**[Start of transcript]**

**Interviewer:** Right, we are recording? Perfect. And I will be asking you about your perspective about your child’s transition to adulthood in relation to his sensory sensitivities and interests. And we’ll be doing something called a semi-structured interview. And this means I have my, you know, planned questions right here. But I’ll also be adapting them based upon our conversation and actually making this conversation make sense and fit for us. Yeah.

**Interviewee:** OK.

**Interviewer:** Do you have any questions before, before we begin?

**Interviewee:** No. I’m OK.

**Interviewer:** OK, awesome. Also, if there are questions that make you uncomfortable or you don’t want to answer: totally OK. We want this to be a pleasant experience for everyone.

**Interviewee:** OK.

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

**Interviewee:** The main sensory we see is, like, touch, like, he, he’ll only, only wear certain clothes. He likes lots of blankets on his bed at night. The summer, even though it’s 95 degrees outside, he walks around in flannel pants, long-sleeved T-shirt and two blankets, which makes for a stinky teenage boy. So, you know, and you know there’s no tags, he wears a lot of hoodies, would be like, to be able to, like, kind of enclose himself in if he’s getting anxious. His food that he eats is pretty limited. You know, he’ll do some pastas, tacos, certain types of chicken. He seems to know if I switch brands with food, which I think is amazing and to be able to tell the difference between my [inaudible pasta sauce brand, Grand Ragu? at 1:22] and Predo, Prego spaghetti sauce.

**Interviewer:** Well, yeah.

**Interviewee:** You know, when he was younger, light seemed to bother him. He used to complain about, like, the overhead lights in the classroom. I don’t know if they still bother him, if he just realized there was no change. And he just had to deal with it. So I’m not sure what he thinks about those now. Um, interest wise, he’s kind of all in or all out with something. So, I mean, unfortunately, this summer, he’s just been playing a lot of video games, because there’s not a lot of other choices. So it’s hard to get him away from that. Because ...

**Interviewer:** Totally.

**Interviewee:** You know, it’s also a way to connect with some friends. But, really, he plays video games and he plays soccer. You know, so, those are his interests. Like, he doesn’t have like, a wide variety [inaudible at 2:11]

**Interviewer:** For the touch sensitivity: so you mentioned, like, he likes certain clothes. Is it, like, certain fabrics he prefers or certain, like, articles of clothing?

**Interviewee:** It is fabrics because if I buy him a new shirt, and I’ll say, “what do you think about this shirt?” The first thing he does is reach out and touches it. That’s his first test. If it doesn’t feel right, like, it doesn’t matter what it looks like, or what brand or what style it is, like, it has to touch, pass the touch test first.

**Interviewer:** Yeah. And is it like, soft things he prefers, like, you know what type of touch he ...?

**Interviewee:** It tends to be soft, but he’s, he’s got one shirt that he refuses to get rid of. And it’s actually a dry-fit shirt, but it’s like, a really thick, dry-fit shirt. I don’t know what the hell you would call that. It’s just ... and we’ve looked all over for it. It’s, like, an Adidas brand. Like, we’ve tried like, every Adidas shirt we look at and he’s like, “That’s not it. That’s not it.” I don’t know. There’s something about that shirt that he just loved. And …

**Interviewer:** And yeah, absolutely.

**Interviewee:** Holding onto … Yeah, but like, too, he would always ask for soft blankets at Christmas time. That’s obviously a new one every year because they kind of wear out over the years. He needs to get a new soft one.

**Interviewer:** Absolutely, yeah.

**Interviewee:** But I mean hoodies is a definite all winter long, he wears hoodies. So, some of it is style. He tends to wear sweatpants. He’s not a big, like, jean or khaki pants kid. Like, he’ll do it when he knows he has to or should, like when he’s going out with friends, he knows he should wear jeans. So he’ll put them on but, like, for school and home? It’s either his flannel pants at home or sweatpants. Like, they’re [inaudible, school uniform? at 3:36] …

**Interviewer:** Yeah. And so, how does he manage or cope with these sensitivities or these, like, preferences you’ve described?

**Interviewee:** I mean, it is, like, I think, one of the challenges of going into adulthood is he’s doing this internship year program and we have to prep him for, like, you’re, you’re probably going to have to wear khakis. Like, I’ve tried to get him to help me look online for shirts he would like, because, you know, we’re not sure where he’s going to be working. It might not be that formal, but I’m like, “You probably can’t wear a hoodie. So do you like Henleys? Do you like crewnecks? You know, like, trying to get him thinking about, like, where can you branch out from a hoodie and wear something else. So, you know, in high school, there’s no dress code. Well there was, but, you know, basically any hoodie he could wear as long as it wasn’t inappropriate and, you know, sweatpants. So, I mean, he’s kind of been OK in that realm. It hasn’t really bothered him and at home, you know, his friends don’t see him. So, you know, like, they don’t know he’s huddled up with, like, all these blankets whenever he’s playing video games with them. And he’s got some pretty understanding friends, like, they understand, like, if they’re going out to a restaurant, they usually let Aiden choose, because they know how fussy ... yeah, he was really lucky to fall in with this group of kids. But you know, they’re pretty flexible in what they eat. And they know he’s not, so they just try to accommodate him with stuff, but ... It won’t always be this way, but at least it is right now.

**Interviewer:** For his food preferences, like, when he isn’t able to eat the foods he likes, how does he handle that? And how does he, like, manage and cope with that?

**Interviewee:** He gets pretty disappointed because sometimes he’ll get really excited to go out to a restaurant and, like, will look ahead of time and he’ll think like, “Oh, you know, I’ll have the burger.” For his eighteenth birthday, we went out to one of those Brazilian steak houses because he does like steak. And he was excited to try all these different meats. And he didn’t like any of them. And you could just, like, see the disappointment on his face. And we’re, like, “Well, we’ll get you some ice cream on the way home and then you can just eat something when we get home.” So, like, behaviorally, he manages, but we can just see, like, the disappointment and, I mean, he tried lots of different things. But, you know, he loves ribs, but every time we seem to get ribs and they’re too fatty for him. So most of the time, you know, what he gets, like, a lot of his favorite foods are just not quite what he envisioned them to be. So … He drinks a lot of whole milk for nutrition.

**Interviewer:** That’s good.

**Interviewee:** That’s how we put weight on him.

**Interviewer:** That’s good. So it seems like, he likes a lot of things. But he’s kind of particular about the things he likes. Is that a fair statement?

**Interviewee:** Yeah, like, he likes grilled chicken, but he probably only likes, like, the marinade I use. Like, if he were to go to a restaurant and get a grilled chicken, it wouldn’t be right.

**Interviewer:** Gotcha.

**Interviewee:** Kind of thing. Whereas he ... like, one restaurant he’ll, like, come from, but even though we cook it at home, he kind of picks around ’em, you know.

**Interviewer:** Got you. And you talked about lights? And, so, you just got … you said he kind of just kind of dealt with it in school? Does he just ... are there other times where he just kind of deals with his sensitivities?

**Interviewee:** Yeah, he knows when he has to, like, put on khaki pants for something. And he’s not comfortable. But I guess he … he knows ... he’s smart enough to know, like, well, this is for, like, two or three hours. And then I could, like, go back home. And ... we were going someplace the other day that I told him he had to wear, like, jeans or dress ... he had to wear, like, khaki shorts. He’s like, “Well, I’m bringing my sweatpants in the car so I can change out of them as soon as we’re done.” Oh, yeah, we did a … we did a, a tour of his gap year program he’s going to go to and I’m like, “You can’t show up in gym shorts.” But he just made sure he had gym shorts in the car. And, like, we did the interview, and we got in the car. And he’s like, “Don’t turn around.” He changed and he was done. You know? So.

**Interviewer:** I mean that’s a great ... like, that’s a great technique, you know, do it when you have to, don’t do it when you don’t have to.

**Interviewee:** Yeah, so he can do it if he has to, yeah.

**Interviewer:** That’s great. And then has he received any specific therapies or interventions to help him with these sensitivities?

**Interviewee:** No, we hadn’t had much luck in elementary school. They gave him an OT consult. But consult’s really not an intervention at all, as you know, it’s more like, the teacher hadn’t asked, “What is what should I do?” or “How can I help him?” You know, they didn’t really turn off the lights for him. So he didn’t really, you know, I think they would, like, to try to put his seat not directly under a light. But then in middle school, like, that didn’t transfer to middle school. We have Kaiser for health insurance. And I tried to ask him for OT when he was younger, and they said like, “It’s a rehabilitation, and he hasn’t had any sort of, like, injury or accident.” So he couldn’t get it. I don’t know. I went back and forth with them, like, to be thorough but, I mean, he’s pretty high functioning. So he was getting along. So I was like, “OK, like, I don’t know.” And it’s kind of just like, you know

**Interviewer:** Yeah, there’s some battles, you’re going to lose with insurance and some battles you probably won’t.

**Interviewee:** Right, yeah.

**Interviewer:** Yeah, that’s a bummer, though. I’m sorry.

**Interviewee:** Right. It didn’t impact his school so much. Like, we couldn’t push to get services there. You know, we tried for, like, speech services for, I mean, not like going out to talk to a [physician?] you know, like, his language, like, he tends to, like, roam off topic. Like, he has great language. There’s no, you know, like, problem with his speech. But, you know, there’s other things speech and language helps with and social skills, but the schools are like, “No.” So yeah, sorry.

**Interviewer:** How frustrating. I’m sorry.

**Interviewee:** It’s OK. All right.

**Interviewer:** So you touched on light, how that sensitivity had changed over time. And so he’s no longer ... it’s that he’s either no longer sensitive or he doesn’t complain about it anymore. Has he changed in other ways in regards to his sensitivities over time?

**Interviewee:** You know, he’s, I guess, with the food, like, he’s willing to try new things, like, we’ve set up kind of like, deals up like: “You just have to try this food and then you can move on for something else.” I don’t know the ... I guess the other sensitivity … he does have some sound sensitivity because the deal in our house is, like, we can have, like, a car windows down if we’re driving under 25 miles an hour. After that, like, I don’t know if it’s, like, the wind or even ... it just gets loud and he doesn’t seem to ... to like that. So would be another one of his sensitivities.

**Interviewer:** It’s ... Oh, sorry. Go ahead.

**Interviewee:** Oh, [indecipherable] somebody got those big, old box fans. And yeah, he doesn’t like those, but those are also noisy and he has a fan in his room that’s nice and quiet, so that might be a noise thing. With those loud box fans going at night, I don’t know.

**Interviewer:** Yeah. And is he only sensitive to that? The sound that happens when you drive really fast? Are there other noises that are bothersome for him?

**Interviewee:** I mean, he does fine with, like, fire drills in school. Like, I know that’s a ... I mean I’ve worked with kids on the spectrum too. And that’s, like, whether they deal with it ... sometimes you have to, have to warn or ...

**Interviewer:** Yeah.

**Interviewee:** He never wore headphones, so he doesn’t complain about, like, stuff like, if we’re out somewhere and a police car goes by, he wouldn’t complain about the siren or anything.

**Interviewer:** Oh my God! Got you. And has his preferences for certain clothes, has that been ... or, like, different fabrics, has that been consistent over time? Or has that changed at all?

**Interviewee:** No, it’s consistent. Like, once he discovered his first hoodie, like, “let go” like, he’s been so … yeah. I mean, like, the type of sweatpants he wears, he wears changes depending on the style. Like, it used to be there was, like, soccer pants. Now it’s, like, the big, baggy straight-legged ones. So the material is a little different, but it’s still, still sweatpants. So yeah. So you can see ...

**Interviewer:** Yeah. And then regarding his kind of openness to trying new foods, do you think that changed related to any independence that he’s gained over time?

**Interviewee:** Um, maybe a little bit because as he can drive more he can ... he’s spending more ... he can ... well, before the pandemic, he would spend more time with his friends. And he would be able to say like, “Oh,” like, “I have this at my friend’s house.” Because I often think he knows … again, like, he has to deal with it. Like, if he’s at someone’s house, he’ll eat it. And sometimes, like, a mom will come up to me and be like, “Oh, you know, he didn’t eat this tortellini soup. Like, you should try that with him.” And I was like, “Oh, he’s sort of leaning it out” and I’ll ask him and he’s like, “Oh, that was gross, because I just ate it.” OK. So he, he, you know, I can see he does, you know, accommodate himself for what he has to do to fit in.

**Interviewer:** Perhaps you have to eat foods you don’t like, and that’s kind of just true for everyone ...

**Interviewee:** Yeah. That’s true.

**Interviewer:** Then do his sensitivities, um, cause anxiety or increase anxiety for him?

**Interviewee:** Um, I mean, we’ve seen him get really anxious sometimes. So not noticeably anxious, like, when he had to wear like, khaki pants and a nice shirt for this interview, you can tell he was just like, “Uh,” but he didn’t, like, voice any anxiety or worries about doing it, just that he didn’t want to do it. Or, you know, we’ve taught him to, like, look online and preview the menu at a restaurant so he can kind of know ahead of time what he can order. So I do that as a way of, like, heading off some of the anxiety of just getting there and being overwhelmed and thinking, “I don’t like this; I don’t like that,” you know. So that’s something we encourage him to do, if he’s going to, you know ... But he doesn’t really voice anxiety about that stuff.

**Interviewer:** And has that been consistent over time?

**Interviewee:** Um, I mean, it’s probably gotten better when he’s gotten older, but also, like, we just didn’t go to restaurants a lot as a kid, when he was little, because it just wasn’t worth it. Or just leave the kids at home with a babysitter and we can go and enjoy. That’s probably also … my younger kid was kind of picky when he was younger, too. I think little kids don’t like good restaurants anyway, so.

**Interviewer:** Yeah. It’s tricky. And then right at the beginning, you mentioned that when he gets anxious, he does use his hoodie as, like, a mechanism. Can you talk a little bit about that?

**Interviewee:** It’s just when, you know, he’s shutting down. Like, he doesn’t wear the hood on the hoodie. But when we see him with the hoodie, and then you can also tell by how tightly it’s getting pulled, like, how upset he’s getting, you know, so you just go and ask him like, “What’s wrong, what’s going on?” And it, but it’s just his way. I mean, when he was little, like, I guess pressure used to be a thing. He would go to his room and take his mattress off his bed, and then he wanted to, like, lay on top of the ... so he would get under the mattress. And then he was supposed to, like, lay on top of it for, like, pressure.

**Interviewer:** Totally.

**Interviewee:** Hiding in closets was this thing when he was little, kind of just like shutting everything out when he’s feeling overwhelmed.

**Interviewer:** Yeah, and he doesn’t seek that pressure anymore?

**Interviewee:** No, not really. Just, he hasn’t done that in a while. But I mean, he does do lots of blankets, but that’s not nearly as much pressure, I would think as, like, a mattress [inaudible crosstalk at 15:00] … on top of you.

**Interviewer:** That’s a little different. Awesome. Um, and then, what goals or hopes do you have for him in terms of his sensitivities?

**Interviewee:** Um, just that he continues to grow, like, I ... it’s not really going ... so that it doesn’t limit him, you know, as he moves on to this internship year, and people are like … The friends he makes are going out to dinner, he’s at an internship, and they’re bringing in lunch that he can, you know, work his way around that, that he can find the clothes that will pass for, you know, whatever situation, whether it’s a social situation or a business situation. And, you know, I think a lot of stuff he does, he hides at home, like all the big heavy, like, pajamas he wears all day and the blankets and just how he’s going to figure that out, when he’s kind of work skills or when he’s with his peers or, you know, in a dorm. So he’ll be in an apartment this fall with four to six other kids and I think there’ll be other spectrum kids there, that’s kind of who they … they don’t totally deal with that. But you can … when you read their website, they talk about that. But when he goes to college next fall, you know, he won’t be in a special program. So he’ll just be in a dorm with all those other college kids. And I’m, like, finding a way to, like, get his sensory needs met, but either, you know, not stand out and fit in and also just feel comfortable.

**Interviewer:** Mm-hmm. Absolutely. And he’s doing that WPI thing in the fall, is that what you said, in Worcester?

**Interviewee:** It’s in Worcester. It’s the [inaudible at 16:38] Dynami. It isn’t associated with like, a university or anything ...

**Interviewer:** Got you. Um ... awesome. Right. Oh, sorry. Just reading this. And now, kind of shifting gears and because, like, we have five sections, now we’re going to go into our second section.

**Interviewee:** OK.

**Interviewer:** As he has grown up and aged, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** Um, I mean, I don’t know if they’ve reacted much at all. I mean, I guess I talked about his friends, who are kind of understanding.

**Interviewer:** Totally.

**Interviewee:** In high school, he was in a mainstream school, but in a program for kids with Asperger’s, so he had a resource class. Um, so I mean, but I, he, I don’t think that, you know, that was one of the ways he was, had accommodations was for sensitivity, but those people understood him. With an active shooter drill, he would get really anxious, and I don’t think that was a sensory thing at all, but, like, they would plan it so he was down in the resource room, rather than, like, in the mainstream classroom. So they would accommodate him in some ways, but not a lot of ways. And, I mean, otherwise, I think people just don’t know. You know, like, he would ... his grandmother in New York, I don’t think she really understands what’s going on. And, you know, she just serves food and like, “Why can’t he just eat that?” Well and, you know, he’s picky … and, you know, so I think some people, you know, they’re not huge, huge sensory things, so he can kind of get by and so I don’t think he gets a lot of accommodation in the community.

**Interviewer:** Mm-hmm. Absolutely. What about other family members? Are other family members more, like, privy to him in that way?

**Interviewee:** Yeah, I think my parents are because they live really close. And, you know, they would be our babysitters when he was younger, so they understand him more. But, you know, for, like, my brothers and my sister-in-law, you know, they just see him here or there, you know, or for a couple hours on the weekends kind of thing. And I think that, yeah, they’re kind of aware, you know, but it’s not, like, the whole all of his needs and stuff.

**Interviewer:** Absolutely. And then, um, what about when he was younger? Was the community equally as, like, neutral? You’re kind of describing it as neutral because they don’t really stand your ...? Or was it different when he was younger?

**Interviewee:** I think it was harder when he was younger. I mean, he didn’t get diagnosed till he was in second grade. So, you know, part of it was, no one really understood what was going on at that point. And, you know, I think some kids and their parents just didn’t fully understand his needs even in, like, later elementary school. And I think, like, the kids weren’t as mature. So he switched out of his elementary school to a brand new middle school, and that’s where he found these really nice kids that, like, are really accommodating. But, like, I wonder sometimes if he had met them when they were five, they probably wouldn’t have had that maturity to, like, accommodate him. So I think, in elementary school, there wasn’t a lot of people accommodating him. Just like, “We’ll just go find some other friends.” But then in middle school, it’s hard to say, middle schoolers for sure. But I think those kids figured it out. And, you know, liked him for who he was, like, you know, they like to do games. They like soccer too and they just dealt with the other stuff, so...

**Interviewer:** That’s great. I’m glad he found that group. That’s really, really important.

**Interviewee:** Yeah, he was lucky.

**Interviewer:** Yeah. Um, and then you kind of touched upon this, but, like, what aspects of the community were more or less accommodating and accepting? Like, what, like, places and spaces?

**Interviewee:** Um, I don’t know if it’s places or spaces, but just, like, the people who are there, like, I think people whose, like, maybe parents were an educator or parents worked in mental health, they could kind of, like, see, figure out what kind of, what was going on, or they had the skills to, to, like, move plate, move to different places, or be willing to switch where they’re going to eat. But where I think the parents who maybe were more, like, accountants or, you know, business people that just have, like, don’t understand, like, human development at all or ... especially. I think they were just like, “But we’ve all decided, like, we’re going to this restaurant. And that’s just where we’re going. Going.” You know what I mean? Like, “No, we’re not moving out of the sun or away from the noise,” you know, like ...

**Interviewer:** Yeah.

**Interviewee:** So I don’t think it’s necessarily places being accommodating. But, like, people and even restaurants, you can tell, like, some waiters and waitresses are really nice. And some are just like, “This is what you ordered. Sorry.” So...

**Interviewer:** Yeah. You just mentioned sunlight. Would sunlight bother him before?

**Interviewee:** Um, I don’t ... I don’t know ... I mean, I was just trying to think of an example. It’s hard to, like, work with the kids, too. I don’t think we ever had to, like, move out of the sun so much for him as, like, “the sun’s bright, too bright for my eyes.” I mean, you wear sunglasses as a kid, but I don’t know … that was sensory or not.

**Interviewer:** I mean, people wear sunglasses all the time, too. Yeah. Absolutely. Um, and then again, thinking kind of to the future. What are your hopes or worries about how his community will react to him as he continues to grow up?

**Interviewee:** Right.

**Interviewee:** Yeah, I mean, he wants to go into STEM. And I think maybe that community is, you know, has a lot of Asperger type kids in it. You know, he’s not looking for, like, a really social job. You know, he’s not looking to be, like, a teacher, or … I don’t know, sometimes when you’re always interacting with people, like, so he can have that chance to be alone. And maybe some of his quirks, he’ll either find co-workers that are like, “Me, too,” or, you know, they won’t really need to be accepting because it’s more of a norm in those places. And, I mean, I guess we just hope when he goes to college, he just gets lucky again, and eventually just finds a really good group of kids that’ll be accepting of him. And whether they’ll come from the dorm or maybe once he starts his computer classes, he’ll start to find kids, he can really click with and so ...

**Interviewer:** Absolutely. Does he want to do computer science?

**Interviewee:** Yes, that’s what he wants to major in.

**Interviewer:** It’s a great field right now.

**Interviewee:** So we hope we can keep up his math, because with the gap year, you’re taking a year off of math. So let’s see how he does [inaudible at 22:53].

**Interviewer:** I’m sure he’ll figure it out. I’m sure he’ll figure it out. And now shifting gears again, to our third set of questions. In that, like, transition to adulthood, where do you see him?

**Interviewee:** Oh, he’s at the very beginning. He’s no … he’s 18, just graduated high school. I mean, part of why we’re doing this gap year, like, we’ve talked about it long before COVID. I know, it’s, like, a new trend with the COVID stuff. But we just felt like he needed a year between home and college because he is pretty dependent on us. And he doesn’t mind that. And as much as we push him to be independent, he just won’t do things, rather than, like, do it himself. And we just then felt like just going from home to, like, a college dorm, taking a full load of college courses, was just a setup for failure for him. So we were looking for, like, a year for him to be independent. And we weren’t looking for, like, travelling the world or, you know, going somewhere and teaching English in a foreign country kind of gap year, we just … I mean, this dining program seems perfect for what he needs to do. He needs to move out into independent living skills and, like, self-management skills, and then, hopefully, he’s a bit more mature and then that moving to college won’t be so overwhelming because he’s gotten the independent living piece done. And he’s done that and now he can just deal with, like, the transition to academics of college and those kind of different demands. So we just wanted to break it up. So, I mean, I think he’s … why he’s at the beginning, I think he’s behind, like, a lot ... most typical eighteen-year-olds.

**Interviewer:** Got you. Could you give an example about how he thinks ... how you view him as being dependent and, like, how he won’t do something if you ask him to do it.

**Interviewee:** Um, he’ll get up in the morning and he’ll say, “Can you fix me some hot cocoa for breakfast?” And I’ll say, “No, you can go fix your own hot cocoa.” He’s like, “Oh, never mind, then.”

**Interviewer:** Got you.

**Interviewee:** A lot of that he won’t do, he just won’t do it. Like, “Can you go get me this from the kitchen?” I’m like, “No, go get it yourself.” He’s like, “Nah, never mind then.” So, you know, and I think eventually he’ll go do it or he’ll just goes hungry, then he eats a big dinner kind of thing, but ...

**Interviewer:** Sure.

**Interviewee:** There’ll be no one next year to do those things for him.

**Interviewer:** Absolutely. Thank you. And then, thinking about, like, specific stages of independence, like, does he want to live on his own eventually? Like, does he want to have a job? Is he able to fix himself food, he would if he chose to, things like that?

**Interviewee:** Oh, he definitely wants to move out. And, you know, he was kind of dragging his feet on this whole gap year thing. And then what really pushed him into buying into it was when he heard all these colleges are starting to do, like, hybrid models, or even some colleges were, like, shutting down and not letting kids live on campus. And yeah, I was, like, he didn’t do well with the online learning in the spring. And so he’s aware that … he’s like, “I couldn’t do college if it’s online.” And I was like, “So if you want, so you can live at home next year and work or something, or you can go to this Dynamy program and get out of the house. He’s like, “OK, I’ll go to Dynamy.” He definitely wants out and, you know, wants to be, like, a typical eighteen-year-old, like, in college, or just out of the home. We’ve been working this summer on meals, because where he’s going, there’s no cafeteria, like, it’s an apartment, and they have one day a week set aside for independent living skills. So they’ll do some ...

**Interviewer:** Great.

**Interviewee:** … work built into that, and, like, money management and grocery shopping and travelling, travel training, but, um, you know, we, we’ve been working on, like, a couple go-to meals over the summer that I’m like, “All right. This is one of the meals you can cook, like, at Dynamy. Like, you need to come upstairs, and I’ll guide you through it.” And so, um, I mean, he can cook, like, ravioli right now. And I mean, like I said, he uses milk as his, like, filler, which is better than some of the, like, junk foods and stuff. Um, so we’re, you know, we’re working on the meal part. But there’s a [inaudible at 26:25] question, not, like, meals ...

**Interviewer:** Just kind of, like, general stages of independence. So you talked about, like, wanting to live on his own, like, food, like, money management, like, does he manage a social life? Does he take care of himself physically?

**Interviewee:** Yeah. So, like, he’s been doing laundry for years. Money management, all through high school, he got $25 a week on a money card, and they were allowed off campus to go buy lunch. So we’re like, “Well, here’s your money, you know, go.” Because he wanted to do that, he wanted to go off campus. He didn’t want to bring lunch. So he was in charge of managing that. And he figured out the cheapest way to eat, like, at the local restaurants and, or he would know, like, well, I’m going to splurge this day, and then just bring some, like, pretzels or sandwich from home to make up for it. So he seemed good with his money.

**Interviewer:** Mm-hmm, that’s great.

**Interviewee:** Yeah. Um, so he’s got some cooking. I mean, no, he has chores around the house. So, hopefully, those will ... you know, transition to the apartment. Like, he can clean bathrooms. He can vacuum.

**Interviewer:** That’s great.

**Interviewee:** His room’s a big mess. But when we push enough, it gets pretty clean.

**Interviewer:**

Awesome, Is he good about, like, personal care, like, personal hygiene?

**Interviewee:** He tries ... like, he does, he showers daily. But again, like, when you go back to wearing, like, all those clothes and blankets when it’s 95 degrees out, even in an air conditioned house, like, you just stink. And we’re telling him, like, “You’ve got to figure this out somehow, like, if this is what you need to do. Do you need to shower twice a day, so you’re not stinky? But, like, you can’t do this at Dynamy. Like, no one’s going to want to sit next to you and play video games.” So.

**Interviewer:** Yeah, absolutely.

**Interviewee:** And to solve it. So I mean, I think he is good, I think dental wise, but I think with, like, not leaving the house, like, he needs prompting, like, “Have you brushed your teeth today?” Like, normally, you would do it when he leaves for school? Like, that was his habit. I think everyone’s had those moments during the shutdown, like, oh gosh.

**Interviewer:** Oh yeah.

**Interviewee:** So he’s got the ... I mean … and that’s also a concern there that, like, some of the skills he’s had, like, that, that he’s losing them. So, hopefully, Dynamy getting in that kind of a different environment than just being home will get him back.

**Interviewer:** Oh yeah.

**Interviewee:** Get him those skills back. So ... yeah.

**Interviewer:** Hopefully. And then you briefly touched upon video games as a way for him to, like, communicate with friends. Does he manage a social life to a degree?

**Interviewee:** He does. I mean, it’s hard. So, because he didn’t go … because he was in his Asperger’s program, he didn’t go to our local high school for middle school or high school. It’s about 20 minutes away. So in middle school, it was hard because the parents were still kind of managing social life. But then, as the boys got older, and they were doing their own thing, a lot of things just happened organically, like, the neighborhood boys would be like, “Hey, let’s go do this.” And then there’s, like, 8 and 20 minutes away. So I think sometimes he got left out or the plans were happening so quick. He just couldn’t like, like, dive in. Um, we got him, got his driver’s license. We thought that would help but, like, even with the shutdown, his friends they, like, go to an elementary school parking lot. And they just, like, circle up their chairs and sit, like, they’re so good. So you know, like ...

**Interviewer:** That’s awesome.

**Interviewee:** Like, he’s like, “I don’t want to drive 20 minutes to sit in a parking lot.” And I’m like, “That’s like, that’s life, like, your friends aren’t doing other things. They’re not playing soccer. They’re not going to parties. Like, that’s what they’re ...” and he’s like, “But it’s, like, two minutes for them.” And so, you know, I guess, so it’s kind of dropped off a little bit with them, but he can connect with them through video games.

**Interviewer:** That’s OK.

**Interviewee:** So he’ll see them a couple ... of times a week to play video games. Yeah.

**Interviewer:** I think that’s also, like, a very normal feeling right now. Because it’s like, “Do I really want to drive to go sit outside?” But that’s all people can do, right?

**Interviewee:** Yeah, like, “Nobody’s doing anything else, Aiden. Like, no one’s going to the movies. Like, they’re not going out to restaurants. Like, that’s what they’re doing.” So. [inaudible at 30:35]

**Interviewer:** Um, and then thinking towards the future, do you think he’ll be able to gain more independence and more skills towards independence?

**Interviewee:**

Yeah, I mean, we presume living independently, you know, hopefully, he’ll make it through college, but if not, I think he can come home and just do some training program and then live on his own.

**Interviewer:** But especially with computer science, a lot of people can teach that to themselves. And you don’t need a college degree for that the way you do for other professions.

**Interviewee:** Right. Yeah. So I mean, that’s what we see in the long ... in the future is, he’s going to be on his own.

**Interviewer:** Yeah. And then what do you think will help move him into adulthood and move him into increased independence?

**Interviewee:** I mean, I guess he’s got his plan. Like, he’s got Dynamy. And then he’s got Drexel, and then there’ll be supports along the way, like, it … So he’s not totally doing on his own. So, like, I think I’ve talked about at Dynamy there’s independent living day. He’s got an advisor he meets with once a week. There’s a residential advisor that checks in on them. And then at Drexel, there’s, they call it DASP, it’s, like, an activism support program. So he’s going to sign up for that. So even when he moves to college, I think you get a counsellor you meet with, like, an advisor you meet with once or twice a week, there’s, like, study sessions. Um, there’s some social stuff, which he says he doesn’t want to be a part of, like, he doesn’t really like to be a part of the Asperger world. So he doesn’t really want to socialize with them. He wants to find his own friends and stuff. So I think, you know, like, he’ll become more independent, because there will be people. I feel like he’s got people watching him along the way, even though the program at Drexel is meant to be a fading program, and then they see upper classman becoming, like, you know, supervisors or mentors for their freshmen and sophomores. So then I think, you know, so then by, by the time he’s ready to graduate from Drexel, he should be, like, independent and ready to go.

**Interviewer:** That’s awesome. So, so great.

**Interviewee:** You’re stressed.

**Interviewer:** Yeah, no, I’m sure, I’m sure. It’ll be awesome. That sounds like two really great programs lined up. And now, kind of putting these two things together—sensory sensitivities and this transition to adulthood—how do they intersect for him?

**Interviewee:** I think he’s just got to keep on managing and then, hopefully, as he gets older and he has more experiences, his, like, tolerance will improve, increase, you know. Like, maybe he’ll start finding other restaurants or other menu items at restaurants that he can eat, you know, and that, you know, the clothes … like we said, he can deal with it so that I’m not so worried about. Like many of us, he can just come home from work and change into his pajamas. After all this COVID stuff, he’ll just work from home and he can work in his, like, maybe not pajamas, but, you know, like, nice, soft, comfortable clothing.

**Interviewer:** Yeah.

**Interviewee:** Yeah. So I think, you know, those seem to be his two big things.

**Interviewer:** Mm-hmm. Absolutely.

**Interviewee:** Yeah.

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

**Interviewee:** Um, I wouldn’t want to call them a vehicle because that seems like a positive thing. Like, I think it’s going to be a struggle, and he’s going to have to work through it or problem-solve along the way. Like I said, like, because he needs to dine here or, like, “Hey, let’s go out for Thai food.” Yeah, he’s going to have to make a decision, like, “Do I just stay home? Or do I go and find, try to find something?” And so I think it can be a bit of an obstacle, and hopefully he’ll choose to kind of make it available and go along with it and not [inaudible at 33:49] doesn’t eat and not sit at home. So ...

**Interviewer:** Absolutely.

**Interviewee:** Yeah.

**Interviewer:** I don’t think I actually asked this in the beginning, but in terms of his taste preferences, is it, like, mild things? Like, is there, like, a theme about the foods that he likes or is it just what he likes?

**Interviewee:** It’s just what he likes. Like, he eats medium spicy salsa, so it’s not mild food, but he likes chicken. He likes lobster. He likes shrimp. You know?

**Interviewer:** OK.

**Interviewee:** You’re from Maryland. You have to like crabs, but, like, he won’t really eat any other seafood. But he likes pastas, but he likes, like, plain ravioli or he’ll eat, like, pasta with meat sauce, but nothing like ... I mean, he needs to eat, that’s one of the things that he was cooking last week was, like, a big CD [?].

**Interviewer:** Right.

**Interviewee:** And he wouldn’t have any, like, he doesn’t do meatballs. He wouldn’t think of having, like, vegetables mixed in with his pastas, even though …

**Interviewer:** Right.

**Interviewee:** … like, “Well you like green peppers, and you like broccoli and you like pasta, so let’s put it all together with some chicken.” And he’d be like, “No, no.”

**Interviewer:** OK. Gotcha. Thank you for clarifying.

**Interviewee:** Yeah.

**Interviewer:** Sorry, I should have asked that earlier.

**Interviewee:** OK.

**Interviewer:** So kind of back to the intersection of sensory sensitivities and transitioning to adulthood. What do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities and preferences?

**Interviewee:** I think, just find a way to manage it around other people. Like, our family, he’s got a brother, you know, me and his dad, and we all know and just, like, you know, sometimes we all joke about it, and he can even joke about it. And but, you know, like, it is what it is, and he’s not embarrassed about it with us. But, you know, how can he have those needs and not be embarrassed about them in front of other people? But he’s got to his wisdom teeth out, so he has to have all soft foods, but the only yoghurt he’ll eat are all these kid yoghurts. He doesn’t like any of the adult yoghurts, I’ve tried to get him. So he’s got all this, like, Disney yoghurt in our refrigerator right now. Because those are the flavors, which … who cares—it’s just yoghurt? But, like, what if he got his wisdom teeth out at 28 and he had two roommates, and he had Pet Paws whatever or Paw Patrol yoghurt in the refrigerator? You know, like, how would he reconcile that? Like, would he force himself to eat something he didn’t like? Or would he be able to just be, like, “It is what it is and this is what I like, guys, and who cares?” You know?

**Interviewer:** Yeah.

**Interviewee:** So I think that is just, like, being like, “This is who I am and this is what I need” and with adults, like, his peer adults.

**Interviewer:** Absolutely, absolutely.

**Interviewee:** Yeah.

**Interviewer:** And what do you think will help him with this?

**Interviewee:** Um, I think just, hopefully, he’ll find good friends. I mean, I think, like I said, he met these, this group of great boys in middle school and, like, they accommodate him. And I think he’s less embarrassed to speak up to them or tell them what he needs. And because he knows they’re not going to laugh at him, or I don’t think … they do tease him but, I mean, boys tease boys, and, you know, you tease your friends, like, it’s that kind of friendly stuff.

**Interviewer:** Yeah.

**Interviewee:** Um, so he’s comfortable with that. So I think I felt that there was no question. So I hope, like, that, you know, hopefully, he’ll just find the right group of people that, like, don’t care, like, what he eats or what he … that he needs more blankets in bed kind of thing.

**Interviewer:** Absolutely. Absolutely.

**Interviewee:** Yeah. Um, so your question ...

**Interviewer:** No, yeah, that was, that was a perfect answer. Thank you. Um, do you think there are any services or interventions that could help him other than just surrounding himself by, like, good people who, like, love him for him?

**Interviewee:** Yeah. Um, I mean, I don’t know, like, how, like, an occupational therapist could help him at this point. I don’t know. This is going a little off ... Like, I’ve tried to get him, like, an executive functioning coach before and whether that … getting that stuff in line would help with other, you know, other parts of his life, his, you know, I don’t know. Like, it would bring his anxiety down and maybe he’d be more comfortable to eat other foods or try new things, you know, and they might help him plan out things a little bit better. Like ...

**Interviewer:** Yeah.

**Interviewee:** I said, we try to get him to look online and pick his food ahead of time, anything. You know, that’s all part of executive functioning, not just sensory stuff, but, like, planning ahead. So I don’t know if that services would have any impact on sensory needs, but I don’t think … I think he’s kind of too high functioning for, like, an occupational therapist at this point. And ...

**Interviewer:** Totally. You just mentioned anxiety. So what does he do to help himself when he does get anxious?

**Interviewee:** Um, not much.

**Interviewer:** Super fair.

**Interviewee:** Yeah. I mean, I tried to give him some pointers along the way. But, you know, not much We have Kaiser and we’ve tried therapists over the years and just really not had much luck with that. And I guess we just won’t make the jump to private therapy, because again, like, he does … There’s been a couple instances where he hasn’t been able to do things. Like, when he was a freshman in high school, there was this, like, big back to school, like, evening picnic and we got there and he’s just like, “I just can’t do it.” I’m like, you know, “Your friends are here.” Like, you know, for, like, 10 minutes, I just tried and he just got more and more anxious and just ‘leave, please just leave him.’ So he does what I’d call a couple things like that. But most of the time, you know, he is kind of nervous about new things, but he can get himself through it and he can, like, go join a new team or go [inaudible at 39:33] kind of thing. So we never really made the jump to private practice. Because down here it’s really expensive. It’s, like, $200 a session.

**Interviewer:** Sure. Yeah, that’s not trivial at all. It’s a lot.

**Interviewee:** So …

**Interviewer:** Um, and then kind of thinking back to intervention. So you said you aren’t really sure, particularly things would help him. But for kids like your son, or not like your son, maybe … but, like, do you think there are gaps in the available interventions and services for, to helping kids in this transition between adulthood and sensory sensitivities?

**Interviewee:** So, I mean, even just general, like, transition to life, like, I feel like our … It wasn’t necessarily the school system, but like, our county was just like, “Sorry,” you know, “he’s not needy enough.” So, like, if he was going to be referred to an adult service in Maryland, he would have been referred to DORS, we call it the Division of Rehabilitation Services, but you start to get into eligibility versus entitlement. And, you know, basically, all the disabled adults get in that one pot, and you look at someone, you know, that’s really, really disabled. And you look at Aiden, and they have to decide where to spend their money, and they’re just rightfully going to give it to other people. But that’s not very helpful because he does still have needs, and I think he could have benefited from some of the services that they offer. But, yeah, the money just wasn’t there. So I think there are gaps ... I think there’s things our school could have done more. I think, because he was in, like, a diploma program that was their focus. Whereas the kids who go to, we call it ALO, Alternative Learning Outcomes, they get a lot more … There’s, like, the certificate kids that stay in school till 21, they get a lot more, like, transition help and independent living skills help. I think they figured he’s a diploma bound kid that, like, he’s OK, I don’t know, or there’s not time for it. I don’t ... you know.

**Interviewer:** Yeah, so they kind of don’t think that those kids also need other, like, additional help. It’s kind of one or the other.

**Interviewee:** That’s what it seems like to me, yeah.

**Interviewer:** Yeah. Extreme. We all need help, no matter where we are, you know,

**Interviewee:** Right. Like, he had a transition specialist. But, basically, she just showed … she would interview him, like, two days before his IAP meeting, she would show up at the IAP meeting and present it. Like, it didn’t even make sense, because it was just for the answers and, and then we wouldn’t hear from her again until the next IAP meeting. So it’s more like, they’re following the law that this has to happen and this has to be part of his IAP versus like, well, like, “We’ve got this great opportunity here to, like, talk to the family and talk to this kid and find out his goals and his needs and how we can help him.” So never really. It wasn’t what it should have been. So...

**Interviewer:** Yeah. I’m just reading. I’m sorry.

**Interviewee:** That’s OK. I went through the whole system so I was well aware of what, you know … that this is what it was going to be. So...

**Interviewer:** Yeah, absolutely. And then so, for the final question for this section, um, how has Aiden’s sensory preferences and sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** I think that’s part of the slowing him down, like, that he needs an extra year. Um, when we visited college campuses, we always made sure we ate at the cafeteria. And that was one of our questions, like, could you do this? Like, at one of the schools he visited was really small and there weren’t a lot of choices. And he’s like, “Well, this one’s OK, but I don’t know about the other stuff they’re serving.” I’m like, “Well would you eat this every day for 10 months?” And he’s like, “Well, not really.” But, like, the bigger schools, there’s more choices. So that was my younger son, I mean, like, you kind of want to see what the cafeteria is like, but my older, my younger son, like, I don’t think that’s going to be, like, part of his decision making, like, the food that’s offered. But that was certainly a, you know, thought we had for him.

**Interviewer:** Totally.

**Interviewee:** Yeah, so I think that that’s the main sensory thing. It’s, like, the food part is slowing him down. And I mean, because he can wash his clothes and take care of himself. And we just have to hope that he would do it. And if he got stinky, someone would say, like, “You’re stinky,” and, like, your feedback would get him.

**Interviewer:** Yeah, absolutely. Especially if you’re living with roommates, you know, someone’s going to be inclined to tell him.

**Interviewee:** Yeah, and I think, like, the clothes sensitivity, like, as a freshman in college, he would fit in just fine wearing sweatpants and a hoodie. So that was not a concern of ours with the transition.

**Interviewer:** For sure. Absolutely. And then on to, like, our last chunk of questions. We’re almost done.

**Interviewee:** OK.

**Interviewer:** As a caregiver, as a mom, as a parent of someone with ASD, but also some sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** It’s that time between graduating high school and becoming an independent adult, though, and I guess the reason, like, Drexel’s a five-year college, so it’ll be a six-year process for him, which is fine, because I think, like we said, slowing it down a lot will help him, but it’s just learning the skills he needs to be independent.

**Interviewer:** Absolutely. And has this perspective changed over time for you?

**Interviewee:** A perspective transition?

**Interviewer:** Yeah. Like, this, like, the idea of, like, what does transition to adulthood mean to you? Has that perspective changed over time?

**Interviewee:** Um, I don’t think, for me, I’ve worked in special ed for 20 plus years, so ...

**Interviewer:** Yeah.

**Interviewee:** I think, I mean, I think if you were interviewing my husband, you’d probably get a different answer. But, like, we’ve been a part, like, that … When I talk about our DORS, I refer kids to that program. So I knew well, I had going in, when they started talking about Aiden’s IET meetings, I was like, “I know what you’re going to say next.” You know what I mean?

**Interviewer:** Yeah.

**Interviewee:** So I think I just had to jump on it. So.

**Interviewer:** Oh, sure.

**Interviewee:** So I don’t really think ...

**Interviewer:** Sorry?

**Interviewee:** So I don’t think my perspective of transitions changed because of Aiden just because being in special ed for so long.

**Interviewer:** Yup.

**Interviewee:** So

**Interviewer:** It’s like, you do.

**Interviewee:** OK, yeah.

**Interviewer:** And then, what do you see explicitly happening in his future?

**Interviewee:** Dynamy. And, you know, going to Drexel. One of the reasons why he picked Drexel is because they do this. I don’t … if you’re familiar with Drexel, they have this co-op program. So he really liked that because he can go to school for six months, and then not, like, take time off, but take an academic break and work for six months. And that was really appealing for him. So, you know, hopefully, he found the right fit school and, you know, all that’s going to work out for him.

**Interviewer:** And do you see him living independently?

**Interviewee:** I think so. I mean, if he can look away at Drexel for five years, because it’s year, almost year round. I’m figuring he’s going to want to do his internships, like the co-op stuff, in Philly, and not move home for six months. So I think by the time he does that, and, I mean, it’s six years from now. So, makes him a bit older than most graduating college people that you’ll be ready to be on his own. And he’ll make a lot more money than me as a computer scientist, so he’ll ...

**Interviewer:** Oh, yeah

**Interviewee:** ... be able to live on his own.

**Interviewer:** More than me, too. Do you see him having a partner and having a family of sorts?

**Interviewee:** He talks about wanting a girlfriend, like, he … I mean, he’s only 18. When he talks to … sometimes he’s just like, “I’m never having kids,” or sometimes he’ll say, “I’d adopt kids.” And so I don’t know, like, about that part with him. But I do think he’ll find somebody eventually. But whether, you know, they, they go and have their family, or if that’s just going to be their family, that part I don’t know. We wonder that sometimes.

**Interviewer:** Absolutely. And then for my final question ...

**Interviewee:** OK.

**Interviewer:** Did Aiden’s sensory sensitivities impact this perspective that you have about his transition to adulthood?

**Interviewee:** It definitely had some impact. But, like, the largest impact, you know … we definitely have other worries about him. You know, like, because his executive functioning, his perseverance kind of thing, sometimes anxiety, like, his lack of independence, you know… So, everything formed our perspective about, like, making his plans for transition, but that was definitely parts of it.

**Interviewer:** Awesome, thank you. That’s actually it, that, for all of my formal questions, would you like to add anything else?

**Interviewee:** Um, no, it was a lot of questions. It was hard for me to, like, think of things and remember things. And so it was an interesting process.

**Interviewer:** I’m glad you enjoyed it. Thank you for sharing your perspective. It’s, it’s so awesome to hear from you and to hear from parents like you. It’s, it’s been really exciting.

**Interviewee:** No, well, thanks for researching this.

**Interviewer:** Yeah. Anytime.

**Interviewee:** OK.

**Interviewer:** Do you know anyone who might want to participate in this study? We’re still looking for participants.

**Interviewee:** Um, I mean, I’m on a list and everything. That’s how I found out about you. Somebody else had just done it with ... [inaudible at 48:59] She put it on the list and I was like, “Oh, I can do that.”

**Interviewer:** Yeah.

**Interviewee:** Yeah. That would be, like, my main source of that, since it’s already been posted there. I can’t really think of any reason. Aiden’s not that into the Asperger world. Like, we met some of the parents in middle school again, because the parents are, you know, more involved. But he’s kind of drifted away from those kids over the years. And we haven’t kept really in touch with the adults. But …

**Interviewer:** No worries. If someone comes to mind, let us know. But, like, no pressure, obviously. But we’re so glad that you got the listserv. You’re on it. We’re so glad you wanted to participate. Such a pleasure.

**Interviewee:** OK, yeah. No problem. And I’ll go and do those two forms.

**Interviewer:** Yes, please. Thank you. And so, once those are done, I will send you a thank you gift card for all of your time and all of your effort. And that, that’s it for me. Do you have any, like, final questions, or can I help you with anything? Can I do anything for you?

**Interviewee:** Do you ever, like, share, like, the study once it’s published, or would there be a way to see that?

**Interviewer:** Yeah. Yeah, so that was the second-to-last question on the demographics form that you filled out. And you said yes. So you’re … we know that you want to know about our results.

**Interviewee:** All right.

**Interviewer:** Yeah. So we will definitely send you the manuscript when it’s done. It won’t be done for a while, unfortunately. But that’s kind of the nature of research. But we can also send you, like, if we do poster, poster presentations at different conferences, we can send you those results, which are much more preliminary, but yeah, we can, we will definitely do that. We know you want it, so …

**Interviewee:** No, yeah, I’m just curious to hear more about it, so...

**Interviewer:** Yeah, you know, it’s, it’s been really great. I think you’re my sixteenth interview. So it’s … perspectives are really, really diverse and they’re very heterogeneous. It’s really interesting.

**Interviewee:** Oh, nice. Yeah.

**Interviewer:** Yeah.

**Interviewee:** That’s really interesting.

**Interviewer:** OK, but, yeah, if you need anything from me, shoot me an email. Happy to help in whatever way we can because you’re helping us so much.

**Interviewee:** All right. Well, thanks a lot.

**Interviewer:** Yeah, this was lovely. I hope your son’s wisdom teeth get ... go well tomorrow.

**Interviewee:** So do we! All right, well, take care.

**Interviewer:** You too. You too.

**Interviewee:** Bye.

**Interviewer:** Bye.