**[Start of transcript]**

**Interviewer:** All right, we are recording. And I will be asking you questions about your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities.

**Interviewee:** OK.

**Interviewer:** And I’ll be doing something called a semi-structured interview and this means I have my planned questions and my script, but I’ll also be adapting them to fit our conversation so they make sense for what we’re talking about.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** Nope.

**Interviewer:** OK. And if there are any questions you don’t want to answer for whatever reason, that is perfectly fine. “*I don’t know*” is a perfectly fine answer as well. And if something comes up, you’re welcome to bring it back up later.

**Interviewee:** OK.

**Interviewer:** Awesome. Could you please start off by telling me about your son’s sensory sensitivities?

**Interviewee:** Sure, so they’re subtle, but prevalent. So, they were a very big part of his profile when he was a little guy. So, we first started noticing it at bath time when he was a baby, where I would have just barely lukewarm water, and he would scream like I was burning him when I put him in the bathtub. So that was kind of the first trigger. Then it got to be big issues with background noise. So we noticed, you know, when it was … he was at home and things were quiet—we’re a fairly quiet household because we have just an only child and a cat—you know, he would perform, you know, no issues, everything’s fine, but then when we would, you know, get him into a loud, crowded environment, he would, you know, break down. So we have a couple memories. There was one time I took him … we took him to a Curious George theater concert in Brookline. And it was lovely, but it was a crowded theater and they had a live orchestra and the music got to the crescendo and he lost it. So we had to take him out screaming, but then he loved it so much, he wanted to be in there, but he couldn’t be in … and so we, you know … He wanted to … he was crying because we took him out. And then he was crying when he was in and he just, you know, couldn’t comprehend it. We had another issue at the circus, which was, you know, a similar scenario. So we **[3:00]** started avoiding those types of things. And then we noticed the busy, noisy classroom ended up interfering with his learning. So, as he got older, into, you know, the more upper grade school years, you know, the distractions … It’s hard to say, but we had a really bright kid who couldn’t … who was going backwards academically. So I guess, the other thing from the toddler years is he was very pressure seeking. So he would want hugs, you know, he would … or his favorite thing was to be squished. You know, we did get him involved in occupational therapy fairly early on. So we were kind of, you know, trying to address some of those things. But ultimately, we found in that first school environment … I mean, I guess that helped with a lot of the self-regulatory things, but nothing really helped with the noise sensitivity. And so we found him a nice quiet school that had soundproofing in it and no more than six kids in a class and, in that academic environment, when we were able to address … and I really think … I mean, there were a lot of things that went with the school that we sent him to, with tutoring and things like that. But the quiet, peaceful environment, without all of that noise, really helped him kind of overcome that. So the funny thing, though, is that, you know, kids on the spectrum have their unique interests. So … and my kiddo has had a bunch of unique interests, but it kind of morphed into sports. So he became very interested in college sports. We had a local college nearby. And, lo and behold, one of his favorite things became going to hockey games, college hockey games, college pro when he could get it, if he could score a ticket, but, you know, his desire—and I guess basketball, too—his desire and passion for that helped him overcome that, you know …. because I never thought he would have been able to have been in that sort of environment willingly. But because he was so motivated, he got to the point where he, you know, he embraced the marching band, you know, all of … he got really into marching band music. So **[6:00]** it’s kind of interesting how he was able to overcome it. But we did have … there was one moment … I had taken him on a vacation to Montreal once and I think he was seven, seven or eight. The sports thing was just emerging. And it just happened to be that the Boston Bruins made it to the playoffs. And while we were there, at the last minute, there was a game against the Canadiens and the Bruins in Montreal when we were there and I was able to score a ticket. So I brought him and he was so excited. And it was so wonderful. But he became overwhelmed and we had that same situation where … and I had paid a fortune for the tickets. And we were out in the lobby and he was crying because he wanted to be in there and he couldn’t be in there and it was the same type of thing from the Curious George, so. But, you know, since that time, you know, he’s really, you know … I guess, when I talked about the college, that was when he was a little bit older. So now, you know, it doesn’t really … you know, he’s 22 now and you see it with some food sensitivities. You know, I think when I answered the questionnaire, like, everything was just a little bit mild, but there’s some … you know, it’s hard to pinpoint, but it’s there. And because probably I know him best and I know the background and I’m more sensitive to it. But the biggest thing that we see now is he won’t wear a coat. And so we live in, you know, the Northeast and he will not wear a coat, won’t let me buy him a coat. He won’t really explain to me why. He doesn’t like how it feels. Doesn’t feel the cold. He’s one of these shorts year-round kids. And then we also see issues, that is a consistent thing that we’re working on is the hygiene. So, you know, he has … you know, we’ve had issues with … I mean, he’s able to shower, he’s struggled with shaving, really struggled with shaving. It’s easier to just grow a big beard when you can. But he’s going to be interviewing for jobs soon. You know, it’s one thing when you’re a college student. So, you know, things like that. You know, he doesn’t always notice if clothes are stinky. And so we’ve had to kind of go through some of his clothes. He tends to wear looser **[9:00]** clothes. So, you know, I know that there were some questions about, you know … He’s still kind of a picky eater. He does tend to, you know … I don’t know if it’s really spice, but he does tend to try to jazz up his food a little bit. So that may be a sensory seeking type of behavior. I never really thought of it too much. So I think hopefully I answered your question.

**Interviewer:** Yeah, you did. I’m going to ask some follow-up questions. But that was a wonderful start. Thank you. Thinking … so you talked about his beard: is it that he struggles with the, like, act of shaving or does he not like how it feels to shave?

**Interviewee:** He’s got fine motor issues, so I think that’s the biggest part of it, though it’s more just kind of getting over that learning curve, you know, because every time he really tries to do it, he cuts himself. And then he’s got the pain. And, you know, we’ve tried electric razors, we’ve tried, you know, different things. And he’s working on it. And he’s … you know, but he doesn’t do the greatest job, he tends to miss patches and then he’s sensitive about it. So I think I don’t, I’m guessing that there’s something sensory going on there combined with motor skills. So it’s hard to really say. I wish I knew because it’s been … the coat and the shaving has been kind of those two trigger items that the more you push, the more they resist. So I’ve kind of tried everything.

**Interviewer:** Absolutely. Thank you. And then you said he is a little bit of a picky eater. What is he limited to in terms of his palate and his diet?

**Interviewee:** Well, you know, on some levels, he’s super adventurous. Where he likes sushi, and he tends to like expensive food. My husband put a lot of stuff like that on him when he was little, like smoked salmon and he gobbles it up. And, you know, any sort of seafood and clams he’ll eat, which I don’t. So I’m much pickier on textures. But when he was little, we did try some dietary interventions. We tried a casein-free diet, and we had eliminated all milk products. And so for several years, formative years, he didn’t have that. We reintroduced it. But he **[12:00]** doesn’t eat cheese and he doesn’t really drink milk. So he’ll have … you know, he’s just very, very … he just thinks cheese is gross. So and so that’s, you know … In one of his college classes, they had a Zoom icebreaker and they were asking everyone to give their least favorite smell. And he said “*Cheese*,” and everyone thought he was crazy. Because if I, like, melt cheese in the microwave on something, it’ll stink up the house and he’ll want to … you know, so he really hates that. So, but I’m that same way with other things, so I can understand it. So he’s, you know, he … I guess, just like most people in general, he’s expanded. He was super picky and super restrictive when he was younger and now he’s getting a little bit better. He’ll have some vegetables, so.

**Interviewer:** Yeah. Are other smells aversive to him, other than cheese?

**Interviewee:** I think overall he’s probably more sensitive to food smells than I am. It’s not a big part of what we deal with or what I consider as part of his profile. So the things that I was probably … I probably should have checked the “estimated” box, because I’m not exactly sure and I’d like to ask him about that.

**Interviewer:** Makes sense. Well, I’ll send you the new form and then you can ask him. And is he still sensitive to loud environments?

**Interviewee:** Well, you know, it’s … not really … I mean, he’s able to be successful in a college classroom, but he’s done much better in the smaller classes than he has in the large lecture halls. And it’s hard to say if that’s the noise sensitivity, or if that’s just … he does better with more individualized attention. I think it’s part of it. He can do it and he doesn’t avoid it, you know, so I think it slightly impacts him, but he generally doesn’t ... you know, as an adult, he generally will not avoid loud busy places. He’s able to travel on his own, he can go on an airplane, be in an airport, no problem. He can go on … He, you know, he went … he got involved in some political, you know … he went to a Bernie Sanders rally. So he did that all on his own and was comfortable with it, you know, so—all pre-COVID certainly—but **[15:00]** so, you know, he doesn’t seem to avoid those situations anymore, so.

**Interviewer:** Yeah. Thank you. That’s really interesting. And what about vision: does he have any sensitivities to any, like, visual stimuli, like lights, perhaps?

**Interviewee:** Well, he actually does have a medical condition with his eye. So it’s called … I think it’s called radial keratosis, but it’s … the curve of the cornea is too steep. And so he did actually have to have a surgical procedure on one of the eyes. And that impacts … it almost gives, like, a ghosting or a delay type thing. So he always had some light sensitivity. It’s not exactly clear if it’s because of that condition or if it’s a sensory thing, or if there’s a correlation at all. So it’s a … they say it’s a hereditary condition and it worsens as you get older into your early twenties and then sometimes it stabilizes and they used to just treat it with hard contacts and now they have this surgery. So they were able to kind of keep it from getting worse. But he does have it in both eyes, so he has to wear glasses. And for ... his vision can’t be corrected 20/20, but he’s good enough to drive with glasses. So, but I don’t know of any … like, he … because of that condition, he’s really supposed to be careful about wearing sunglasses in a bright light scenario. But we actually spend a lot of time at a beach house. But he … when he was little he used to, you know, love the beach and go on the water. And now as an adult, he doesn’t like the seaweed. So he’s probably sensitive to that. He doesn’t like the feel of the saltwater. So he’s much more of a lake person. Now that we spent the money on the beach house, so, you know, he will be on the sand, but he doesn’t really like the sand on his feet. So just kind of a little bit sensitive. He’ll, like, want to keep his shoes on and, you know, just be a buzzkill at the beach. So.

**Interviewer:** Got you. You’ve been alluding to this, but how have his sensitivities changed over time?

**Interviewee:** Well, generally, you know, they’ve just kind of morphed into his personality and who he is and, you know, **[18:00]** they don’t really prevent him from leading a normal life. They’ve just kind of become just personal preferences like anyone has, but probably a little bit more sensitive than most.

**Interviewer:** Absolutely. And then, this change you just described: do you think that is related to any independence that he’s gained over time?

**Interviewee:** So the change in having the sensitivities be less prevalent? Yeah, I guess I would say it’s part of more of the maturing process, you know. Certainly, as a parent, we’ve been focused on his independence. So, and he’s been, you know, pretty strongly independent for quite a while. And so, you know, he does still live at home, but he’s been able to be, you know … he, you know, was able to spend a couple months more or less on his own. So yeah, probably, you know, when you’re independent, all of a sudden these little sensitivities, no one cares. So you just got to have to get on with your life. And so I guess I would say, yes, it’s caused him to focus on it less.

**Interviewer:** Yeah, that makes sense. Thank you. And then—this question may not be super relevant, given how you said they’ve kind of morphed a bit and abated, perhaps—but how does your son manage and cope or handle his sensitivities?

**Interviewee:** Well, he has always tended to kind of withdraw or, you know, avoid has been his MO, as opposed to some kids would more act out. So he’s always, you know … and so that was a little harder sometimes to get him the attention or services he’d need, because he wasn’t causing problems, but he just was, you know … everyone was over here and he was separate. And so I think self-isolating, you know, kind of limiting his exposure to situations that might be overwhelming or scary, you know, certainly, you know, show, you know, that, you know, given his interest in sports, you know, he’s actually made some wonderful friends. And he’s had the opportunity to travel to different cities across the country and go to some pretty high-profile games. And, you know, so he’s, you know … and **[21:00]** now that he’s, you know, 21, he decided he was going to check out the best sports bar in Chicago on his own. And so, you know, he did that on his own. You know, and so, you know, he’s, you know, but, you know, I don’t know how comfortable he was in that environment, but he was motivated to be there and wanted to be there. So, you know, he’s done a few types of things like that. And also, the other thing is, you know, he got a job working at … I don’t know if I should even mention the name of the stadium, but, basically, the pro sports, the pro football stadium in our area, he’s been working … I mean, it’s been cancelled due to COVID, but he was able to work all of the NFL games and all of the summer concerts. And so he was so motivated. And, you know, he was able to see the Rolling Stones, Bruce Springsteen, all for free while working, while getting paid. And those, you know, he managed OK in that environment. He did it for several years. So that’s kind of proof that he’s able to do it and seeks that type of thing out now.

**Interviewer:** That’s amazing. That’s great. And probably so much fun as well.

**Interviewee:** Yeah, although I think we’re … anyway, go on to your next question.

**Interviewer:** No, thank you. So, you mentioned OT earlier in the conversation, but has he received other services or interventions to help him with his sensory sensitivities?

**Interviewee:** Not really, you know. I found a real gap in kind of recognition of the issues. And, you know, the services that were available were very weak and very limited. So, you know, in the school system, they were happy to help him work on handwriting or keyboarding skills. But once he got beyond kind of the preschool, kindergarten ages, the OT was very, very bad, the school-based … and then we ultimately just gave up on it. Because, you know, there were things that we could spend a fortune kind of trying and, you know, there were some private providers that seemed to offer that type of service that I was certain he would have benefited from. But we didn’t have, you know, really the bandwidth to put it into his schedule, above and beyond the expense and trying to fight the school to get them to cover the private service and all of those things. So, you know, when he was in the preschool ages, you know, there were sensory gyms and everything and it was … he loved it. So they did some co-training with speech therapy, where they would have them do obstacle courses and all sorts of great things. And I would have loved to have had stuff like that continue, but what did … what they did do, and it wasn’t formal occupational therapy, but the school that we were able to find for him from age six through, grades 6 through 12 had a special program that was almost like Outward Bound, where on a … you know, once a month, they would do some sort **[25:00]** of active field trip where they did things like rappelling, kayaking, hiking, camping. So they incorporated kind of real world things, you know rock climbing wall, things with heights, so combined with some life skills. So it was more about kind of teaching about healthy risk taking and kind of pushing your limits type of thing. So that was kind of the closest thing to some sort of OT that I think he benefited that way.

**Interviewer:** And the OT he received, you know, formally when he was younger then also this more informal OT you just described: do you think those services helped him with his sensory sensitivities?

**Interviewee:** I think so. You know, it’s hard to say. It’s hard to measure. But, you know, I think a lot of it was kind of just innate. And some of it was just normal maturity. I think it helped, you know, I think we learned a lot of strategies, you know, like fidget balls and things like that, but I think all of the therapy was more designed at mitigating versus … and more strategy based versus improving it. I think nobody believed that it could be improved. I’m not sure. I guess the only other thing that we tried privately … we tried something called interactive metronome. It’s weird. It’s kind of like a brain training, where you integrate the … kind of the left and right side of the brain. And it’s almost like you do these repetitive movements where you try to match your physical movement with a like, a beat that’s given. And they invoke things like crossing the midline. And basically, you know—I don’t really understand the science of it—we did a couple of courses and we did notice some improvements during the course, more with verbal language and learning and maybe some of the sensory sensitivities. It’s hard to really say. There’s a lot of different things that we’ve kind of tried in fits and starts over life.

**Interviewer:** Yeah. Absolutely. Thank you. And so when your son **[28:00]** is in a, like, an environment that has sensory experiences that are aversive to him, does that cause anxiety or increase it?

**Interviewee:** Yeah, I think so. You know, maybe, you know, like, things like cigarette smoke, you know, he’ll … you know, just can’t be in the room. Or if they’re … you know, if there’s something uncomfortable, he’ll just leave without saying goodbye or something like that. But, you know, it’s not overly prominent or not overly interfering in his current life. But he also has a lot of freedom in his … you know, as a college student and living at home. You know, there’s … he’s not put in uncomfortable situations too too often that aren’t choice.

**Interviewer:** You talked about, like, leaving. Is that how he manages the, like, sensory-related anxiety?

**Interviewee:** Well, yeah. I mean, I can’t say that that’s a big thing. And I can’t really say he’s got a super high anxiety profile and even when he was younger he definitely did. He had a lot of anxiety, like, you know, he had trouble … like, he … on, like, a little league team, he put so much pressure on himself that, you know … and he was a really good athlete, but he just got so anxious about it that he avoided it and missed out on a lot of opportunities through school sports. And now he realizes he should have done that. And then he just started getting involved in intramural sports at college, right pre-COVID. So.

**Interviewer:** Oh. That’s a bummer.

**Interviewee:** I know. But he also self-selected to be involved in a course through his university. He had taken a music course and the college professor was running kind of an everybody’s welcome course. And he joined the chorus. And he’s not a real singer or musical person and he loves to rehearse, he just loves being part of something bigger. And it’s been just kind of a challenge for him to kind of moderate his voice to not stand out. But he’s gotten excellent instruction. And so he’s been … you know, he keeps surprising me with the things that he’ll **[31:00]** get involved in or want to get involved in to be able to be successful in. And so, you know, sky’s the limit.

**Interviewer:** Yeah, absolutely. That’s wonderful. You talked about anxiety when he was younger: did he also have more anxiety about sensory experiences when he was younger?

**Interviewee:** Yes. So, like, if we had to, like, take him into a store or something or a restaurant, we probably had a decade that, as a family, we couldn’t really go to a restaurant in peace because it was just so hard for him to, with the background noise. So that was all … you know, it was anxious. If he knew he was going to be in a place that he couldn’t, you know, that he was going to be stuck at and couldn’t escape, which I know is kind of a thing with anxiety. So yeah, I would say that that was a big part of his profile, probably until, you know, maybe the teenage years.

**Interviewer:** Absolutely. That makes sense, thank you. And then, thinking a bit more broadly, what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** Yeah, well, you know, I kind of feel that he’s achieved them, you know. He doesn’t let them hold him back from, you know, his desired career or his school for his, you know, social things. I guess, you know, the other thing, I … it came up in one of the surveys, you know … He’s kind of behind on the whole dating scene. So, you know, he’s not had a relationship yet. I don’t know that he’s even had a first kiss yet. For years, I was on a kiss ban as his mother because I kissed him to death when he was little and he had to put the brakes on that and so I had to go for years with no kisses. So I try to respect his, you know, his space. So he’ll let me sneak one in now and again now, that I try to respect him, he doesn’t like it, but he will let you touch him. He will give a stiff hug once in a while. But, you know, as he gets into adult relationships and this sort of physical **[34:00]** intimacy is not something he’s comfortable with. So I’m hoping that he’ll continue to mature in that way and have that as part of his life, if he wants it. But I guess, yeah, just my other aspirations is, you know, I guess I just want him to, you know … If he does have certain sensitivities, so say he gets a job and he’s going to … and if he needs some sort of accommodations, I want him to be able to be comfortable identifying those and being able to self-advocate for whatever he needs, rather than failing. And I do have a story to tell you that I probably should have come up. He … in between the working at the sports stadium, which was very intermittent for a job, he was looking one summer—not last summer, but the summer before—for another job to just kind of do … get more hours. And so he signed up to be a pizza delivery person. But the pizza delivery, you know, when he was new, he was the lone man on the totem pole of side work. And the job that they gave him for the side work was to shred massive amounts of cheese. And knowing that the smell and the … it probably had a noise and it was probably hot. And, you know, my guy has … he’s got a lot of determination and he tries really hard. But he actually got fired from the pizza delivery job, but didn’t really understand that he got fired. They kind of just stopped calling him for shifts. And he didn’t disclose anything. He, you know, he just, you know, he clearly had trouble following instructions. And, you know, he was really good at the delivering the actual pizzas, because he’s really **[cuts out at 36:19]** directions and things like that. But, you know, just kind of … that got me worried, like, if he was struggling for a pizza delivery job. And, you know, we’re really hoping that he’s going to be a professional. So, anyway, that’s kind of a scenario where I think the sensitivity and some of the other things came into play. It was kind of eye-opening to us because, when we found out, you know, … and we only found out because my husband called looking for the tax forms, like, “*Why didn’t he?*” You know, “*We just need his … we’re doing the taxes,* **[37:00]** *why didn’t …?*” And they said, “*Well, we didn’t issue it because we,*”you know,“*he,*”you know *…* and then my husband explained and they said, “*Oh, we didn’t know*.” And they’re like, “*Well, we, you know, we could have, you know, for those kids, we have them make pizza boxes*,” and it’s just like, he’s not, he’s too advanced for that. He just needed a little bit more support. So, and it’s hard to say how much of the sensitivity factored in. So anyway, but it was a learning experience for all of us.

**Interviewer:** I’m sure. Thank you. That was a wonderful anecdote. Thank you for sharing it. We’re going to move on to our next chunk of questions, but that was still a really lovely segue. So, thinking about community: as your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** Well, we more or less keep it to ourselves. You know, it’s really … because he’s so high functioning on the spectrum we’ve generally opted to keep it private, which is why I had some … I wanted to be anonymous here because I want it to be his decision on when to disclose. Because, you know, it’s not obvious at all. So but, you know, he can be perceived in his community as perhaps quirky. So, you know, his university community is accommodating, you know. They do have a disability center that he has access to, so they have given him, you know, accommodations, but he generally doesn’t use them. A lot of the time, the accommodations they make available really to any student and so … but, you know, he’s eligible for extra testing time, if he wants it. He can go to a quiet test center if he feels the need to, you know. All students have access to tutoring. So he really … you know, I think he does have the support if he feels he needs it in that community. The sports community, you know … I mentioned that he got really involved in college basketball and one of the big university coaches in our community is an autism dad. And I think he just saw this kid that … and he kind of was very kind to him and kind **[40:00]** of adopted him as an adoptive mascot, let him, you know, go on the team bus, you know, let him go to the games, gave him a pass and really kind of welcomed him. And, as a result, he was kind of part of the family. And now, the assistant coaches from that team and the main coach are all at different universities, they … and they’ve stayed in touch with him. And so, you know, he’s accepted. And we’re actually, you know, hoping that, you know … My son really wants some sort of career in that industry, so we’re hoping to be able to leverage that network because I think, once people kind of know him and accept him and they see his talents and what he can contribute … So, I guess that’s good. And then it’s really just his community, his family, you know. Being an only child, he’s been very close to his grandparents and to some aunts, cousins to a lesser extent. And he’s the youngest grandchild and the youngest of the cousins, you know, and so some of the older cousins have been super kind and accepting to him. So, I think, family … and he definitely notices that, you know, that family treats him like … they get him, he’s accepted. And so, you know, but it’s harder when he’s meeting new people, so, or entering into new communities. So, his school community, he … you know, he did struggle a little bit socially with his peers, but felt like he belonged, felt accepted. He tended to gravitate towards all the adults. So he developed great relationships with his teachers. You know, before we him to the grade school that was small and accepting and quiet, he was kind of an outcast, so, and not really accepted.

**Interviewer:** Yeah. And these different places, community you’ve just described, do they also understand, like, his sensory sensitivities, as well as just kind of who he is as a whole person?

**Interviewee:** Well, not … it’s not really something that we talk about. As a family, I **[43:00]** think, probably, you know, some of the people in our family that are closest to him understand that about him because they’ve known him his whole life, but it’s not something we really … You know, there were … I remember there are a couple times … it’s just like, you know, “*I can’t explain it. We just have to go*. *I’m sorry*,” you know, and it’s accepted. But that’s happened much fewer and it doesn’t really happen anymore.

**Interviewer:** Yeah. And was the community more or less accepting of him when he was younger?

**Interviewee:** Yeah, I mean, I’m not sure how to answer that one. I guess it depends. I think the kids in the school were not, were less accepting, but I think the adults and teachers that knew him best were and always were and always will be, so.

**Interviewer:** No, that makes sense. That’s perfect. Thank you. And then again, thinking a little bit more broadly, a little bit largely: what are your hopes or worries for how the community will react to his sensory sensitivities in the future?

**Interviewee:** So overall, he’s been able to manage them and kind of pass as being a non-sensory sensitive person. So he’s largely been successful masking them, to the point where it’s not noticeable. So I don’t really see it being a big issue as long as, you know, whoever he gets involved with, you know … I think there’s other issues that are more prominent than the sensitive, than the sensory issues now. So, but it’s just kind of all morphed into just a component of who he is at this point. It’s hard to really pinpoint it, but I don’t see it, the sensory issue’s being a big factor with him being accepted, wherever he ends up going.

**Interviewer:** Got you. Thank you. We’re going to shift again. So thinking about the, like, transition to adulthood, quote unquote: in this transition, where do you see your child?

**Interviewee:** Is that supposed to be really open ended? I’m not really sure **[46:00]** what you mean.

**Interviewer:** Yes, I think it must be open ended, I guess. Do you want me to rephrase? Would that be helpful?

**Interviewee:** Sure.

**Interviewer:** OK. Do you think that your son is kind of, like, on par with his peers in terms of where he is in terms of independence? Do you think he is approaching independence? Do you think … those types of … there are other more specific follow-up questions I can ask as well.

**Interviewee:** OK.I mean, for a kid on the spectrum, he is above and beyond any expectations. He’s just a real success story, as far as the challenges that he’s overcome. So we are very hopeful and preparing for him to be fully independent. And we’re hoping for that, but we’re worried about it because it’s difficult, really, for a typical kid at this stage. So we’re … you know, he’s, you know … after this semester, he’s expected to graduate from college and then we have to figure out, you know, the, you know … He wants to find full-time employment and we know that, you know, a lot of people are … the vast majority of people on the spectrum are underemployed or unemployed. So we’ve been taking a lot of steps to make sure that he’s in that, you know, that 10%. So, you know, but we’ve struggled with things like internships. I was able to get him a great internship this past summer, but he’s … you know, he’s applied for a bunch of jobs, no one responds. You know, so he’s probably going to need some extra support. But we’re really hoping that he’ll have some sort of opportunity in, you know, in the college sports world with somebody that knows him. We’re also … in addition to the college, you know, we found this separate program called Sports Management Worldwide that has coursework and internships available. And it’s, like, film editing and scouting preparation. And so our plan is that he’s … it’s … we have to pay for him to do this internship, but it seems as though a lot of people start with that and that leads to a full-time job. So we’re hoping that something like that happens. He’s not … you know, at one point, he was on track for sports broadcasting. We **[49:00]** got involved in a Sports Broadcasters of America, like, kids sportscasting program when he was younger and he was really, really good at it. And it was kind of a pseudo speech therapy, which was fantastic, because he was super motivated, and he’s still got connections there. So because of the sports interest … and he’s got some really unique talents with sports statistics, like, he remembers every and knows every sport statistic. So, you know, I think that there’s … he’s going to find his kind of way he can uniquely contribute in a way and really kind of, you know … I think the people on the spectrum that are successful are the ones that kind of take their unique gifts and try to leverage that and I really see that happening for my guy. But, you know, so we’re working on all the life skills now. We have been for a while. And so, you know, he ended up … he lived at home and, you know, commuted to college. So he didn’t have that … you know, the challenges of a roommate and being away from home and that was just what we decided. A lot of kids on the spectrum that go to college, there’s a special program, but he never did well with a bunch of kids on the spectrum, he always did better with typical kids because he sees himself as typical. He does. He’s like, “*I’m not like those other kids*.” And so he just doesn’t really belong in either set too well. And so that’s why we, you know, we kind of started with a part-time schedule. We tried to just not overwhelm him, just give him a little bit additional time. And so we’re getting him some coaching, you know, we hired a resume service. So we’re working on his LinkedIn profile. So we’re, you know … we’re kind of giving all of those supports to help him be successful on our own and trying to leverage the University Career Center, but I don’t really know, but we’re not really tapping into any disability types of services yet. We’re trying … we’re looking into any sort of state programs, you know. There’s one we’re involved in, but they don’t really help that much. And so, you just kind of … just, like, anything that you … we kind of feel like we’re on our own, but we’re very, very hopeful. So we’re nervous about the transition but we do feel that he’s on track. And I have, you know … I am very optimistic that he’s going to find his way.

**Interviewer: [52:00]** That’s wonderful. That’s great. I’m happy to hear that. Could you talk a little bit more about his stage of independence, thinking about what are some things he’s able to do independently, versus where are some things he needs some support on—so, like, you talked about hygiene in the beginning were something that’s a little bit harder for him.

**Interviewee:** Yep. So we’re still working on hygiene and kind of, you know, caring about your appearance and dress and things like that. You know, he’s starting to notice, like, other people, like, “*Oh yeah, he’s shaved really well*.” And, you know … and he … like, he’s finally noticing things about how people are dressed and things that he may not have been aware of before. So we’re working on things like shopping and cooking. He’s long been making his own doctor’s appointments, which is good. We’re kind of going through financials and budgeting. He’s actually very good with managing money. So we had one negative experience with online sports gambling, but he learned his lesson. So, you know, I think he’s got a strong independence to … a strong will to be independent: He’s pretty sick of being with his parents all the time now, which is a good sign, and so he really wants to be independent, so he’s researched cost of living, apartment prices. And, you know, well … you know, “*If I had a car, if I lived somewhere where I didn’t need a car*,” and so, you know, he has been successful working, other than the pizza place. So, but yeah, we’re … I mean, we’re still … we’re working on kind of cooking because when we’re home, you know, he tends to rely on us or just eat what’s in the house, versus when he’s alone, he’s kind of forced to go out and shop for himself and prepare things for himself. And he’s learned some lessons the hard way about burning things. And so, you know, we have a … we started a new pandemic tradition. We have soup Fridays in our house, and we alternate who does the soup, and so he’s had a couple of soup nights. And he had … he blew us away and I never would have expected he would have been able to, you know, pull off such a phenomenal soup. And he did so. It’s, you know, it’s kind of the same thing that we did when he was little. You kind of … you do it with him first and then he has to do it, you know, and then you’d fade the support and then he **[55:00]** does it, but that’s how you learn by doing things on your own in an environment that hopefully the failure doesn’t have too many consequences. But he’s still kind of sensitive about, like, using knives and things like that, some of the fine motor things—like, peeling an apple is just kind of beyond him. So I got, like, apple peeler things. And so … all right, so hopefully I answered your question.

**Interviewer:** Yes, no, you’ve been wonderful, thank you. How is he with helping around, like, the house for, like, household chores and things like that?

**Interviewee:** Well, he wants to be helpful and is generally very helpful when asked, but left to his own devices, you know … When he was on his own for a couple of months and, you know, we had to kind of set the expectation that, you know, things aren’t going to be trashed. And so we’ve had to go through that experience a little bit. And we’re kind of focused on, you know, like, “*Mom doesn’t have to remind you to change your sheets and you’ve got to do that on your own*.” And he’s been doing his own laundry for a while, but lets it pile up, and he’ll wash and dry it, but not fold it and put it away. And so, you know … but I know that that’s probably pretty age appropriate. But so he can do it not that great, you know, so we’ve been trying to be a little bit more demanding in terms of assigning tasks. You know, he’s long been the dishwasher emptier in our family, you know … after several years, he’ll still put stuff in the wrong place and so, but so does my husband. So, you know, I tried to be less picky about if the big spoons are mixed in with the little spoons, things like that, like, they’re still the spoons or with the spoons, but this is not how I would have done it, but that type of thing. So he can do it and he’s been able to do it and he’s … and all of a sudden, he’s also becoming more aware. Like, he was helping out cleaning the kitchen recently and he’s like, “*I never noticed all these fingerprints all over the refrigerator*.” I’m like, “*Yeah*.” And so he started working on … and then he saw more and more. And then he’s like, “*Oh, there’s crumbs underneath.*” I’m like, “*Yeah*.” So it’s just, you know … and I probably was oblivious to that stuff when I was that age, too. **[58:00]** But it’s more, you kind of have to point it out what … that kind of thing. And, once you do point it out and he’s aware of it, then it’s more noticeable. Then he’s more on top of it. So he’s trying hard.

**Interviewer:** That’s you can ask, right? You mentioned that he has friends through sports: does he manage his social life to some extent?

**Interviewee:** It’s pretty limited. You know, it’s still with kind of these trusted adults mostly. You know, he’s got one friend from school that lives nearby that … they’ve gotten together a couple of times to hang out, but this kid is probably less socially motivated than mine. And they both need each other desperately, but they don’t tend to be too proactive about it, but they have gotten together periodically. So, you know, he’s generally used his grandparents kind of as the outlet to pick up the phone and call someone or some, you know … He does, you know, do some texting and social media. You know, back when he was, you know … there’s been a … you know, when he was on his own for a couple of months in the fall, he did reach out to a friend and they went hiking. And I had kind of put … maybe put that in his ear. But they went once, you know, but it happened. So it’s … again, it’s hard with COVID. I think he was starting to get more involved with some of the students in his intramural before that happened. So.

**Interviewer:** Got you. Thank you. And does he want to live on his own one day?

**Interviewee:** Yes.

**Interviewer:** Fair. And—you’ve alluded to this before—but do you think your son will be able to achieve more independence in the future?

**Interviewee:** Yes.

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

**Interviewee:** Employment. I think, you know, if he’s able to get a job, you know, that will lead to a career path that he’ll be able to support himself. That’s … it just really means connecting with the right employer and having that right career opportunity.

**Interviewer:** Absolutely. Other than employment, do you think there are any services or interventions that could help him move into independence and move into adulthood more?

**Interviewee:** Maybe some sort of job placements services, more training on the whole issue of disclosure because he’s still kind of coming to terms with that himself. You know, some kids, identify and are very vocal about it, you know, but he’s not and doesn’t want to really be viewed that way. So, you know, I’m not … he could probably use a dating **[1:02:00]** service, some sort of relationship skills type of training.

**Interviewer:** Got you. Thank you. And so, now, putting these two things together—his sensory sensitivities and his transition to adulthood—how do they intersect or how do they impact each other for your son, if at all?

**Interviewee:** Yeah, I mean, if he hadn’t overcome the whole sports stadium thing, I would say that, you know, he would be limited, but knowing that he wants to be involved in sports and his dream is to have a job where he gets to go to every game for free, you know, I think it’s … from that perspective, it’s not going to be an issue. From, like, an auditory processing if it’s, like, something where he’s going to have to communicate in that environment, it might affect him, you know, because communication skills are still … you know, he’s largely overcome them, but, you know, it’s the whole thing with kind of conversation turn taking and jumping into the, you know, the social conversation and the reading those social cues is still a challenge and it’s probably more challenging if there’s a lot of sensory overload. So if he has to work under pressure in a busy environment, that’s probably … it might be hard for him. Like, I almost … you know, even thinking of working in a newsroom, providing the sports statistics or something like that. On deadlines, I think it might be hard, but, at the same token, he’s so motivated and he might just be able to overcome it. And I don’t want to put limitations on him. So that’s a longwinded answer of saying I’m hoping that the sensory thing will not be an issue.

**Interviewer:** Yeah, absolutely. That makes total sense. Thank you.

**Interviewee:** If they don’t give him cheese.

**Interviewer:** Fair. But hopefully it’s a little bit easier to avoid.I think I know the answer, given what you just said, but do you view his sensitivities as an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** Yeah, I think I’m going to say neither. I think, of all the things, that’s a lower priority. Although if you had asked me, you know, 15 years ago, I would have probably answered that differently.

**Interviewer:** Absolutely. Then again, this next question will be a little bit … **[1:05:00]** might be a little null. But what do you anticipate as being challenging for your son as he does gain more independence, in relation to his sensory sensitivities?

**Interviewee:** I think as you become independent, you know, there’s more cases where you just have to kind of suck up your own feelings and overcome them. And, you know, there’s … I guess you can kind of expect less accommodations or no accommodations as you’re an adult, so, and less ability to quit things. Or, you know, if you have a rent to pay and, you know, and they’re making you shred cheese, you kind of have to deal with it, I think. So I think it’s just kind of facing the realities of the real world, that you have to be the one to adapt rather than to expect everyone to adapt around you. But I also think, kind of that self-awareness and being able to self-select … like, if he has the opportunity for two jobs, and one he knows might be a little bit less pressure or less, you know, less busy or less, you know, that kind of loud, busy environment that can be hard, that we know, that has historically been challenging, then he might want to choose the one that’s a little bit quieter or not on deadlines. But yeah, again, that’s going to be his choice. And I think we can probably learn, once he gets in those environments if he does have any failure episodes … and I think being mindful of, you know, the extent to which, you know, the sensory issues were a factor, and maybe they will be or won’t be, more often than not, you know, or, you know, just being aware that that could be an issue and trying to figure out how to deal with it going forward.

**Interviewer:** Thank you. And then, do you think there’s anything that could help your son at this intersection of sensory and his transition?

**Interviewee:** Maybe just more self-awareness, more information on … You know, it’s … you probably see it, but I don’t, I’m not that on the radar screen of other people with this **[1:08:00]** profile and how they’ve overcome it. And so, you know, I guess that was part of my interest in being in this research, because I would love to see the results of it. And, you know, I know that there’s, you know, more trends towards acceptance and neurodiversity and … you know, in the workplace. So I think, you know, more awareness in the larger community of people’s differences in people’s sensitivities. And, you know, you’re already seeing it with people’s food sensitivities and, you know, everywhere you go, “*Does anybody have any food …?*” You know, and so I almost would like to see the world expand to be more sensitive to people’s differences there and more accommodating.

**Interviewer:** Yeah, absolutely. Thank you. Besides this community awareness and accommodation, are there specific services or interventions that you think could be helpful at this intersection?

**Interviewee:** I would love to hear about them. I am not aware of any. So I know of nothing.

**Interviewer:** Yeah. Fair.

**Interviewee:** So if something is out there that exists, I would be open to learning about it. Although, you know, it … there’s so many types of services out there. It’s a lot of snake oil and it’s hard to know if things are proven and they’re expensive and you don’t know. So it’s just so hard to sort through and figuring out what’s available and what’s worthwhile and what’s not. So.

**Interviewer:** Yeah, absolutely. That’s a great segue to my next question, so thank you. Do you think there are gaps in the available services and interventions at this intersection?

**Interviewee:** Yeah. Yeah. Because basically, you know, once we got past those preschool years, there was next to nothing that we could find. And so, you know, for us, this small, quiet, peaceful school was a godsend, but if … you know, if … but there were trade offs for that, so not every kid can have that. But I … you know, we were choosing between the school that seemed perfect on paper because they had more services and the one that had soundproofing and, like, a lovely little landscape and only 60 kids in the **[1:11:00]** school and we just knew we’ve … you know, in our gut, we knew that he could be successful there. And so I think, at least for the types of sensitivities that we had, then that environmental was the most important for us. So now that that’s less important, it’s not exactly clear what, if anything, can be done to help.

**Interviewer:** Yeah, thank you. And then, thinking once again broadly: how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Yeah, I mean, I think I’m just trying to understand them, because a lot of the things that he just doesn’t give me answers for, or that I … like, the coat thing. I’m probably not answering the question, but there’s things like the shaving and the coat that, you know … To be a successful adult, you know, you just kind of have to wear a coat in the cold weather or clean shave or be able to do that and … but when you ask him why, he can’t give you an answer. He doesn’t see that it’s a sensory thing and it comes across as just being stubborn. But I know there’s kind of something to that and if … Could you just repeat the question because I don’t remember?

**Interviewer:** Absolutely. You were answering it great, but I will repeat it. How have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Yeah, so I guess, they … I guess, they’ve just caused me to be just a little worried. I still have those high expectations and still am hopeful and feel confident that he can attain independence at a high level. But there’s just kind of a … still a couple of things that, you know, are a little weird that could be an obstacle, that just make me feel that, you know, we still have an uphill battle or challenges ahead. So it just kind of impacts my confidence level.

**Interviewer:** Yeah, that makes sense. Thank you for sharing that. We’re at our last chunk of questions. It’s the shortest one, we’re almost done. **[1:14:00]** So finally, as a caregiver, as a mom, as a parent of someone with autism, but also with some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** To me, it means kind of being entirely self-sufficient or getting … I mean, we’re in transition now, you know, with, you know, ever since kind of high school and graduating off the IEP and going through college but really preparing and giving those tools for, you know, living independently and, you know, and in all ways, you know, financially, you know, physically … and also having kind of a full life with kind of relationships and a social life and those types of things.

**Interviewer:** And has this perspective changed over time?

**Interviewee:** I would say, I guess I’ve built more confidence over time. You know, so it’s, like, at every transition point, like, “*Oh no, we’re going from kindergarten to first grade. Oh no, we’re going … we’re changing schools, and oh no, we’re graduating from high school and we’re going off the cliff and is he going to succeed in college?*” And then, you know, now we’re at the point where we’re just within just a grasp of college graduation. So, you know, every … at the last transition point, as you get through it, you know, you just kind of, you know, look back and see how far you’ve come. So, I’m hoping, you know, five, ten years from now, to be able to look at this moment … and yeah, we are really nervous because we’re right on the precipice of kind of the next big transition but … and, you know, he may need to live at home for a little bit longer, you know, before we start charging rent, or, you know, he may need to start with an unpaid internship before he can get a full paying job. So we’re trying to not put a lot of … we want … it’s a fine line. You want to put some pressure on him, so he’s motivated to do the work, but not too much pressure that he’s going to crumble, so, and he’s the type of kid that does crumble under too much pressure, so, but also needs a little kick in the pants sometimes, so, I think, between my husband and I, we balance that. I’m a little bit more **[1:17:00]** naturally coddling and my husband’s a little bit more pushing and we have that yin yang that probably a lot of parents have. But I’m signed up, you know, I’m always just maybe a month or two behind when my husband thinks he’s ready for something, so.

**Interviewer:** Got you. Thank you. What do you see happening in your son’s future?

**Interviewee:** Yeah, you know, I really see great things for him. Because he’s really got so many strengths. And he’s always, you know, he’s, you know, he’s been very successful in many ways. And so I continue to see that for him. And he’s a good person and he’s a kind person and he’s a smart person. And, you know, just like any mom, you know, I want the world to see that and recognize that and give him a chance to shine. So I guess that’s just kind of what I want for him. But I really see him doing something, being really successful and finding his, you know, his thing. And it may be a little bit of a winding road for him to get to that, but—you know, just like it is for all of us—but I really, in my heart of hearts, feel that, you know, he’s going to make it, but he’s going to need some support along the way. I’m just hoping to be around long enough to give that to him.

**Interviewer:** Absolutely. That’s wonderful. And I’m assuming you imagine that he’ll finish school because you mentioned he’s going to graduate shortly and you imagine him holding a job.

**Interviewee:** Yes.

**Interviewer:** What about … do you think he’ll have a family of sorts one day?

**Interviewee:** He’s a confirmed bachelor at the moment, doesn’t seem to want kids. He sees, with his parents being married, how we have to compromise on things all the time. And he’s, I think, part of this Gen Z generation that kind of likes the idea of having your freedom and being single, so that’s kind of what he plans for himself. He feels, I think, more comfortable with that, you know, not sure how that will change, but I just try to accept him for who that is and not try to force anything on him that he doesn’t want or doesn’t feel ready for. Yeah certainly … I want him to have important relationships in his life, however those may be. **[1:20:00]** But I do worry that, you know, he may be a little bit too isolated. But I think he’s got it in him. And it’s really, you know, that’s part of being independent is being able to make your own choices.

**Interviewer:** Absolutely. And do you see him moving out one day?

**Interviewee:** Yes. Yep.

**Interviewer:** Awesome. Last, final question—though again, I think I might know your answer—how have your son’s sensory sensitivities impacted this current perspective you describe, in terms of what it means to transition to adulthood?

**Interviewee:** Well, I think probably what I alluded to before. They’ve gotten to the point where they’re really just part of his personality and his personal preferences that are displayed the same way anyone else’s would. You know, it might impact his ability to become a ski instructor, say, if you are in below weather temperatures with no coat. So, but … so, I guess … and I forgot the question, but …

**Interviewer:** Oh, that’s OK. I was asking you if your son’s sensory sensitivities impacted the perspective you described in terms of what it means to transition to adulthood and you said it means being self-sufficient.

**Interviewee:** Yeah. OK.

**Interviewer:** That’s it. That’s my final question. Would you like to add anything else?

**Interviewee:** No, no.

**Interviewer:** OK. Thank you. This has been wonderful.

**Interviewee:** I hope I was able to stay on point for …

**Interviewer:** Oh no, you were perfect. Thank you. It’s been very helpful. You give wonderful answers.

**Interviewee:** OK. Thanks. So I don’t know if you can stop the recording now, but I would … my other … my only question was about next steps.

**Interviewer:** Yeah, I can stop it now. Absolutely.

**Interviewee:** OK.

**[End of interview]**