking like as he goes, what does he need, but I haven’t really given a whole lot of thought to how they actually … impacted those goals, you know what I mean? I just was kind of like we have to work around them and we have to find the right people to work with him when need be … so yeah, I guess I haven’t really [*laughs*] given it a lot of thought.

**Interviewer:** Yeah, no that is totally fine, thank you. Then moving into our last chunk of questions, we’re almost done. As a caregiver, as a mom, as a parent of someone with autism and some sensory needs, what does transitioning to adulthood mean to you?

**Interviewee:** [01:08:27] Basically, you know, learning how to … I guess learning how to, how to advocate for himself and learning how to … ask for accommodations that he needs or … I think that’s kind of the main thing. With him, I mean, there are going to be other things along the way and we don’t know, I don’t know yet like what the services will look like. You know, of course I would like to see him with, as with my other kids, like gain as much independence as possible. I mean even knowing, I don’t think that, you know, I think he’ll always need support, which is totally fine. But kind of having, you know, just kind of gaining the skills and having people say like, “*I have confidence in you that you can learn these skills*,” and kind of giving them little pushes here and there to get them to be as independent as possible and to make, to be able to make decisions that are, being involved in decision-making, kind of throughout their lives is … I mean as children a lot of the time we don’t think about, you know, you just kind of, you know, you kind of pick their school, you think, “*Oh this doctor seems good*,” you pick their doctor, you enroll them in things. And then as, transitioning to adulthood, I mean I’m not saying I, of course I ask them if they’re interested in things, but, you know, you kind of do a lot more for your kids when they’re little and then as they grow up and they transition to adulthood more and more it’s, there’s a lot of, you know, like “*Ok, wow, you’re actually an adult and I need to really really involve you in all this stuff*,” and, you know, things like where a doctor, for example, would like talk to me, I would say, “*Well talk to him too because he needs to hear*,” you know? [*laughs*] And explain things to him and kind of advocating for people to talk directly to him in different scenarios. So I think, yeah, it’s also kind of him kind of taking on those things too. You know, kind of being able to take on those things, so being able to think, “*Oh, ok so the doctor is also going to talk to my mom and to me about my checkup or my health needs or whatever*,” you know. So yeah, just kind of getting, transitioning to me means self-advocacy and learning how to become part of the conversation, which, you know, getting more involved and saying, “*Hey, I have a say here even if I don’t speak, I have a say*,” and, you know, and just making sure that they’re more involved in all aspects and making sure that they understand that they have choices and they have, anything that they want or don’t want that they express is going to be honored.

**Interviewer:** Absolutely.

**Interviewee:** Not that it wasn’t, not that’s it’s not when they’re children, but I mean making them really, more, yeah just more active and involved in their care [*laughs*].

**Interviewer:** Totally. Has this perspective changed over time?

**Interviewee:** [01:12:10] No, I think I wasn’t thinking about it as much, you don’t think about it as much when they’re little, but then as they’re growing up you kind of start realizing that like it’s going to look different or if you have a kid who isn’t disabled, they just naturally, they grow up and they start making their own decisions and when they are you kind of realize, “*Ok, I have to* …” Some parents just say, “*Oh, I’ll just be their guardian and I’ll just make all the decisions and they don’t have to be involved*,” but I feel like it’s more important, like it’s part of their growing up. They know, “*Ok, I’m growing up*,” and I’m saying, “*No, I want, I want, it’s important that you understand that you* …” In other words you have to consciously involve them instead of just going, “*Oh, I’m just going to continue* …” you know, instead of treating them like they’re always children, you have to kind of more actively involve them in like all aspects of like their care and making decisions, medical decisions, any programs, or “*Do you want self-directed care? Are you interested in working with an agency or going to a program during the day?*” You know, “*What do you want to do?*” kind of thing, so … [*laughs*]

**Interviewer:** Thank you. And then a little bit more specifically, what do you see happening in Aiden’s future?

**Interviewee:** [01:13:45] I … don’t know for sure. You know, he’s, he’ll live at home as long, you know, as long as he wants to. You know, I definitely see him … I think he could do some kind of work or some kind of program as long as, you know, everyone could try different things and see what works best for him. I think, I mean he definitely with people who he works with there are certain people that he really has a bond with so he definitely forms relationships with people. So … yeah, you know, it’s hard to know for sure, but, you know, he would definitely continue to live at home and I’ll have to, you know, I’ll have to look into what’s available and what, you know, what he wants to do when he graduates.

**Interviewer:** Awesome. So you first see him finishing his school program?

**Interviewee:** I think so yeah. You know, we’ll see what the school’s like in North Adams, like what … and yeah, you know, unless it’s a really crappy program and he doesn’t like it … [*laughs*].

**Interviewer:** I hope not [*laughs*].

**Interviewee:** Yeah I hope not too [*laughs*]. But yeah if he likes it, if he’s happy there … he’d be eligible for service until he’s twenty-two so.

**Interviewer:** Absolutely. And then last formal question, how have, if at all, how have your son’s sensory needs impacted this perspective you articulated in terms of what it means to transition to adulthood?

**Interviewee:** [01:15:35] … I don’t really know how much they have beyond like what I’ve said already, like I … you know, with regard to like … his sensory needs, I just … kind of take it day by day because I know that things are going to change, you know, he’s going to change in the next few years. There’ll be some things that might become bigger issues and some things might become less of an issue or some things will just kind of stay, you know, what they are, like things that are not really a problem but are just things that he kind of needs to be Aiden [*laughs*].

**Interviewer:** Totally.

**Interviewee:** Yeah.

**Interviewer:** Perfect. So that’s it from me.

**Interviewee:** [*inaudible* …]

**Interviewer:** No that was a perfect answer, thank you. So those are my formal questions, would you like to add anything else?

**Interviewee:** [01:16:54] No, I think we’ve pretty much covered [*laughs* … *inaudible …*].

**Interviewer:** Awesome. Thank you, this has been so wonderful to learn so much from you and to talk with you so much [*laughs*].

**Interviewee:** Well thank you.

**Interviewer:** Yeah, I appreciate how much time you’re giving us, it’s been such a great opportunity to learn from you.

**Interviewee:** Oh, thank you. It’s been good talking to you too.

**Interviewer:** Thank you. Do you know anyone else who actually might want to participate in the study?

**Interviewee:** I’m trying to think … I could ask … Oh yeah, if there’s a link in the original email I could ask like at the … the high school … you know, the … what do you call it … the … Strands specialist – [*laughs*] my brain’s fried – at the high school might want to, I could ask her if she wants to like send out an email to the other parents and see if any of them want to do it.

**Interviewer:** Sure, I can send you a flyer for that.

**Interviewee:** Oh great, yeah I can ask her and she could forward it to the parents, you know, to see if anyone’s interested in doing it.

**Interviewer:** Yeah, that would be wonderful, but, you know, again … oh sorry?

**Interviewee:** Oh no, it’s just because there’s a lot of kids, well the age group is actually, I can’t remember but it was like what, sixteen or seventeen to …?

**Interviewer:** Yeah it’s sixteen or seventeen to just under twenty-six so it’s pretty broad.

**Interviewee:** Oh ok, well there’s certainly a lot of kids in that age range so … so yeah I can give that to her yeah.

**Interviewer:** Thank you. But there’s no pressure, I mean if she isn’t comfortable distributing it that’s perfectly fine, it’s ok.

**Interviewee:** Have you also tried TILL?

**Interviewer:** No, what’s that?

**Interviewee:** It’s called Toward Independent Living and Learning, it’s an agency and they handle some autism services, and also Bay Cove Human Services.

**Interviewer:** Oh, I know Bay Cove, my … yeah.

**Interviewee:** Yeah, they’re the ones who kind of like broker the services for the DESE program.

**Interviewer:** I didn’t know that. My boyfriend’s sister works at Bay Cove actually [*laughs*].

**Interviewee:** Oh really?

**Interviewer:** Yeah she’s a nurse there.

**Interviewee:** Oh wow, oh ok. Yeah there’s actually, I think there’s a lot of different locations, but one like branch of it or whatever handles a lot of autism services and they handle the DESE program and stuff like that, so they might be … I could definitely forward, I could also, like if you send me that flyer I could forward it to the high school and see if she wants to, if she’s comfortable sending it to parents, and Bay Cove too, they might be, they might want to ask families if anyone’s interested in participating.

**Interviewer:** Thank you, that would be lovely, I will send that to you. Is there anything that I can do to help you? You’ve been so helpful for us.

**Interviewee:** Nothing comes to mind.

**Interviewer:** Ok, well if anything comes to mind let me know.

**Interviewee:** We’ve actually done, we’ve actually done quite a few different studies with you guys too and the kids have always had a great time doing them.

**Interviewer:** I’m glad to hear that. Well if there’s anything that you need, you know where to find us, so we’re happy to help however we can.

**Interviewee:** Oh thank you, I really appreciate it.

**Interviewer:** Of course. And then as soon as this audio file is done rendering I will send you another gift card as a thank you. I placed the order last week so it should be coming in any day now.

**Interviewee:** Oh great, ok.

**Interviewer:** So as soon as that’s in it will be in your inbox.

**Interviewee:** That sounds good.

**Interviewer:** Well I hope you have a great rest of your day and I hope your move continues to go well.

**Interviewee:** Thank you, yes. It will be worth it in the end but boy is it hard [*laughs*]. Especially because the house [*inaudible* …] so we’re like coordinating that and … [*laughs*]

**Interviewer:** It will be worth it.

**Interviewee:** Yeah, finding out this and you know, oh god, there’s always another thing, but yeah … [*laughs*]

**Interviewer:** I know, yeah, I can imagine.

**Interviewee:** But yeah it will be great. Ok well thanks for everything and it’s been a pleasure.

**Interviewer:** Likewise, absolutely. Bye

**Interviewee:** Ok take care, bye.

**Interviewer:** You too, bye.

**[End of transcript]**