**[Start of transcript]**

**Interviewer:** OK, OK. And I will be asking you questions about your perspective about your child’s transition to adulthood in relation to his sensory sensitivities and sensory interests, and we’ll be doing something called a “semi-structured interview,” which means I have a set of planned questions here on my script. But then I’ll also be following your lead based upon what you say, and adapting our conversation to actually fit what we’re talking about. And ...

**Interviewee:** That makes sense.

**Interviewer:** Awesome. Great. Do you have any questions?

**Interviewee:** No.

**Interviewer:** OK. And if there are any questions that make you uncomfortable or you don’t want to answer them, that’s perfectly fine. We want to make this as positive as possible.

**Interviewee:** Sounds good. Thank you.

**Interviewer:** Of course. Thank you. So for my first question, could you please start off by telling me about your child’s sensory sensitivities and sensory interests?

**Interviewee:** OK, do you want current or past history or, like, our history, just to **[1:00]** clarify?

**Interviewer:** I’ll be asking you about both. So whatever makes sense for you to start off with.

**Interviewee:** OK, so when my son was little, he was, like, the best way to describe him was always on the go. He had difficulties in that for long periods of time. Fortunately, he had access to occupational therapy services and sensory integration. And so, therefore, over time, he has gotten to a place where he can sit and attend for long periods. What I will say now, like, there is some sensitivity to, like, noise, like, for example, if, if I have, like, if I’m playing something on the radio, or, like, playing a CD—yes, I still have CDs. And if it’s loud, like, he will just come and, like, turn it down. Or, like, the radio, on the radio in the car, you know, he’ll ask because he can’t access it based on where he’s sitting. Or depending on where he’s sitting. He will ask for the radio, you know, to turn it down, what’s that … I can say, fortunately, I prompted him, like, over the years to, like, ask for that. So I’m glad that’s a mainstay and he can request for it to be turned down. I would also say just sometimes in terms of, like, I will see him you know, with his eyes closed, or, like, he’ll cover his face. Sometimes I think that it’s, like, when we’re in larger crowds, and/or if it’s, if it’s, like, bright in that area, I’ve noticed that more so now. So I still, like, if we’re out, which we’re not out as much because of COVID …

**Interviewer:** Yeah.

**Interviewee:** … but I will say that like, like, if we go to the store or whatever, because in our home environment, it is just four of us primarily. It’s my mother, my father, my son and I, and so, you know, he’s the only, you know, under-18 in the house. And so it’s for the most part, like, there’s no yelling and screaming, like, everybody’s just kind of, like, chill doing their thing. So the environment is a lot more quiet. So I think, like, when we go out into the community now, like, if we need to go to the store, because oftentimes he … with us, we go as a mom, son and I, like, go as a group. We go out on these epic grocery store or Costco or BJ runs, and, you know, it’s a little, I think, overwhelming, not just … but I mean, it’s overwhelming for me because I’m in … everyone’s in a house too. So, but that, but that has been kind of, like, what I have noticed, kind of, like, throughout the years, that it’s been primarily like that, like, the light, multiple **[4:00]** stimuli coming at him. And, like, the, the auditory. The only other thing I would say, in terms of this three in the past has been, like, challenges with his vestibular system, like, he didn’t necessarily, like, know where his body was in space, but we have, like, he went to PT, like I shared before, OT and the sensory integration. And, like, now he’s gotten, gotten older, like, with the school program, like, he has a fitness schedule that we have continued since he’s been at home. So I think, like, having those opportunities … that we do yoga every week. So I think all of those things kind of helped him to stay modulated. But it’s definitely different. You know, there’s been a huge shift. He’s not necessarily all over the place, like he used to be when he was little.

**Interviewer:** Awesome. Thank you for sharing that. I have a couple follow up questions if that’s OK.

**Interviewee:** Oh, yeah, definitely.

**Interviewer:** Awesome. Thank you. So I’m going to go down kind of in order of what you just talked about. So, for noises you just talked about, like the radio and CDs, is it also the case that he doesn’t like loud crowds? Or is it more like these musical contexts?

**Interviewee:** That’s an interesting question. I think it’s definitely the music. Well, I’m not going to say it’s musical. I mean, I see it more so in those situations, but, like, a lot of things, it’s … a lot of things aren’t necessarily loud all the time. I mean, even if we go to the store, it’s not, like, loud. So it’s hard for me to say. But I mean, I think, more so in the crowd. It’s the, like, I think it’s the visual, visual, like, all these people trying to navigate because that’s when I see, like, the hand over the face. I don’t necessarily … because I’m trying to think back to like, when we’re in large crowds, when we could be, like, if we would go to, like, ZooLights at the National…

**Interviewer:** Yeah.

**Interviewee:** … like, because we live, you know, in DC. Or, like, with the zoo, like, like, sometimes I think I would see more of the covering of his face versus the hands in the ear. So I definitely think it’s, like, volume level in general, but, but I think the nature of the beast is that it’s more so with, like, the music or, like, if it’s a TV, that type of thing. Because the crowd, it might … there might be crowds, but, like, we’re not in crowds where there’s a whole lot of people yelling or a whole lot of talking. Does that make sense?

**Interviewer:** I think so. Can I just try to reiterate? So I, like, I see if I understand what you’re saying.

**Interviewee:** Yes.

**Interviewer:** So you’re saying it’s like … has to do with volume with, like, TV or something that, like, has like, a literal dial. But then when he is in bigger crowds, where there’s lots of stimulation, both, like, auditorily and visually, that’s when you see him covering his eyes, as opposed to his ears. **[7:00]** Is that correct?

**Interviewee:** Yes and no. So, what I think … what I was trying to say is that in the crowds, it’s not necessarily a whole lot of noise. And it might be a lot of people, but it’s not a lot of noise. So therefore, like, we’re not in this … we’re not, like, at a concert where it’s a lot of people, you know, you know what I’m saying? But you know, I’m trying to think, like, we went to Kennedy Center, and if there were … because they try to have the … and I mean, I think also too, like, the … a lot of the places where we go where there are crowds, with the exception of us going to the zoo, a lot of those places are sensory friendly. So now that I think about it, I mean, like, even if we go to the theatre, because there’s a lot of local theatres that do sensory friendly, have … offer accessory-friendly theatre and all of that. And all of that are the movies, like, he has his headphones with him. So we kind of it’s, like, a preemptive strike. So, like, we go to the movies, even if it’s sensory friendly, he has the headphones on, so he doesn’t have to put his hands over his ears. Whereas if we’re in a crowd, like, at the zoo, which is, like, twice a year, it’s not, they’re not. There’s not a lot of, like, talking. People are just kind of, like, moving and kind of going, to, like, you know, they’re looking at the lights over there. You know what I mean, so I think if there was a lot of volume, I think that we would see the hands over the ears.

**Interviewer:** Got you.

**Interviewee:** But you it doesn’t nec ... in those environments. We’re not in a lot of environments where that’s happening. Does that make sense?

**Interviewer:** Yes, yes. Thank you for clarifying. That was perfect. And so, relatedly, you talked about, like, lights and brightness. Is that, like, sunlight? Or is that just, like, bright lights from, like, a lamp or something?

**Interviewee:** So I should and I see, like, sun brightness. I also see it if it’s, like, light brightness. So I see it in two different places. But I also, like, to your point about, like, crowds I also see it if it’s a lot of people and we’re needing to walk through the, like, in the, in that, like, zoo situation, for example, because that’s the first that kind of comes to my head. Like, if there’s a lot of people, like I’m saying, because it’s just, like, so many people coming at him. I think it’s, like, the stimuli of so many people.

**Interviewer:** Absolutely, thank you. And then you also talked about his vestibular, vestibular system. Do you ... and you talk about him previously not really knowing where he, his body was in space. Do you think he, do you think he now knows where he … his body is in space or do you think that’s improved?

**Interviewee:** Oh, yeah, I definitely think he does. I mean, I think it’s, you know, he has really been fortunate to have, like, a multimodal approach towards, like, his sensory stuff, like, he got to the point at school where he, like, graduated from OT and even with, **[10:00]** like, his PT, which we were doing outside, he really had, like, space to work on those things one on one. And so, over time, like, we were able to, like, target those areas where, like, for example, like, throwing a ball, like, he had difficulty doing that. And catching and all, you know what I mean, and so there’s definitely, there’s definitely improvement. I would also, like … what I will say, like, in terms of thinking about, like, the sensory, like, his visual spatial has always been a, like, high on his, like, on his list, like, of his strengths. Like, to ... like, Aiden is an artist. And so, like, that, like, that has always been, like, his thing, like, writing his name, like, all, like, it’s interesting, you don’t realize, like, how all of these systems, like, play together until you have to work to support those things, right?

**Interviewer:** Yeah.

**Interviewee:** But, like, I would say, like, getting back, you know, to your question, like, I just … I think that there has been … he’s really come a long way, like, but what’s interesting is, like, the handwriting has always been, like, a strength. So, like, that is definitely, like, one of his gifts. But, but, but it’s been, you know, it’s been a long time coming. And, like, fortunately, like, now we’re in a place where, you know, he has, like, supported school, like I said, where he has his fitness schedule. We do yoga, he, you know, like … we’ve done swimming, we’ve done, like, we’ve done horseback riding, like, all of these things, these active therapeutic recreation programs, where he’s been able to, like, or to ski and snow ski and all. And, like, he’s just really had a whole lot of rich opportunity to … I think, to build on that.

**Interviewer:** Awesome. You just gave me two great segues to my next question. So you just mentioned a whole bunch of, like, therapies and supports that he’s received. So my next question is, how does, how does Aiden manage? And how do you help him manage these sensory sensitivities and sensory interests?

**Interviewee:** So, one, I think, you know … just very general, it’s like, giving him access to all of these types of opportunity, right. So that’s one of his … you know it’s a little bit more challenging in COVID. But, like, he does his fitness schedule every day independently. And we do yoga, like I said before, like, one day a week, which I think has been really great. Then also too, in terms of, you know, like, when we go out, if we think it’s going to be loud, like, we have the headphones. If he goes out, I’ve got to … like, if it’s going to be sunny, like, I’m thinking about when he was going to his job, say, if he had to take the metro. Like, he took his sunglasses and he would wear sunglasses, which I think would help. But even still, sometimes **[13:00]** I still see the hands over the eyes. But I think again, it just depends, like, really how bright it is.

**Interviewer:** Yeah.

**Interviewee:** But, like, that has been really, like, that has been really helpful. And he, like, seeks those things out. I mean, when he vacuums which I totally forgot, like, thinking about chores at home, he vacuums, like, he knows to go get his noise-cancelling headphones, and he puts them on before he even starts the vacuum. So that’s, like, that’s another situation where it’s, like, there’s a loud, larger volume, right, of sound that’s coming at him and he puts the headphones on. So he does not vacuum without headphones …

**Interviewer:** Yeah.

**Interviewee:** … but, like, just have any supports to help him and available.

**Interviewer:** Do you think these supports have helped him?

**Interviewee:** Oh, yeah, definitely. I mean, I think it would probably … and I … you know, I’m only speculating because I’m not him and that, that’s, that’s not how I process the world. But I think it would be torture unfortunately and overwhelming for him to navigate if he didn’t have these supports in place.

**Interviewer:** Absolutely. And then would you say that these sensitivities have changed over time? Like, were they more severe when he was younger?

**Interviewee:** I think that, over time, things shift, right? Like, I think when you … and again this is me speculating, when you are more aware of, like, what’s going on with your body I think in some way because … I’m trying to think back to when he was little, like, I think the, like, always being on the go, like, I didn’t see as much or nothing. I recall a lot of, like, the … maybe there was fingers in the ears and hands on the eyes. I guess it was, but I think when you work on some things to kind of, like, help them sit, like, I think the focus becomes those other things. So I’m not going to say it isn’t, like, an improved, improvement. I think it has improved. I just think, you know, as we get older, and we’re in the world more, you know, things shift.

**Interviewer:** Yeah.

**Interviewee:** And so, I mean, oftentimes the environments we’re in when we’re little are not the same as the environments we’re in when we become older. And so I guess from my standpoint, it’s like, how do you, like, once you get into these newer environments, you know, because, OK, school is one thing … And, like, going out in the community is another thing. And, like, we had a whole conversation, like, about, like, the, the sunglasses, right? And so, and there’s always a split, we don’t want, you know, want him stigmatized, blah, blah, blah, blah, all these things. You know, we talk about this, you know, the … talking with the school. And so that’s kind of, like, how the, like, sunglasses came, because, like, we would do sunglasses, summertime, you know, when it’s really bright outside. But, I think, again, like, looking, you don’t really know what’s going to happen, go into these other environments, and, like, trying to, like, troubleshoot and support, like, as things arise, **[16:00]** has been helpful.

**Interviewer:** Yeah, absolutely. So this then may not be super relevant. You just talked about, like, a shift in him as, like, a shift in what’s happening, as opposed to, like, a change in sensitivities. But do you think any changes that you have observed, whether they’re a contact, like, they’re because of a true change or just because of a shift? Do you think they are related to any independence that he’s gained over time?

**Interviewee:** I don’t know. I mean, I think, from my standpoint, like, him being able to access these things, independently has definitely shifted … Like when he, like … I would say, “*OK, you can go vacuum*,” and, like, he knows to go get his headphones or, like, if we leave out, like, he’ll, like, you know, get his sunglasses, you know, that type of thing.

**Interviewer:** Yeah.

**Interviewee:** So, I, I mean, I think there’s some correlation, but I’m not really … you know, I mean, like, I’m not really sure how to best answer that.

**Interviewer:** Totally. Yeah. No, that’s totally fine. It seems like, maybe, like, some self-awareness of knowing that he needs these supports in those new contexts.

**Interviewee:** Yeah.

**Interviewer:** Awesome. And then, when he isn’t able to access these supports, like, say, he isn’t able to use his headphones, or he isn’t able to use his sunglasses for whatever reason does that cause or increase anxiety for him?

**Interviewee:** Not so I would say anxiety, but, like, you’re definitely going to see the fingers in the ears. And you’re definitely going to see the hands over the face, which, of course, is not safe, if you’re walking with your hands over your face.

**Interviewer:** Yeah.

**Interviewee:** Maybe, maybe the hands is not so much but you can’t walk with your hands, you know.

**Interviewer:** Yeah, absolutely. And have you always noticed that?

**Interviewee:** I think, I think I have, I think I have, because I was like, when I was thinking back to when he was little, I’m like, “*Did I see that?*” And I’m like, “*Yeah, I guess maybe I did*,” but I think, like, it was, like, mixed in with all these other things, right? It was mixed in with, like, him standing up in front of the TV, it was mixed in with, like, him kind of having to always being on the go, you know and not being able to sit. So, you know, you know, when they’re little it’s like those behaviors, those things are OK. As they get older, you know, become stigmatizing. So, you know, just try to figure out best ways to support him.

**Interviewer:** Yeah. Absolutely. And so you say, you, you wouldn’t really cause it, cause ... sorry, you said you wouldn’t really call it anxiety. Has he always not really had anxiety in this context?

**Interviewee:** Yes, I would say that, is that is fair to say?

**Interviewer:** Awesome. Right, I have one more question in this set of questions and we’re going to move on to a different topic, but related. **[19:00]** What are your goals or hopes for Aiden in terms of his sensory sensitivities?

**Interviewee:** I would say my goal is for him to know when he needs to take breaks or know when he needs supports and be able to independently access them. And/or if he can’t independently access them be able to ask for support in getting what he needs. I think that is, that’s the big thing for me.

**Interviewer:** Absolutely. Thank you. Now, shifting gears a little bit, we’re going to go on to our second chunk of questions. As Aiden has grown up and aged, how has your and his community reacted to his sensory sensitivities?

**Interviewee:** I would say … OK, well when you say “*community*,” are you saying large community, people that just don’t know us? Or are you saying, like, the community, people we know …

**Interviewer:** I’m kind of … what he … **[crosstalk at 20:04]** I’m sorry.

**Interviewee:** Are you saying like, school community, like, our outside activity community? Like, which community are you referring ...?

**Interviewer:** I mean all of the above. I use the word very broadly because people define it differently, differently for them and their families. So, whatever makes most sense to you, and you can also answer it in different, from your perspective ...

**Interviewee:** OK, so I will, OK. I would say—thank you for that—I would say, in terms of, like, node communities, like, school community, and, like, family and friends, and, like, the community, like, his therapeutic recreation program, or, like, the programs he’s in and, like, those … that type of community, like, it has … what I would say is, that community in general has grown over time, right? Like, when, when Aiden was younger, there weren’t these opportunities early on. And so now there are. So in terms of, like, these … these environments are places where youth like Aiden are accepted for who they are, right? And so they can, if they have their sensory stuff, they have their sensory stuff, but it’s interesting, because he’s in that situation, he’s in these environments with kids who have similar or, I wouldn’t say necessarily similar profiles, but, like, similar diagnoses. And so, you know, depending on who we’re with that particular day, like, he might be, like, middle of the road, it might, you know … his, you know … you might notice his, his sensory stuff, like, his, his, his hands and his ears more so for me, you know what I mean, like, it just, it just depends on that environment and who else is in it, but it’s accepting. I would say, in the broader community, you know, you still notice, unfortunately, even with all the quote unquote “awareness,” **[22:00]** right, these looks when you’re out. Sometimes Aiden will do, like, the self-talk. Not often, but sometimes a little, you know, a little bit of hand flapping—again, not often, but sometimes, most of the time, he’s like, it’s under control. So there are these looks and stares, but, like, we just keep it moving. Like, I don’t, we don’t have time for that.

**Interviewer:** Yeah. Absolutely not.

**Interviewee: [inaudible at 22:30]**

**Interviewer:** Sorry?

**Interviewee:** I said, “*Who has time for that? No one*.”

**Interviewer:** Nope. No one has time for negativity, especially now, it seems.

**Interviewee:** Exactly.

**Interviewer:** And kind of thinking back when he was younger, was his community—both maybe this node community and this broader community—more accepting or less accepting?

**Interviewee:** That’s an interesting question. I think … so, he was in the public schools for a year and so I actually remember, like, more of the stares, like, him not feeling as accepted, right? Like, the people who knew who he was, it was fine, but I think that when, I think when they would have, like, a family day or something, like, who would … it was more noticeable. But then they also like, “*Oh, that’s the autism classroom*,” you know. You know what I’m saying. So, so, but I, but again, it was, like, they’re in this school, but then they were, like, still segregated, where it’s, like … Since then, he’s been in, unfortunately, like, in schools that are—I mean I don’t want to use the word “segregated” but they are, you know, schools specifically to work with kids with autism. And so this is a different culture. So I think there’s more acceptance now versus then.

**Interviewer:** Absolutely. Thank you. So, you also kind of just answered my next question, which is, like, which aspects of the community are, like, more or less accepting? So, I know you talked about your known community in terms of, like, his family, your friends, like, his school, his therapies being more accepting than the broader community.

**Interviewee:** Yes. Yes.

**Interviewer:** Can you think of other places where maybe you see some differences? If you can’t, it’s OK.

**Interviewee:** Yeah, I was going to say … no, I mean, the reality is too, like, we don’t … like, we kind of, like, do our stuff, like. This is before COVID, like, Aiden had a whole, like, list of, like, activities and things to do and they were all for the most part, like, we know around, like, sensory friendly, like, Smithsonian has, like, their Morning Museum, which is, like, you know, again, specifically for **[25:00]** this population or, like, when we would go to the movies, like, it’s sensory friendly movie or … you know what I mean …

**Interviewer:** Yeah.

**Interviewee:** … so a lot of … so he … we’ve been sheltered in a lot of ways.

**Interviewer:** Yeah.

**Interviewee:** But, I mean, it’s great that we have access to that … well, those several environments.

**Interviewer:** Well, hopefully, you get them back soon, when hopefully it’s safer to venture back out into the community.

**Interviewee:** Unfortunately, I don’t think it’s going to be until next year, unfortunately.

**Interviewer:** I don’t either, but you … one can still hope.

**Interviewee:** Yes, exactly.

**Interviewer:** And again, now thinking towards the future, what are your hopes or worries for how the community will react to his sensory sensitivities in the future?

**Interviewee:** Well, I mean, I would say, like, my biggest concern is, like, around the police.

**Interviewer:** Yeah.

**Interviewee:** Just in terms of unease, you know, African American black male, so …

**Interviewer:** Yeah.

**Interviewee:** I just have real concerns that things will be misconstrued it. So, like, that’s a big, that’s a big worry. I mean, my hope is that we can get, you know, the police trained up. I’m on the DD Council in DC. And so I know there’s going … there’s some efforts kind of moving in that direction. So I haven’t been able to join. I was able to join the very first meeting, which was over a year ago, they’re like, re-ramping up. So I’m hoping that we’ll be able to leverage some stuff with DC Metropolitan Police.

**Interviewer:** Yeah. That would be awesome. I know you’re not the only, you’re not the only parent who’s talked about that concern. So, hopefully, it will … there will be able to be a shift so parents can feel safer about their children in the community.

**Interviewee:** Yeah, yeah. It’s tough.

**Interviewer:** Yeah, absolutely. Thank you for sharing that. Now … **[inaudible from interviewee at 27:03]** Thank you. I’m now shifting gears once again. Could you please tell me about where Aiden is in the transition to adulthood?

**Interviewee:** So, Aiden is 16. He’ll be 17 in September. He has been going out to community job sites.

**Interviewer:** That’s great.

**Interviewee:** But, you know, of course that’s on hold with COVID.

**Interviewer:** Yeah.

**Interviewee:** But he’s been ... yeah, he’s been doing really good with … in those environments, like, there’s a, there’s a quote unquote, “job coaches,” staff from his school that goes with them. And he, like, he’s been doing a really good job. And my plan was, because I think I’ve mentioned earlier, he, he’s been doing therapeutic horseback riding for a number of years …

**Interviewer:** Yeah.

**Interviewee:** And so his last job site before the shutdown was at Wheaton **[28:00]** Stables in Montgomery County and they, and they think that he’s great. I mean, everybody thinks he’s great, thank goodness. But they have this transitioning youth program. And so, this summer, my plan was to enroll him into their transitioning youth program so that he can actually go … so it was like, it was a huge step, actually, for me to actually have him in a program, like, outside of school because, like, we’ve never really had to do … like, he did camp last year, do the ridings, like do the stables or he rides, but I was, like, there with them, because they didn’t have, like, a component for a kid with autism or, you know, related disability. So I was, like, his aide and I was literally with him.

**Interviewer:** Yeah, yeah.

**Interviewee:** … there every day. We could leave, thank God, every day for lunch and, like ….

**Interviewer:** Yeah.

**Interviewee:** … come back home. It’s only, like, 15 minutes away and, like, go back, whatever. But um, yeah, so we saw, like, the plan was for him to, like, basically be in this camp, like, like, on his breaks, because what happened was the people who … there were a couple of people who used to work at Aiden’s school. He didn’t know them at that point. It’s been some years since they left but they established this, like, nonprofit, where they work with Wheaton, with Wheaton Stables, but basically they hire staff, oftentimes, I don’t know, school staff to, to, like, be aides, or you can bring your own personal staff. And so the plan was to basically have him do this, do this therapeutic camp, and so he would get more than what he was doing at the job site, even though at the job site … because Aiden has riding experience, he actually, like, the …. One of the ladies who works with kids, like, actually pulled him from, like, the normal job site duties. Like, they were, like, cleaning, like, helmets, like, no, they pulled him and had him, like, actually taking care of the horses, like, that’s some of the stuff he’s learned how to do over the years ...

**Interviewer:** That’s great.

**Interviewee:** … and work with him. And so, like, the plan was then to have him, like, at, at that program in the summer, like, doing even more through this Vision for Youth program. So that obviously has stalled. So … but my plan is, you know, when things reopen, I’m sure they’ll be, you know, they’ll be ready to, you know, support, support these students. Because the last I heard, they were, you know, like, they, they were … they had cancelled the summer program, rightly so. But I know they were trying to figure out how they could engage the students who—oh excuse me, like, the young, the youth …

**Interviewer:** Yeah.

**Interviewee:** … the young adults who were already in the program, because basically what happens is they, they have some youth that, like, they, they … families will use, like, self-directed funding, and then, like, enroll them in that program. So they’re so … like, that these youth who transition out of school that’s, like, basically the place where they go.

**Interviewer:** Gotcha.

**Interviewee:** And families use self-directed funds. And then, like, when **[inaudible at 30:59]** has breaks, **[31:00]** because they can hire **[inaudible at 31:02]** staff to support students if needed, if they don’t have their own staff, they, they offer those weeks for transition. So, so yeah, so what’s **[inaudible at 31:15]** kind of, like, my plan would be to, you know, get him a role, because, like, they had, like, a spring break camp that I like, we were ready to do the spring break camp. I thought it was going to be free this summer, so I was really …

**Interviewer:** Aww.

**Interviewee:** … bummed that, couldn’t do that.

**Interviewer:** Yeah.

**Interviewee:** So, you know, things happen for a reason. And, I mean, I’m looking at this, you know, getting back to your question of, like, this transition, like …

**Interviewer:** Yeah,

**Interviewee:** What I will say positive about this time is that we have had, like, a peek into, like, what life will be like, after he transitions, and so …

**Interviewer:** Yeah.

**Interviewee:** … what’s been really great about his school program, they have, you know, they, they’ve been really supportive. They offer office hours every week, which my mother and I literally meet with his teacher and program coordinator, like, every week for office hours for 30 minutes.

**Interviewer:** That’s awesome.

**Interviewee:** And so we’ve been, like, implementing goals and, like, generalizing things to home, and it really been, like, trying to work on skills, to, like, help with transitions. So like, he’s learning how to, like, fill out forms. And I mean, he already knows how to do, like, basic chores and stuff here. You can get him to change the sheets and he can make his bed, so, like, literally strip the sheets off. And, like, you know, he can wash clothes. He can put dishes in the dishwasher, he can vacuum, he takes out trash, like, he does, like, all those things, which are great. I think what’ll be good too, is like thinking about, like, as we transition to the fall, like, going out, like, getting leaves and stuff up.

**Interviewer:** Yeah, yeah.

**Interviewee:** You know, this? Yeah. So it’s just like, really, you know, things that you don’t do as frequently is a little bit harder to teach. But yeah, so he’s … I think he’s well on his way.

**Interviewer:** That’s awesome. That’s such a nice silver lining to think about how this is a good, like, sneak peek into what it’ll look like, outside of school, and you can kind of start to bolster his skills before he gets there. You know, when he’s out of school, that’s … I haven’t heard that before.

**Interviewee:** Yeah.

**Interviewer:** Such a lovely perspective. And I think also a reality.

**Interviewee:** Yeah, and I mean, I’m, I’m totally taking that from his program coordinator, because we just talked about it. And I, and I was like, “*Yeah, it’s, like, it’s nice to see.*” She was like, “*Yeah*,” she’s like, “*Yedda*,” **[? 33:39]** she was, like, “*What happens is*,” she was like, “*our kids, like, they transition and they don’t have access to, like, staff to support them*.” So she was like, “*So, like, they’re home*,” she said, “*you know, parents are just working*.” Like, I’m still working, you know what I mean? And so, I mean, fortunately, my mom is here, and she can, like … so if, like, there’s … if there’s, like, a class that he, he has, like, **[34:00]** normally one of us sits with him, but they’re also working on, like, leisure skills. So like, you just need to make sure that, make sure you’re all set up and he … apparently you just walk away. So, like, if he has … we have, like, a card table here in the living room where he sits with his laptop and, like, I was able to sit in the dining room and, like, have earbuds on and, like, work on some stuff. And they, like, totally were, like, working on him, like, where he was. He had already learned how to do, like, an independent, like, activity schedule where he has, like, activities that he does and he writes out what he wants to do.

**Interviewer:** Yeah.

**Interviewee:** And then … but it was nice to kind of be in his environment. So, like, he picked, like, I think it was something like words or, like, he has to think about stickers and, like, in pictures. So, like, he was literally sitting here, like ….

**Interviewer:** Yeah.

**Interviewee:** … working on those things, right? But then we ate, but like, staff were on the computer and, like, they were actually his program coordinator and, like, literally reinforcing them so, like, “*Oh, you’re doing such a great job. What are you working on? Oh, this is great*. *Blah, blah, blah*.” Working on leisure skills and then we’ll give them, like, built-in breaks. So like, “*OK, you take a break. Stay down here,*” like, “*don’t go*….” **[inaudible at 35:07]** But then he’ll, like, take a … his break with his iPad or whatever and then, like, “*OK, break’s over*” and we’ll come back and so like, totally. I mean, yeah, like, he’s in an advanced group, which I really like. And so, yeah, he has a lot of great, a lot of great skills.

**Interviewer:** That’s so awesome. What about other independent skills? Does he have, like … you just talked about, like, doing lots of household chores—is he able to also take care of himself physically?

**Interviewee:** Yes. So yes, so he, so he takes a shower, gets dressed, brushes his teeth. I’ve asked him, like, to go behind him and make sure stuff is, is right. But like, yeah, for the most part, like, he’s not walking around smelly, thank goodness.

**Interviewer:** Absolutely. What about food—is he able to prepare, like, simple things in the microwave, or, like, a sandwich?

**Interviewee:** Oh, so, yeah, so he gave me … Normally, he could make like a PB&J. Like, if I have, like, much meat and cheese and stuff he, like, he can put together a sandwich. He’s not, he’s not a salad guy. So, like, don’t give him no tomato, he’s not doing that. But he likes his vegetables cooked. But, like, even, like, yesterday, he can … he will put his … like, if he’s heating up leftovers. Like, he puts the leftovers on a plate. And then he puts it in the microwave and he eats up his food. He likes to, like, bake and stuff.

**Interviewer:** Oh!

**Interviewee:** So, like, my mom, like, worked on a cake together last week.

**Interviewer:** That’s fun!

**Interviewee:** Yeah, he can use a toaster. Because I remember that for one of the questions, he needs to use the microwave and I was almost like, “*He can do that*” because, like, **[inaudible at 36:57]** and my brother wanted to literally share my screen on the Zoom as I’m going through this thing at the, the forums. And **[inaudible at 36:57]** he’s like, “*He eats oatmeal. He can use the toaster*,” like, the **[37:00]** original there’s-nothing-in-it oatmeal and he adds a certain amount of sugar. So, like, he does that in the morning. So like, like, you can put the water on the kettle and turn it on and turn the kettle off and, like, gets a potholder. And, like, my mom’s taught him how to do that, how to get a potholder and, like, pour his water in and do … and get his oatmeal. He’s taking his medication independently. We have a goal. And his IAP. I kind of, like, tapped into his, tap into his, his I, his IAP goal of filling out forms. So, like, list medications, so, like, we, I’ll be working with that with him. So, yeah. So, like, stuff is, stuff’s happening. **[crosstalk at 37:41]**

**Interviewer:** That’s great.

**Interviewee:** Like, for him to learn how to, like, unlock and lock the door and I’m like, “*Shoot, we’re home. Like, we could totally work on that*.” So I’m going to check in with his program ….

**Interviewer:** Yeah.

**Interviewee:** … here.

**Interviewer:** That’s awesome.

**Interviewee:** Yeah.

**Interviewer:** With some of his job experience that you talked about, is he learning about, like, money and money management?

**Interviewee:** Oh my gosh, my mom would like, fall out. So he, he has this … so yes, he does have, he does have a couple of IAP goals related to money. One has been—oh gosh, I can’t think of the name of the, of the program—but like … Dollar Up. We’re, like, looking at, like, giving him change, like, you give someone … you tell someone how much something is and you give them cash … my mom. So that was the goal that he had mastered at school and so it’s been generalized at home and my mom is an accountant by … like, that’s what she was before, working for the federal government. She’s retired now. Now she’s like, “*Oh, I can use the Dollar Up program*.” It has been, like, so frustrating for her, but she’s, like, a trooper. She’ll help with it, like, “*I don’t think I’m doing it right. Ah*.” It’s been kind of crazy. So, but yes, so he has that … he used … he’s been for the past, like, year or two, like, he … so I don’t have a debit card for him with his account, but I use, like, the prepaid, like, the Visa gift cards. And so he has those … then also worked on him, like—I forget—using—I forget the program—but like, him keeping track of, like, what he was, like, keeping track of purchases. So I can’t think of that program. But, yeah, so there’s been a multi … again, multi … multi—what’s the word? –multimodal … multi, multiple approaches on how to, like, the money piece.

**Interviewer:** Yeah, that’s awesome. And so, like, with the job sites you talked about, does he, like, like his job? Does he want jobs in the future?

**Interviewee:** Oh, yeah. Yes. So Aiden loves to be out in the community and, and be busy and do stuff. So I’m trying to think … Hey, Aiden, what do you …? Where have you gone for job sites? Come here, please. I’m talking to Miss Rachel. You can’t … you’re not going to be able to see her. You worked at Personify and where else? **[40:00]**

**Aiden, Interviewee’s Son:** Moorenko’s.

**Interviewee:** Moorenko’s Ice Cream. Where else?

**Aiden, Interviewee’s Son:** Black Hill.

**Interviewee:** Black Hill Regional Park.

**Aiden, Interviewee’s Son:** Autism Speaks.

**Interviewee:** Yeah, you did go downtown to Autism Speaks.

**Interviewer:** That’s awesome.

**Aiden, Interviewee’s Son:** Black Hill.

**Interviewee:** You already said Black Hill and, and, and Wheaton Regional … Wheaton Stables, right?

**Aiden, Interviewee’s Son:** Wheaton Stables.

**Interviewee:** Yeah. So yeah, so he’s had, like, five job sites.

**Aiden, Interviewee’s Son: [inaudible at 40:19]**

**Interviewee: [to her son]** Yes, they do. Thank you. And they have other jobs, you know other in-school jobs they do. So, like, learning how, like, how to … going around to the classroom and, like, cleaning the microwaves, they clean the tables, there’s something called—oh gosh, oh paper what?—paper products. So, on Fridays … and I’m so upset the guy who was in charge of that, he left …

**Interviewer:** Aww.

**Interviewee:** … the school.

**Interviewer:** Oh.

**Interviewee:** He … but he was also, full disclosure, one of the few black, like, male staff there. And he literally, like, saw that Aiden, who’s, like … Aiden’s, like, a really good and hard worker. And so, if he was, like, pressed for time, or, like, other stuff came up on the agenda, he would, like, call to the classroom for Aiden to, like, come down and help him. So basically, with the paper products, they have, like, these carts where they have, like, a one in two. So either it’s the first floor or the second floor, and they have, like, a laminated list. So each classroom would say that they wanted X, XYZ for, for the classroom. So, like, maybe they need two plates, and they will tell you how many plates and they will tell you, like, how many forks, like, **[inaudible at 41:31]** like, he literally would fulfil the orders, put them in their bins, and, like, then they would … the other students would … so, like, Aiden would oftentimes be brought down early before because they would have, like, a paper product class …

**Interviewer:** Yeah.

**Interviewee:** … like, a time where like, the whole classroom … but Aiden would oftentimes be, like, called down to come and do it, like, early with his, with his other, like, his, his one-on-one or his two-to-one. So, like, he could come down and, like, or so ….

**Interviewer:** Yeah.

**Interviewee:** He works, he works really, really hard. Like, if he knows how to do it, he can, he can do it. He’s really good.

**Interviewer:** He sounds like it. And at school, or through some of these other groups he’s part of, does he have friends?

**Interviewee:** So yeah, I mean, I think that there are kids that he, you know, identifies and always says hi to. So, like, even on, like, with Kids in Action, which is part of the therapy reparation program he’s a part of he, like … there is this one kid who he sees and knows, and, like, he’s always, like, “*Hey*,” you know, “*Hi*.” And so, like, they’ve been doing, like, Jeopardy. So they’ve been on, like, Jeopardy teams together virtually. So yeah, and so he doesn’t … that little boy—or teen, he’s a youth. He doesn’t have … because Aiden’s older. He’s, like, 13 and then Aiden is, as you know, 16, going to be 17.

**Interviewer:** Yeah,

**Interviewee:** But he, so he has a trait. So he doesn’t really talk, like, he can make just, like, noises and stuff. But, like, they’ve been kind of, like, doing stuff the same, you know, **[43:00]** the same amount of time.

**Interviewer:** Exactly.

**Interviewee:** So it’s been probably, you know, it’s been a number of years. And then, like, my best girlfriend, her daughter has autism. And she … I mean, we became friends like, because of the kids …

**Interviewer:** Yeah.

**Interviewee:** … so he doesn’t see her as often. But, like, we used to go to the beaches and stuff. So I mean, I would consider them friends I met on the, on the forum. I’m trying to think if I put my … “*yes, friends*.” No, I, I can’t remember what the question was. But I think I kind of said no, based on, like, what the question was, but like …

**Interviewer:** Yeah.

**Interviewee:** … I would say, like, in terms of, like, outside, those are the two, but, like, that we don’t really do stuff outside. I mean, no one can do anything now. But, like ...

**Interviewer:** Yeah.

**Interviewee:** I mean, yeah, I mean, it really depends. Like, we don’t really have, like, people who we meet up with regularly outside. So, like, I think that’s probably why I said no.

**Interviewer:** No, it makes total sense. And has Aiden ever expressed interest in wanting to live by himself when he’s older?

**Interviewee:** No, no, I don’t think we’re really there with that yet. So, yeah, that’s not really something, something that we’ve broached.

**Interviewer:** Absolutely. And then do you think moving forward, he’ll be able to continue, continue to gain more independent skills?

**Interviewee:** Oh, yeah, definitely. Definitely. We have a lot of good supports in place right now. So yeah, I think he will. Like, I’m very involved in, like, like I said, the DD Council with DC and I’m also co-chair of the Family Support Council, which is looking at, like, you know, adult services through DC Department of Disability Services. I’m also on the National Healthcare Transition Advisory Board through, through this organization, well, it’s the National Alliance. I can’t think of … that, the whole National Alliance thing, but, like, that trans … if you look up that … transition, you can find them, which I could actually send you that info if you want …

**Interviewer:** Yeah.

**Interviewee:** … but I’ve been on that on that board for the past year. And so, I’ve been doing some other transition-related work with them to try to set up the system. So I think, you know, a lot of people, they’re thinking about transition. And so systems are being built to help families to navigate a lot easier. And so I think with all that, plus the supports we already have in place, I think we’re in a better place versus where a lot of families were maybe five, ten years ago.

**Interviewer:** Absolutely. And what do you think will help Aiden continue to move into adulthood?

**Interviewee:** I mean I think, you know, do, doing the things that he’s doing, plus, like, really looking at, you know, what should be happening, you know, during transition. So like, for example, with the health, with the guided transition, like, there are, like, these benchmarks about, like, “*Oh, when your kid is at this age*,” like, “*this is what you should be doing or thinking about*.” **[46:00]** I think one of the things too, like, with guided transition, they specifically look at healthcare transition, and so, like, thinking about things to support him, like, with him, like, going to, you know, going to the doctor, but, like, not necessarily still staying with the pediatrician, but, like, moving to an adult doctor, you know, internal medicine doctor. Um, so, yeah, so, like, just really continuing to help push him forward and supporting him. Because I think that the, the challenge, right, like … we as parents get, like, stuck on, you know, where we’re most comfortable and, rightly, because we want to keep them safe, but then also, like, recognize, like, hey, like, he’s going to be 17, you know, next month, and, like, in two weeks. And so, like, what does that mean? Like, he’s becoming a man. And so just because, you know, intellectually, you know, there might be delays, that doesn’t mean that he doesn’t have a male, a man body and, like, you know, you need to be able to start, so just like, thinking about, like, all these things.

**Interviewer:** Totally. Thank you. Do you think there are particular services or interventions that would also help him? Or, like, help facilitate this transition?

**Interviewee:** Yes. So also, in looking at my many hats, I … and this is funny, this is about, like, ten o’clock today.

**Interviewer:** Perfect.

**Interviewee:** I’m finishing up this, this Ambassador Series for Charting the LifeCourse, which I want to send you to, Rachel.

**Interviewer:** Yes, please.

**Interviewee:** So, I don’t know if it’s part of it, but Charting the LifeCourse came out of the University of Missouri, Kansas City, their UCEDD, the University Center of Excellence. And so, basically, it was created so that families could, like, plan and support their person, you know, the person with a disability in their life. And so they have, like, they have, like, care map … relationship mapping and, like, this integrated start, where you, like, look at … because I think the challenge is, you know … and this is something I learned to go into this series is that only 25% … when you think about, like, actual services, only 25% of people with disabilities actually access these services. And so, what are the other services? What are the other things, like, what’s the technology that you need? What is the relationship that you have? what are the community resources that are not just eligibility specific, you know, supports that can help the **[inaudible at 48:31]**? And so, Charting the LifeCourse is, is a great framework to help families think about supporting, you know, that transition. So, yeah, I’m really excited about it.

**Interviewer:** Yeah, that sounds fantastic. And so, so helpful.

**Interviewee:** And it helps you to think about, like, what you want to help the individual think about, like, what a good life is, and also, you know, what you don’t want. And, like, what are the things that would be, **[49:00]** like, that would get you somewhere where it’s like, “*No, I don’t want this*,” versus, you know?

**Interviewer:** Absolutely. Thank you. And now putting these two things together—sensory sensitivities, and this transition to adulthood—how do they intersect for Aiden?

**Interviewee:** I think that, you know, when you’re thinking about how people perceive him in the world, like, really making sure that he can navigate in a way that—how do I want to put it?—like, making sure that he has supports can, can either help or, like, deter, like, his progress, I think, in terms of transition, right? Like, if he is, if he’s not able to, like, sit and do his work because it’s, like, too loud …

**Interviewer:** Yeah.

**Interviewee:** … or, you know, it’s so many people and he’s distracted, like, that can affect his work. And so, I think having supports available can help propel him to, like, you know, the best transition possible.

**Interviewer:** Yeah, absolutely. And would you say that his sensitivities are an obstacle, a vehicle or a bit of both towards his independence … or neither?

**Interviewee:** Yeah, obstacle, a vehicle? I think that they can be, I think that they could be a little bit of both, right? Like, I mean, it’s the obstacle because it can, I think that it can, you know, deter progress, but if, if he can independently, like, access those supports, like, that, can, you know, that can be supportive and be positive.

**Interviewer:**

Yeah, yeah.

**Interviewee:** So, I think it’s a little bit of both.

**Interviewer:** Yeah, absolutely. And then, what do you anticipate as being challenging for him, as he does gain more independence in regards to his sensory sensitivities?

**Interviewee:** I haven’t really thought about that and I’m not sure how to answer that.

**Interviewer:** That’s totally fine. Do you think there’s anything that will, that could help him in this transition in relation to his sensory sensitivities?

**Interviewee:** In some ways, I mean, this is literally, like, pie in the sky off the top of my head, like, in some ways, I wish there was some type of … like, I’m all into, like, framework and resources, like, that’s, again, kind of like who I am.

**Interviewer:** Yeah.

**Interviewee:** In terms of **[inaudible at 51:47]** who I am as a person. So some type of, like, roadmap or support that can, like, help families figure out how to, like, further support. Um, because I, I mean, I think, you know, doing this work, **[52:00]** like, there’s not, like … it’s focused now, more so on transition, but this is a newer thing, so I think, like, maybe further research done in this area, and or, like, some type of a framework or something to, like, support families in thinking about, like, how, you know, this sensory piece could possibly affect and or, you know, could help or hinder, like, I think, when things are, like, laid back and give something for family, so like, you utilize … and, like, a toolkit type of thing, or, you know, a roadmap, that would be helpful. And I don’t know what that would look like, I mean, but I think that could be a way to, like, help support growth.

**Interviewer:** Totally. You almost basically just answered my next question, which is awesome. So thank you. **[crosstalk at 52:50]** My, my next question was: do you think there are gaps in the available services and interventions? So, you just talked about this toolkit and this roadmap that you wish existed: do you wish there were other things that existed?

**Interviewee:** I mean, I think like, the big thing just in general about transition, not just the sensory, because I mean, I think the sensory is underneath that, right? Like …

**Interviewer:** Totally.

**Interviewee:** Families have described transition as going off a cliff and, like, figuring out a way to, like, not make it be that would be helpful. And so just, like, we think about when, when our children are little and we have, like, we have transition from, like, early intervention into, like, the schools, right, like, I almost think that there needs to be some type of, like, support to help transition to adulthood. And I think a lot of different places are, like, working on it. Like, I’m on a project now in DC, where we’re putting together, like, this document that, like, will help families figure out who all of these agencies are and where they can get supports. So I think that that’s, like, one start, but I think there’s so many, like, who knows, like, what other things can be created to help support that, and I’m excited for, like, that DC-specific document. Because there’s so many people who do not know, like, what the heck is going on.

**Interviewer:** Yeah, no, totally. Yeah, I think you’re so right. There’s a lot of parents I’ve talked to have said that they wish they had, like, a document to tell them what’s available because they want to help their kids, but they don’t know what’s out there.

**Interviewee:** Yeah, you don’t know. Right.

**Interviewer:** Yeah.

**Interviewee:** And it’s different, like, you know, like, in … when they’re in school, you know, you’re under Individual Disability Education Act (IDEA). Whereas, when you come, you know, to eligibility versus entitlement, right, like, you’re entitled to a free and appropriate public education when you’re in school versus, you know, you become adults and each state is different, like, what that means. So in DC, unless you have an intellectual disability, you are not able to get services …

**Interviewer:** Yeah.

**Interviewee:** … through the Department of **[55:00]** Disability Services. You can access the Rehabilitative Service Administration. So, like, they can help you with, like, the job piece, but, like, not any other services.

**Interviewer:** Absolutely. And so with a … taking kind of, like, a broader lens right here: how has Aiden’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** I mean, I guess I would say, like, we have been, you know, this … he’s 17, like, he’s going to be 17, we’ve been, you know, navigating, we’ve been navigating this since he was, like, two and a half, three. So I would say that, in terms of, like, my expectations, like, my expectations are always high for him, like …

**Interviewer:** Yeah.

**Interviewee:** … I want him to reach as far as he can reach. And, like, that has always been, I think my, my thought process in terms of, like, him becoming an adult. I mean, I think there, you know, there are other things, you know, that I worry about, like, I talked about police earlier, like, these other things …

**Interviewer:** Yeah.

**Interviewee:** … that are scary that I worry about. But in the same token, I’m like, you know, I just try to focus on, you know, the positive and, like, making sure that he has supports that he needs and help to advocate for him, and hopefully get him to a point where he can advocate for, know how to advocate for himself. Yeah, so that’s kind of, like, that answers the question.

**Interviewer:** Yeah. Did any of his sensory sensitivities play into these, like, expectations or hopes for you?

**Interviewee:** I don’t … I mean, I think in terms of, like, hopes, like, you know, I just want him to be able to, like, navigate the world safely. So I mean, I think that’s the biggest, that’s like, the biggest hope.

**Interviewer:** Yeah, absolutely. Thank you. So now, I have one final chunk of questions. We’re almost done. As a caregiver, as a parent, as a mom of a child with ASD, but also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** It’s, I would say it’s the process of, of, you know, becoming an adult and, you know, moving towards a space where, I mean, unfortunately, you don’t have as many supports …

**Interviewer:** Totally.

**Interviewee:** … or, you know, as you had **[58:00]** when you were at school, you know what I mean? Like, it’s a different space, it’s transition to the … adulthood is, in some ways, the unknown.

**Interviewer:** Yeah.

**Interviewee:** So I would say, that’s the best way I would describe it. It’s a little, you know, it’s a little scary.

**Interviewer:** Yeah, absolutely. Has this perspective changed over time?

**Interviewee:** I think, I think it has. I’m feeling more calmer, even though it’s scary, like, I’m feeling more confident. And …

**Interviewer:** That’s great!

**Interviewee:** … and more grounded in the unknown. Whereas two years ago, I don’t think I was there. And I mean, part of the reason for that is, like, I’ve done a lot of, like, mindset work, and thinking about, like, personally, thinking about transition and how I can support him. And yeah, so that’s kind of, like, my stance. So where I’m coming from, like, it’s just been, it’s, there’s been a mindset, a mindset shift for me. And then it’s interesting. It’s like, when I kind of shifted, like, these opportunities came about where I’ve been able to, like, like I said, work on this healthcare transition board. And, you know, like, last year, like, all these things have, like, come up, like, transition wise, where I’m able to do some work around it. It’s support from these agencies, organizations and I think that has also been really helpful for me, because I’m someone who likes to, like, dig in and do the work. So …

**Interviewer:** Yeah.

**Interviewee:** I think having these experiences really has been helpful to me in thinking about transition.

**Interviewer:** That’s fantastic. I’m glad you’re able to have those experiences.

**Interviewee:** Yeah.

**Interviewer:** And so kind of again, looking to the future: what do you see happening in Aiden’s future?

**Interviewee:** It’s my hope that he will have a job and will be able to sell his artwork

**Interviewer:** Yay!

**Interviewee:** … and be able to **[inaudible at 1:00:15]**, you know, more independently. He’ll probably you know, need some supports and I’m OK with that. Yeah, like, I think, yeah, I think he’ll, he will rise to the occasion.

**Interviewer:** Yeah, absolutely. What type of art does he do?

**Interviewee:** So, right now he is drawing and basically doing these pencil drawings. And he is using colored pencils to fill them in, doing color blending with colored pencils, which I did not know was a thing.

**Interviewer:** Yeah.

**Interviewee:** About a year, year and a half ago. I have to send you pictures.

**Interviewer:** Yeah, I’d love that.

**Interviewee:** But, yeah, so he … yeah, he’s, he’s coming, he’s coming along. **[1:01:00]**

**Interviewer:** That’s so awesome. And so I have one final question for you. How has Aiden’s sensory sensitivities impacted this perspective that you’ve just described?

**Interviewee:** I mean, I think again, like, just making sure … I feel like I’m saying the same thing. But just in terms of impact, I think just making sure that these supports are available to him.

**Interviewer:** Yeah.

**Interviewee:** I’m going to be … some, you know … to making sure that he can, he can do these things well. Yeah.

**Interviewer:** No, that’s perfect.

**Interviewee:** As long as he has supports, he’ll be fine.

**Interviewer:** I mean, he seems like … it seems like you really, really set him up for success and are advocating for him and helping him advocate for himself, too. So that’s it for my formal questions, actually. Would you like to add anything else?

**Interviewee:** No, I think, I think we’re good.

**Interviewer:** OK, perfect. So, well, I just want to say thank you. And I’m also so sorry Zoom isn’t cooperating this morning. I appreciate your patience and flexibility.

**Interviewee:** No, it’s OK. It’s no problem at all.

**Interviewer:** No, but really, thank you for taking the time out of your morning to help us and for us to learn from you. We so, we so appreciate it.

**Interviewee:** I’m glad that you all are doing it. I sent, I sent the study info to, I think, two other friends.

**Interviewer:** Thank you.

**Interviewee:** So I don’t know if you’ve heard from them yet.

**Interviewer:** I don’t think so. They haven’t mentioned you. I have gotten some other responses, but I don’t know if they have been from you.

**Interviewee:** Yeah, we also sent it out through DC Autism Parents to my nonprofit. So …

**Interviewer:** Thank you.

**Interviewee:** Hopefully people will, will jump on that.

**Interviewer:** I hope so. Thank you. I so appreciate that. I have one small question. It looks like, the second survey, the ABC2 still isn’t fully complete. Do you need me to resend it? **[inaudible at 1:03:15–17]**

**Interviewee:** Sorry. I thought I had finished it. Hold on. Let me, let me look.

**Interviewer:** No worries. Take your time.

**Interviewee:** I thought that it would be here ... **[inaudible at 1:03:29].** Do you want me to look at it again?

**Interviewer:** Yeah. No worries.

**Interviewee:** You said that was … it was the second one.

**Interviewer:** It’s the ABC2. So I guess it’s the first one in the most recent email I sent you. Or it’s the second one in the first email I sent you.

**Interviewee:** Oh, maybe I thought … OK, maybe I thought … oh, shoot, but there’s a return code. Hold on.

**Interviewer:** I can send it to you. I have it on my computer. **[1:04:00]**

**Interviewee:** OK.

**Interviewer:** I’ll send you the code. It’s not a problem.

**Interviewee:** OK. I’ll do that again. I’ll do that again as soon as you send it to me.

**Interviewer:** OK, yeah, no worries. So like, on my end, I can see how far you’ve gone. And you, I think you only filled in the date. So I’ve also ... if you restart it, you don’t need the code, but I’ll send you the code. Not a problem. OK. Thank you. It won’t take a … **[inaudible crosstalk at 1:04:19]**

**Interviewee:** Because it’s prompting me. But when I click on that link, it’s prompting me to go to a, a ... **[crosstalk at 1:04:32]**. It’s prompting me to put in a code, like, where you can restart it. Is there a place on there that I’m missing?

**Interviewer:** It ... I’ll send you the code. It might be hard to see on a phone or sometimes, you know, different platforms cooperate differently. I’ll send you the link. Not a big deal. It’s just a safety measure. That way we help … we do our best to keep your, like, data **[inaudible at 1:04:50]**

**Interviewee: [inaudible at 1:04:51]**

**Interviewer:** Sorry?

**Interviewee:** I’m sorry. Go ahead.

**Interviewer:** Oh, I just was saying it’s, like, a security measure. So, not a big deal.

**Interviewee:** No, I get it. I think … what I think … what happened was I didn’t realize when you resent some yesterday, I think it was, I thought it was the whole list. And so I knew I had finished the first one. So that’s why I missed it because I think I maybe started it when I did the first one. And that … and then when we sent it, I was like, “*Oh, this is the* ….” I was like, “*Oh, well, I just have these left*,” like, so I totally **[inaudible at 1:05:21]**. It must have been my fault.

**Interviewer:** Oh, no, no, no, no fault at all total. It’s an easy thing to solve. Don’t worry about it. But **[Shirley? Chirtley? inaudible at 1:05:28]** thank you for your time and your insight. It’s so wonderful to learn from you and from parents like you and we couldn’t do this without you.

**Interviewee:** Awesome. I’m glad to be of help. And I’m glad that, you know, you might be up in, up in Boston, but, hey, like, thanks to COVID, thanks to COVID we were able to get, like, a, I think more of a diverse sample. Have most of the people been on the East Coast that you know of?

**Interviewer:** Yeah. So I’ve had a good chunk from, like, Boston. I’ve had a couple from New Hampshire, someone from Connecticut, one person from Canada ...

**Interviewee:** Oh wow.

**Interviewer:** ... a good chunk of people from, like, the DC, Maryland, Virginia area. And I have, like, a couple of people from Arkansas.

**Interviewee:** Oh wow.

**Interviewer:** I’ve had three people from Texas and I’m trying to nail someone down from California. So …

**Interviewee:** Wow.

**Interviewer:** It’s pretty awesome how diverse this will be. And just, like, because people are not geographically in the same place, I think their experiences will be quite diverse as well. So …

**Interviewee:** Yeah, yeah, definitely. No, that’s great.

**Interviewer:** Yeah.

**Interviewee:** I’m glad to hear that.

**Interviewer:** Me too. It’s been pretty inspirational. So …

**Interviewee:** Yeah. OK, so you’re going to send me that link? I’m going to get that done.

**Interviewer:** Yeah.

**Interviewee:** And meanwhile I’m going to send you I’m going to send you a picture of Aiden with his art just …

**Interviewer:** Yes, please. I’d love that.

**Interviewee:** And then I want to send you the Charting the LifeCourse and the guided transition stuff.

**Interviewer:** Yes. And I have a couple papers that you made me think of that might be relevant to you. So I’m going to send them to you also.

**Interviewee:** OK, awesome.

**Interviewer:** I will also send you a thank you gift card for your time and effort because we so appreciate it.

**Interviewee:** Awesome. Sounds great.

**Interviewer:** Well, have a nice day. I hope your meeting goes well at ten and I hope Zoom works for you then.

**Interviewee:** Oh, no. Oh my gosh, like, to your point. I’m like, “*Yes, that is another freakin’ Zoom. Ugh.*”

**Interviewer:** Oh well, hopefully it decides to cooperate in 45 minutes.

**Interviewee:** Yes, I hope so, too. All right, thanks, Rachel. You be well, it was good to meet you and work with you.

**Interviewer:** You too! It was so nice to meet you. Have a nice day.

**Interviewee:** You too and you take care of yourself, all right?

**Interviewer:** You too, stay safe.

**Interviewee:** You too. Bye.

**Interviewer:** Bye.

**[End of interview]**