**[Start of transcript]**

**Interviewer:** OK, we are recording. And I will be asking you questions about your perspective regarding your child’s transition to adulthood in relation to his sensory sensitivities and sensory interests. And I’ll be doing something called a ‘semi-structured interview,’ which means I have my planned questions and my script, but I’ll be adapting them to follow our conversation and to make it actually fit for what we’re talking about. Any questions?

**Interviewee:** No.

**Interviewer:** OK, awesome. And if there are any questions that you don’t want to answer for whatever reason, that is perfectly OK. We want to make this a positive experience. And also if there are things you think about later in the conversation, that’s perfectly fine. It doesn’t have to be a perfectly linear thing.

**Interviewee:** OK.

**Interviewer:** Awesome. Could you please start off by talking about your child’s sensory sensitivities and sensory interests?

**Interviewee:** OK. And you’re talking about the present time, or …?

**Interviewer:** Right now I’m talking about the present. I will be asking about the past, so if it makes more sense to start in the past, go to the present, whatever works for you is totally fine for us.

**Interviewee:** Yeah, so let’s see … in terms of sensory considerations—my son seems to have a lot of auditory sensitivities. He’s quite sensitive to sound. He has excellent hearing. We … my husband and I will sometimes be having a quiet conversation on one side of the house and he can hear us, like, two rooms away.

**Interviewer:** Really?

**Interviewee:** Yes. He also has perfect pitch, so he’s very sensitive to musical sounds. And, you know, I sometimes wonder if that interferes with his ability to just enjoy a piece of music because, you know, he’s a little bit more like, “*Oh, this is in a certain key*,” or, you know, “*Oh, that’s a little off*,” you know, but on the other hand, it gives him some musical abilities. And he’s managed to share that with his brother and sisters as well. Yeah, so they all listen to music and say things like, “*Oh, look, listen to that key change*.”

**Interviewer:** Do they all have perfect pitch or is it just him?

**Interviewee:** It’s mostly him. The others mostly have some pretty close … He has another sister who’s … she’s very close too, like, you know, when she sings something it’s right on. I’m not sure she’s as good at identifying pitches as he is. And then a couple of the others are … they’re pretty good too, but, you know, they sort of tie it into their musical talents, their ability to sing. He does as well, but he has … it sort of … he does it outside of singing and playing musical instruments, if that makes sense. He’ll even really … even sometimes hear a sound made by a machine, you know—like two glasses clinking together, he can pick out a note from that.

**Interviewer:** Wow. OK. So it kind of is, like … he can do it in all contexts, not just, like, musical contexts.

**Interviewee:** Yes, exactly. You know, so, yeah, he says, as people say, “*It’s a blessing and a curse*.” Yeah, because sometimes he can get fixated on that and not really pay attention to what he’s supposed to, you know, and … but yeah, he does seem pretty sensitive to sounds. He doesn’t seem to complain a lot about unpleasant sounds, though. Like, it’s not like he’s putting his hands over his ears to keep certain sounds out. So I guess he seems kind of fascinated with sounds in a way.

**Interviewer:** So they’re … they don’t bother him. He’s just very … he’s skilled at picking them up, maybe?

**Interviewee:** Yeah, it bothers him when there’s too much sound, he has trouble focusing.

**Interviewer:** OK. And it’s not like …? Oh, sorry.

**Interviewee:** No, go ahead, ask your question.

**Interviewer:** So you said he is bothered when there are too many sounds—is it like too many people talking? Could it be, like, highway noise? Like, is it a particular type of too much sound that …?

**Interviewee:** I think mostly when there are a lot of people talking, then he has trouble picking out from the field of noise, you know, and then he … but if people are singing, he can pick out, you know, like, he can even identify, “*Oh, this person’s a little sharp, this person’s a little high*.” So in the context of singing, he picks out individual things, but, in conversation, sometimes he seems to get a little, you know … he’ll go like, “*Oh what?*” and … yeah, so.

**Interviewer:** Got you. Awesome. Thank you. What were you saying before I asked my question earlier?

**Interviewee:** Oh, I’m not sure.

**Interviewer:** Sorry.

**Interviewee:** That’s OK. So, I’m trying to think what else … he doesn’t … I don’t know, I’m trying to think about tactile sensitivities. You know, he’s not one of those people who, like, complains if there are tags in his clothes or, you know … he likes things to be comfortable, but I don’t find that any more so than any of my other children. Visually, he seems to be rather sensitive to certain visual things. I know that he still has an issue … you know, like, he tends to have a lot of things on his desk and, you know, and that creates a, you know, confusing visual field for him. But if I say to him, “*You need to clean up your desk*,” he seems to be able to do that now, though, he can take things and start sorting them. I just asked him last week **[inaudible at 06:16]** if he could do it. Sometimes when I, you know … if his father walks through and says, “*That’s a mess*,” he looks at it, and he just sees, like, the whole mess and he … you know, but, you know, when I asked him to sort through it, he was able to do it.

**Interviewer:** Do you mean sometimes he gets, like, **[crosstalk at 06:36]** overwhelmed by, like, a busy visual field?

**Interviewee:** Yeah, I think he does, yeah. And it ties into other things like his executive functioning. So he sees this busy visual field and his executive functioning says, “*I don’t know how to prioritize. I don’t know where to start to* …” But he was able to do it last week when I asked him. I said … because I started asking him questions, you know, “*Where does … does all of this stuff belong here? Where can it go?*” You know, I gave him a couple of organizers, you know, “*What can go in here?*” And, of course, he’s 21 now, and I left the room and about half an hour … I came back later, and I was like, “*Wow, that looks really good*.”

**Interviewer:** That’s great.

**Interviewee:** So, you know … yeah, so he was able to do that on his own. In the past, that wouldn’t have been the case, the visual confusion would have just overwhelmed him. But he does have this thing … like, a few years ago, he said, “*Can you make me an eye doctor appointment?*” And I said, “*Oh, is something wrong?*” And he said, “*Well, I feel like my vision changed a little bit*.” When we went to the eye doctor and they examined him, they said, “*It has, but for most people that would have been practically imperceptible*.”

**Interviewer:** Wow. OK. So it’s, like, kind of his senses seem sharpened both, like, visually and auditorily?

**Interviewee:** Yes.

**Interviewer:** Interesting. And so did his … did, like, his vision decrease or, like, did his prescription get …?

**Interviewee:** Slightly—but like a really, like, really slight … like, the eye doctor’s like, “*Most people wouldn’t have noticed that*.” So, yeah. And he has a pair of prescription sunglasses because he wanted to have sunglasses and he said, “*Well, yeah, I’ll get a pair of prescription sunglasses*.” But as far as I know, the prescription is very mild, very mild.

**Interviewer:** Got you. We were just talking about, like, a busy visual field in the context of, like, his desk—does that confusion … unless he’s provided with supports by, like, you, does that carry over to, like, maybe a crowd or some other … or, like, a city block or some type of other busy thing?

**Interviewee:** I don’t know. It’s interesting because sometimes he does seem overwhelmed when there’s a lot going on around him. But then again, if I say to him … if we’re in a crowd and, say, his brother and sister have gone off by themselves and I say, “*Do you see them?*” he can spot them, generally … so … in a big crowd of people, you know.

**Interviewer:** Does he experience other types of, like, sensitivities to smell or taste?

**Interviewee:** I … his … so he does maybe have a slightly heightened sense of smell, because he’ll come in and he’ll say, “*What’s that smell?*” And sometimes he’ll even, like, identify the smell and say, “*It smells like cinnamon in here*.” I’ll be like, you know, like … I think there are a lot of smells mingling together and he picks out one. But I wouldn’t say that’s quite as heightened as the hearing and the vision.

**Interviewer:** Yeah.

**Interviewee:** And taste doesn’t seem to be an issue for him. He’s not a picky eater, you know, so that … his sense of taste to me doesn’t seem unusual. You know, he has a few things he doesn’t like, but that’s kind of on par with … actually he has siblings, who are … who have a longer list of foods they don’t like so, you know, and he doesn’t go and say, “*Oh, I can really taste, like, a certain spice in this*.” Like, he might say he can smell something, but when he eats it, he doesn’t say, “*Oh, it tastes like* …,” you know … and pick out one taste from it.

**Interviewer:** Got you. And how have his sensitivities changed over time?

**Interviewee:** Let’s see. I’m trying to think. How has he …? Well, I think when he was younger, there were … I mean, he went through a period of time where he didn’t want to eat certain things but, you know, some of that was age related, because a lot of three-year-olds, three- and four-year-olds go through that. You know, my husband’s from Italy. And Antonio through a white pasta stage, which threw my husband into a loop, you know, like, “*What do you mean he doesn’t want sauce on his pasta?*” But he didn’t say … he just didn’t want it for a while. He didn’t say, “*Oh, this tastes funny. It’s weird*,” you know. And then he came back to it. So it was just a short-lived thing.

**Interviewer:** How long would you say it was? **[crosstalk at 11:29]** Oh, sorry.

**Interviewee:** Maybe six months.

**Interviewer:** OK. Kids have preferences like that that change.

**Interviewee:** Right. He might have had a few textural issues—again, nothing that I’ve found unusual. You know because, personally, I have some issues with the texture of certain foods.

**Interviewer:** Fair. Absolutely. What were the textures? Oh, I’m sorry.

**Interviewee:** I don’t know. I’m trying to think if … I mean, he didn’t like cooked spinach and he still to this day doesn’t like cooked spinach so I don’t know if it’s that sort of, you know, about texture. But he’s … oh, he … from a young age we encouraged all the kids to try different foods. And so when I served spinach raw in a salad, he was willing to try it. And then he found out he liked the spinach raw, he doesn’t like it cooked. So it’s not that he doesn’t like spinach. Maybe he doesn’t like the change in texture. You know, but he, for instance, really likes onions, raw and cooked, so he’s … so … and that’s been, you know, since he was fairly young. I would make something, you know … I’d make pasta with peppers and onions and he would eat all the onions. He doesn’t like peppers, so … but he’d pick out all the onions. But, you know, the auditory—I don’t think that’s really changed much. It’s just been kind of developed as he’s learned more about music. And so he’s always had that sort of auditory sensitivity. But as he’s grown, he learned to play the piano. He was in chorale in high school. So he’s learned more about music and then he was able to identify the sounds he was hearing and I think visually as well, he’s … his vision has always been pretty sharp. But, as I said, when he was younger, he seemed to have more of an issue with the … with a chaotic visual field. You know, so if I went in and said, “*Clean up your bedroom*,” he just couldn’t start. I had to sit with him and say, you know, “*What about that pile you’ve got over there, where does that go?*” And give him a lot of direction. And, you know, now, with a little bit of prompting, he can do more of that on his own. Yeah, I know, he still feels overwhelmed and he’ll sometimes express that and say, you know, “*I don’t know where to start*,” or “*It’s kind of a lot*,” and, you know, I’ll just have to encourage him. But when he was younger, you know, just even cleaning up the toys, I would sort of … I would have to stay nearby and say, you know, “*Where does this go? Can you put it away?*” He did seem to have maybe, you know … I think this falls into sensory, he used to spin. So he had this thing about movement. And that was actually one of the things that led to his diagnosis because he was in preschool and his teacher said she had an office chair that would spin. He would sit on her chair and spin himself around and so many times that I mean, like, the teachers thought he would throw up because he was spinning so much. And for some reason the spinning didn’t bother him. It actually seemed to help him think and he would jump off the chair and say things, you know, like, he would have an answer to a question or he would just have thoughts that came to him during the time that he was spinning. When he went into school and it was … his first grade teacher had issues because he would … when they would have circle time, he would sit on his backside and spin around on the floor. And she wanted him to sit. And he started karate … around the time of his diagnosis actually, he started karate classes and that helped a lot. It helped him with things like balance, it actually … by second grade, we … when we had a meeting with his team, they wanted to take away his physical therapy because they said, “*He’s doing much better*.” And I said he was taking karate and they said, “*That probably has a lot to do with it*.” But, you know, coordination, balance … and even in the class, you know, he had all these chances to move and when they would sit in the … and the instructor would talk to them, he would still do the spinning. But he had a really good instructor who would just say, “*You know, Antonio, I really just need you to just pay attention to what I’m saying right now*,” and kind of get him in … but you know, in a situation like that when, you know, he had to listen to something, the spinning seemed to help him. **[crosstalk at 16:23]**

**Interviewer:** Yeah. Sorry, what grade was this?

**Interviewee:** Well, preschool? So I think from the time he was, like, five. Definitely, I know he was doing it when he was five. Probably six, seven, maybe by the time he was eight it was sort of tapering off and then … but he still seems to have some stims. So he seems to need some physical, you know, something sensory, he needs to do something physical. And so sometimes he’ll actually jump, which … I had to say to him a few years ago, “*You’re really too big to do that in the house*.” You know, because when he gets to be like, you know, five six, five seven, you know … Not that he’s a big guy—he’s only about, you know, five eight and a half now.

**Interviewer:** That’s not small.

**Interviewee:** No but he’s kind of slim and kind of small … like, he’s all muscle because he fidgets a lot. So that’s part of it, too, like, there’s always some form of movement and sometimes it’s just his hands or his legs, but sometimes he’ll actually jump. And, you know, and I have to say to him, you know, like “*Could you do that in the basement? Could you do that outside?*” You know, so kind of transition … he did have an interesting stim. Maybe in the transition between the spinning and the jumping, he started doing … he started tapping his face. And so I don’t know if that was a sensory thing. He would tap his face so much that sometimes after a while there would be, like, pink marks on his cheeks.

**Interviewer:** Oh, so he would, like, actually kind of irritate the skin a little bit.

**Interviewee:** He would, like, do it a lot.

**Interviewer:** Yeah. And he doesn’t do that anymore: the touching, the tapping?

**Interviewee:** No, I don’t see him doing that. Oh, there are … I’m thinking of a couple other things he used to do. He went through a time where he … and I know he’s not the only child who does this, but he would lick his lips to the point where he had a chapped mark, like, around here. He had a ring around his mouth like this.

**Interviewer:** Does he …? **[crosstalk at 18:42]** Oh, sorry.

**Interviewee:** No, he doesn’t do that anymore, but he did for quite some time. And his diagnosis is … was Asperger’s with some … with ADD and OCD tendencies. So if he did something like that, it would sort of become a habit, a compulsion that he didn’t seem to … You know, like, we made him … we told him, “*You need to stop*.” He couldn’t stop. It got to the point where … I forget what context that was … when somebody asked him, “*What’s the best thing you can do with your lips?*” and his answer was, “*Chapstick*.” He was probably … was, like, nine or ten. But he went through a lot of Chapstick because, even though I explained to him that, if your lips are chapped and you lick them, it will get worse, he couldn’t stop doing it. Whether that was a sensory issue or was connected to his OCD, I don’t know.

**Interviewer:** When did he stop doing that?

**Interviewee:** I would say he was probably ten or eleven. I don’t think it lasted that long, maybe two or three years. Because, you know, there gets to be a point where, I think, even for somebody like my son, he starts to realize that “*Oh, this is a little embarrassing*,” you know, because it’s the sort of thing that people see and … **[inaudible at 20:11]**

**Interviewer:** Yeah, for sure. That’s a great … Oh, sorry. Go ahead, please.

**Interviewee:** Yeah. Another thing that he had a little more trouble with was … he has attempted to overwash his hands. So … he uses very hot water, so, which surprises me because that seems like that … he would … might have a sensitivity to the heat of the water. But he turns the water up really hot and he washes and he has been known to wash, like, all the way up to his elbow. And I would say, this has probably been going on for five or six years. Because I know that several years ago, because actually … it’s been going on for at least five years because we saw his pediatrician and I said, “*Can you talk to him about washing his hands up here?*” Because he would wash them and then he would wash, you know, with soap all the way up there and with the hot water and his hands were turning red and chapped. And I would think that that would actually bother him and the sensory, you know, context, but what it took was the doctor explaining to him that, if he was worried about germs, he was actually making it worse, because by washing and getting his hands to the point where they chapped and then the skin would crack and so letting more germs in. So when it was explained to him at an intellectual level, he was able to scale it back.

**Interviewer:** OK. Yeah. So does he, like, wash his hands a ‘typical’ amount now, quote unquote, or, like, when necessary?

**Interviewee:** No, it’s still a bit more than necessary, a bit more than typical, but less than he used to. I don’t think he goes as far up anymore. I don’t think he washes for as long. I don’t know about the temperature of the water, though. He still seems to go for the really hot water.

**Interviewer:** Does he also shower with really hot water or just wash his hands with really hot water?

**Interviewee:** Yes. He showers with pretty hot water. And he showers for a long time. I actually have to stick my head in the bathroom and ask him, you know, like, “*How long have you been in? How much of yourself have you washed?*”

**Interviewer:** Got you.

**Interviewee:** We went through a long period though, where he wouldn’t take showers. So I sort of let the long showers go because if it had been more than a week that he had taken a shower, I figured he’d better get himself clean.

**Interviewer:** Yeah, and it might take longer.

**Interviewee:** And I don’t … Yeah … and I don’t know. I mean, and he was a teenager then, so it’s … you know, like, we would sit down and say, “*Antonio, you need to take a shower because it’s just not really comfortable to sit next to you right now*.” So, you know … and then at some point, within the last, I guess three years, he started becoming better about taking the showers more regularly, but he hasn’t really been good about decreasing the length of the shower. And I don’t know how much that is sensory. It could also be executive functioning—like, he’s standing under the water kind of forgetting what he’s supposed to do next. I don’t know.

**Interviewer:** Yeah, it could be a lot of things.

**Interviewee:** It could be a lot of things. You know, maybe one of the points that fits into the sensory is that it doesn’t seem to bother him to stand under the water for half an hour. I don’t know.

**Interviewer:** Yeah. Does he seek out water in other contexts, like swimming or the pool or rain?

**Interviewee:** He really does like swimming. It’s not that … something he does a lot. He doesn’t … maybe just not having that much access. But when he does have access to a pool or when we go to the beach, he really enjoys being in the water.

**Interviewer:** OK, so maybe it’s a water thing, too. You talked about some changes—do you think any of these changes in his sensory sensitivities or, like, sensory actions, so to speak, are related to any independence that he’s gained over time?

**Interviewee:** Oh … and I thought of something that I didn’t mention … **[inaudible at 24:15]**

**Interviewer:** That’s OK.

**Interviewee:** But if you don’t mind if I go back …

**Interviewer:** I don’t mind at all.

**Interviewee:** OK. One issue we had when he was pretty young … his hair grows really fast. He needed … his first haircut happened when he was eleven months old. The barber was actually surprised because my husband mentioned it to the barber and he said, “*Oh, eleven months is pretty young*,” and then when he saw him, he said, “*Oh, wow, he has a lot of hair*.” So he had his hair when he was eleven months old and then we realized, you know, his hair was still growing pretty quickly, he needed regular haircuts. So he sat through the first haircut, probably because it was novel. After that, he didn’t want anybody to touch his head. So we actually had haircuts that he protested, I had one that he screamed through, partly because the barber just basically wanted to hold him down and cut his hair. So yeah, somebody finally recommended a barber who was very patient and because of that, he became the only person that Antonio trusted to touch his head and cut his hair. So he … actually, he’s still his barber, although he’s kind of semi-retired, so once in a while Antonio has to let someone else cut his hair. But, you know, but he’s … maybe that’s something that … you asked if things have changed as he’s gained more independence. As he’s gotten older, he’s been more willing to … you know, when I said … say to him, “*Your barber isn’t available. He’s away and he won’t be back for three months. And if you wait three months to cut your hair, it’ll be down to here*,” you know, and then he’ll say, “*OK. Well, I guess I can let someone else cut my hair*.”

**Interviewer:** OK, that’s awesome. That possibility’s really great.

**Interviewee:** Yeah, so that’s definitely a change. I think I mentioned that, you know, there was that time where he wouldn’t take showers. And I don’t know how much of that was sensory, but … and he did start increasing his frequency of showers and doing it independently, like, I didn’t have to keep reminding him to take a shower. You know, so, at this stage, I don’t ask him, “*When was the last time you took a shower?*” generally. I mean, it comes up once in a while, but not, you know … I mean, that seems kind of normal, you know. You know, at a normal level, not the sort of thing where I ask, you know … I used to ask … three years ago, I asked him, “*When was last time you took a shower?*” And he’d go, “*Ummmm*.” And, like, if you really have to think about it that hard, it’s been too long.

**Interviewer:** Yeah, for sure. What about the impact of that chaotic visual field? You said he’s a little bit better at that now. Do you think that’s really …?

**Interviewee:** Yeah, he just seems to be better … I … yeah, I guess … well, he’s … maybe because he’s had to and he has a job **[inaudible at 27:13]** a job. He’s in college. And, you know, I did say to him, as he was getting into his last year of high school, you know … he also has a sister with … she had a language delay. And I said to him, I said, you know, “*You’re finishing high school, you’re moving on to college, I need to focus a bit more of my energy on your sister*,” you know, “*so I need you to do a few more things on your own*.” And he started doing that. You know, but the … he has a … the visual field probably still gets him. He probably needs to develop more systems to help him deal with that. You know, for instance, he recently went to the bank with a stack of checks, you know, like, he’ll collect … part of the problem is … and then not only did he go to the bank with stack of checks, but a few days later, he found more, because, in the visual field, he didn’t find them all. He probably also … he needed to move things. You know, like, that’s part … he looks at the visual field, he wants to see everything like on top, you know, and it doesn’t seem to occur to him that, “*I need to, like, pick up things and look underneath*.” So he found some more checks underneath. He had to go back in the bank. But he has checks that are weeks old. I was a little concerned, I said “*Are*,” you know, “*are you going to run into a problem where some of those checks have expired?*”

**Interviewer:** Yeah, it’s definitely possible.

**Interviewee:** So, that still happens with him, because … but that’s also sort of … it’s partly the visual field and partly his executive functioning, because if he had all the checks still in this place, he would be able to find them and deal with them.

**Interviewer:** Absolutely. Going back a bit to his aversion to, like, not being … not … his head not being touched—is that in the context only of haircuts or is it, like, any type of touch from any type of person including, like, yourself or other family members?

**Interviewee:** He … over time, he has become better with us. Like, he’s not a hugger. You know, like, he’s been OK with me touching him, but that’s … I mean, I’m his mom. And, you know, we started, like, you know, if I can go back to actually … back 21 years, when he was born, we … he came a little early and the pediatrician … we met the pediatrician at the hospital, we hadn’t had a chance to meet the pediatrician beforehand. The pediatrician had been in practice for probably 40 years, kind of doing things the old fashioned way. And even though I was nursing, he said things like, “*Nurse him on the schedule and don’t … if he cries in between, don’t pick him up*.” Now, in hindsight, that … I mean, I followed my instincts. My husband said, “*The doctor said, ‘Don’t pick him up.*’” And I was like, “*I don’t care. I’m picking him up*.” And I went with my instincts. And I was like, “*I’m going to hold this child. I’m going to hug him*.” If he got upset when he was little, I would just hug him really tight. And I kind of knew that that wasn’t what he wanted, but in a way it was what he needed. You know, we changed pediatricians, so, you know … obviously, I didn’t go with somebody who didn’t agree with my style of parenting, but I always … like, I … somebody said something. I don’t know. People asked me something when he was young and I said, “*Well, I had to teach him to be affectionate*,” which … after having more children, I realized that was unusual. At the time, it didn’t stand out to me as much, but when we realized the other kids were affectionate on their own at a much younger age, you know … So, in that sense, I guess I taught him to tolerate touch. But he would let me hug him, but he wouldn’t hug back and … but I find that he’s much more affectionate and much more willing to touch his siblings and be touched by them. Well, you know, we have … the kids were just laughing because I have a picture of his sister there. She’s almost three years younger than he is. So she was ten months old, and he would have been about four and she actually pinned him to the floor because … And this would be another sensory issue. He’s extremely ticklish. So she was only ten months old. You know, she’s, like, not even half his size. She’s got him pinned to the floor because whatever she did to him tickled so much he just collapsed. And she’s on top of them thinking, “*This is a great game*.” But I think in time, you know, like … because I was able to teach her, you know, “*You can hug him, but don’t do that because that tickles him too much*,” you know. And I should mention … yeah, I said … maybe the touch … I said he didn’t have an issue with clothing, but maybe there was more to the touch because I actually had trouble giving him a bath because a washcloth tickled him too much. I had to switch to one of those nylon scrubbies and he tolerated the nylon scrubbie better than the washcloth. So, yes, he has had some touch issues. But not that he would be like, “*Don’t touch me*.” He didn’t … it wasn’t that sort of reaction. It was just that he was very sensitive, very ticklish and he’s not good at reciprocating hugs, but he tolerates hugs. But over the years, like, people outside the family know how he is … they, you know, they’ve learned that he’s not all that comfortable with being touched, but I’ve known people to say that … people that he’s known for years and in certain situations, they’ll ask him, “*Is it OK if I hug you?*” And he tends to say yes, but I think he appreciates that people ask first.

**Interviewer:** OK, that makes sense. Regarding the ticklishness, like, does he have to pick out different, like, washcloths or different things in his life to avoid being tickled, in a way? Like, does that make sense?

**Interviewee:** Oh no, I haven’t asked him. I mean, you know, he’s been showering by himself since he was about ten with the nylon scrubbie so that … it’s probably, like … once he finds something that’s comfortable for him, he sticks with that.

**Interviewer:** Yeah, that makes total sense. Generally speaking, how does he manage or handle his sensitivities or how do you help him manage them?

**Interviewee:** I don’t know. I’m trying to think how … you know, I mean, over the years there have been different things. And when he was in school, you know … if we go back to the auditory sensitivities, there was a time when they gave him noise-cancelling headphones in school, to sort of block out … because if he’s in a room … because you said that, you know, “*Does he has trouble when there’s a lot of noise?*” and if he’s trying to do something and there’s a lot of noise around him, he’ll pick up all the noises around him. So his noise-cancelling headphones were supposed to help with … you know, help him focus, you know. They didn’t cancel enough noise for him and stuff. As long as something gets through, he can … you know, he still picks up on it

**Interviewer:** Did it help a little bit or, like …?

**Interviewee:** Yeah, it helped a little bit and … but he’s … I don’t even remember the last time he used those headphones. He still has them and it would be, like … the ones he got from school, they basically let him keep them. He used them mostly in middle school and then I saw him using them less and less as he went through high school. So I’m not sure exactly … you know, like, he adapted, he decided to, you know, try to manage without them … but he does still get, you know … if he’s working on something … it depends … If he’s working on something and he’s not focused, everything will distract him—every noise, every, you know. So he can be … like I said, he could be in another room, we’re having a conversation, he’s supposed to be doing something for class, for a competition, about something else, he walks in the room and answers the question that one of us asked. You know, but part of that is that he doesn’t really want to do whatever he’s doing in the other room and he’s not focused. On the other hand, if he’s doing something and he’s hyper focused on it, like, nothing gets through. You know, noise … I can walk through the room, sort of tapping him on the shoulder and sometimes even that doesn’t seem to break his focus immediately. You know, so if it’s something that he’s very focused on, then he can be … yeah, then nothing … then even his hypersensitivities don’t seem to break through that. But at other times, he’s just … he can be all over the place because he’s … everything’s just, you know, coming through.

**Interviewer:** Absolutely. Has he ever received, like, particular services or interventions to help him with his sensitivities?

**Interviewee:** Well, I mentioned the headphones. And then … I’m trying to think … You know, to try to help him address the executive functioning, we went to someone who called himself a ‘therapeutic tutor.’ Not sure how much he talked about a visual field, though. You know, we tried to set up workspaces at home that were not too visually distracting. You know, it’s kind of hard. I mean, we only have so much space in the house. And we ended up with, you know … well, he’s 10 years older than his youngest sister. So he was still in high school when she started school, you know, so then we had five children trying to find space to do schoolwork.

**Interviewer:** It’s a lot.

**Interviewee:** It was a lot easier … yeah, it was a lot easier when he was younger because I could send the others … they would finish their schoolwork and go off to play in another room. And he could continue working with less noise, less activity around him. In school, I think they tried a lot of things: having him work in a separate room, having him use something to block his vision, you know, but he’s often said himself, he could distract himself in a totally empty room just with whatever’s going on in his head. Even if there’s, like, no real stimulation, you know, to distract him, he’s still got enough going on. So I think they tried a lot of things and just found that it was just … nothing was particularly effective.

**Interviewer:** Got you. That makes sense. When he is in an environment where there are sensory things that he’s sensitive to, like, say, like, smell or noise or, like, a busy visual field, does that cause or increase anxiety for him?

**Interviewee:** I think it used to. In general, I don’t know that it does as much. But yeah, when he was younger, we had trouble … he had trouble being in crowded places. I see that that’s improved over time. You know, but he still … as he gets older, he learns to handle these things on his own. So, he’s feeling overwhelmed, he’ll move to a quieter corner. You know, and I guess he probably seeks out activities that suit him better, like, one of his jobs is at the church, which is nice, because things are pretty quiet there even when there are a lot of people around, you know, unless it’s, like, a church potluck or something, you know, with the social events, but, you know, if you talk about … because he … his work is generally around church services. And that’s the time when people tend to be quiet even when there are a lot of people in the space.

**Interviewer:** Yeah, absolutely. You … oh sorry, go ahead.

**Interviewee:** Nope. I was just … **[inaudible at 40:01]**.

**Interviewer:** Oh, thank you. You said that he used to get anxious in, like, busy or, like, crowded spaces—what did that anxiety look like or, like, manifest as?

**Interviewee:** We have some pretty extreme examples. Like, when he was around three, we went to a circus. We took him to the circus, which is … a funny event … one of the things that happened early on was they turned off all the lights. He had a hard time. And I think the doctor said this, when we went for a visit, when it’s dark, he couldn’t orient himself in space, so he started freaking out, you know, “*Oh, they turned off the lights. Oh no, what’s going to happen? Oh, no, oh no, oh no, oh no*,” you know, just getting really, really worked up and anxious. And we tried to tell him, “*They’re going to turn the lights back on*.” And he’s like, “*It’s dark. I don’t know what’s going to happen*.” And one of us had to take him out of the, you know, seats and go to a place that was lit and, you know, so … that was a pretty extreme example. And then, even then, I think he might have come back to the show, but it was very loud. You know, circuses are very sensory … it’s sensory overload for normal kids. Yeah, so for him, it was like hands over the ears, “*It’s too loud*.” I think he had to go out multiple times during that show. And, but then he would want to go back. He wanted to go back—but then it would become overwhelming for him and we would have to go out again.

**Interviewer:** Were there other instances where, like, he couldn’t place himself in space in … when it was dark or was it kind of just isolated to that incident?

**Interviewee:** Well, it came up because the … you know, we brought it up with the doctor because he has never been able to sleep well. And the doctor said that that could be part of it, that when you turn off the lights and it’s dark, he can’t really orient himself in space. And so then it sort of gets his brain going and he actually can’t fall asleep.

**Interviewer:** Does that still happen now, like, trouble sleeping?

**Interviewee:** Yeah, the trouble sleeping, yeah. He’s been taking melatonin for years. He has an alarm set for him to take it every night and it seems to help. It helps him settle down at night. But he still doesn’t … probably doesn’t sleep enough. I mean, you know, the last time he slept what I would consider, like, a normal, you know, normal night’s sleep, he probably, like … he was young. He was, like, five.

**Interviewer:** Oh, that’s a long time.

**Interviewee:** I know. But it’s … you know, and it wasn’t … but it wasn’t as dramatic as … you know, it’d be, like … and for years, you know, we had a fairly early bedtime, you know, lights out by eight thirty, even though he was, like, ten, twelve. And … because I said … as I said to my husband, all I can do is put him to bed; I can’t make him sleep. But we … you know, we started the melatonin, which he took with warm milk for a long time because warm milk also helped him. And he said if he took the melatonin, he could probably fall asleep in about an hour. If he didn’t take the melatonin, he would be awake for, like, two to three hours. You know, so the time when he should have been getting, like, probably ten to ten and a half hours of sleep, he was probably getting eight and a half to nine. As he got older, like, the amount of sleep he actually got decreased. But he … as he’s gotten older, he realizes the consequences of getting too little sleep. So he will self-correct. He will say, “*I went to bed too late last night. I haven’t gotten enough sleep for the last two or three nights. I need to go to bed early tonight*.” He will do that.

**Interviewer:** That’s good.

**Interviewee:** So, that’s definitely something that’s come, you know, as he’s gotten older.

**Interviewer:** Yeah. And going back a little bit to the anxiety—you said that it’s gotten less over time.

**Interviewee:** Yes, he did actually … he had … I said they dropped the physical therapy in school, but they kept the occupational therapy for him, mostly for anxiety-driven behaviors. And some of it was sensory, but some of it was probably just, you know, like, “*I have to do this work and I can’t get focused. I know I need to stay focused*.” And he … you know, it became a vicious cycle. “*I have to do this, I can’t do this*,” you know.

**Interviewer:** And then you think about not doing it and that makes you nervous.

**Interviewee:** Yeah. Right. So, you know, they gave him different exercises to do and they tried different **[inaudible 44:45]** for him to, you know … also to try and keep his hands busy, so he wasn’t doing things like this anymore. You know, but in general, I think these things just sort of seemed to naturally decrease as he got older. It took some time. You know, he was in eighth grade when he was invited to come to his IEP meetings, because at fourteen, you know, at the age of fourteen, students can be invited to their IEP meetings and the school he went to was really good about that, really including the students in their own education.

**Interviewer:** That’s lovely.

**Interviewee:** So he learned to, you know, like, to advocate for himself, “*What do you …?*” you know, “*What things help you? What things don’t help you? What can we do? What can you do yourself?*” And I think having that self-awareness really helped him a lot.

**Interviewer:** Absolutely. Thinking a little bit more broadly, what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** Well, some of them, you know, like I said, like, the auditory thing, he, you know, he refers to as a blessing and a curse, and I can, like, sort of focus on the positive parts of that, you know, like, “*In what ways does this help you or what ways you … can you use this in your life?*” You know, we’ve actually said to him a few times … because he started out in college studying computer programming, and we said to him, “*Why aren’t you studying something with music?*” You know, because that’s really a gift that he has. So we’re kind of wondering, you know, like, why doesn’t he capitalize on this gift and, you know, try to find a career with that? You know, we would like him to finish college right now. You know, he’s been struggling a little bit. The shutdown in the spring didn’t help. So remote learning was really hard for him. You know, but we’d like to see him become … you know, it’s hard. I mean, we see improvements, we see a lot of improvements. The school is hard, but I look at the things that he has done and I talk to other people whose kids have similar diagnoses and they’re actually impressed with things that he can do. Like, he learned to drive. It took him two years to get his license. But he did it.

**Interviewer:** But he has a license.

**Interviewee:** So, yeah, he has a license and we got him a car and he drives himself places. He has two jobs: one at a grocery store and one at the church. He gets himself to the jobs. He tends to be late because he has a very odd relationship with time, but, you know … and when his boss says things to him like, you know, “*I was going to have you train on the register, but based on your habit of getting here late, I don’t think I can do that because I would really need you to be here on time*.” And he picks up on that and realizes, “*Oh, gosh, I need to start showing up on time* *for my shift*.” You know, somebody … something happened at church where somebody said, “*I thought you were going to take care of this and then you weren’t here on time*.” And he started getting better about getting there. You know, it’s the fact that he has two jobs and that he’s responsible, that he gets himself there because he drives himself. He also volunteers at a monthly food pantry in our town. And the people there … it was funny because there was … last year there was a festival in our town and, you know, different groups set up booths. And so, as I’m walking by, the people in the food pantry were like, “*Hi! Have you heard of the food pantry?*” And I said, “*Well yes, you see, my son volunteers*.” And when I told them his name, they were like, “*Oh my gosh, we love him. He’s great. He comes and he works really hard*.” And just to hear people say that about him. So these are already good things that, like … these are … like, when he was younger, I was like, “*Oh, if he could just, like, be independent and, you know, and hold a job*.” And so we’ve already achieved those things. I mean, you know, it’d be good to see him finish college and maybe get a job that’s more of a career, you know. I don’t know how much time that will take, you know, because, like I said, he has a grocery store job and he’s still working on getting that … getting there on time for his shift. You know, if he has, as you would say, a real job and if he’s too distracted and he’s not fulfilling his responsibilities, you know, so … but I would love to see him get to that point, if he can, like I said, with the music if he could find something that he’s really passionate about and then he would probably be so hyper-focused he probably wouldn’t think of anything else.

**Interviewer:** Yeah, absolutely.

**Interviewee:** Although could be the kind of person who would be so hyper focused, he would forget to eat so I would be one of those moms calling him saying, “*Did you remember to eat?*”

**Interviewer:** I understand that.

**Interviewee:** Yeah. You know, it would be nice to see him living independently, you know, at this point. You know, he’s at community college, so he’s home with us and that’s not a surprise. His sister’s eighteen. She’s on campus. You know, she went to college, you know, and his brother’s a sophomore in high school and in a couple of years, he’ll probably go off to college, you know. So it would be nice to see him move on, you know, because the other kids are going to start moving on. And it would be nice to see him do something on his own, you know, maybe live on his own, live with somebody else, you know, I don’t know. He has his own goals that are … he has some goals that are church related so he’s kind of exploring those. You know, I’d love to see him realize his own dreams because he has some goals and aspirations of his own and I’d love to see those come to fruition. Yeah, so, you know, I think those are the main ones. You know, we’ve talked about relationships and he doesn’t see anything happening there so, you know, I don’t … I guess I don’t count that as a goal. Like, some parents would say, “*Oh, have a family of his own*.” I don’t know.

**Interviewer:** No, absolutely. We’re going to shift gears a little bit to our next chunk of questions, if that’s OK.

**Interviewee:** OK.

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

**Interviewee:** Yeah. I think when he was younger, a lot of people were like, “*Why does he do that?*” And that actually was hard for me, as a mother. I got a lot of, “*Why does he do that? Why does he spin? Why does he touch his face like that? Why does he jump? Why does he*,” you know, “*why does he jump if I touch his shoulder?*” And I got that from family and I would have to say that, probably because we live … we don’t … you know, I have a pretty large … my immediate family is pretty large, but we don’t see them all the time. You know, we used to live within a couple of hours of my parents, but they moved, you know, so my family is all, like … the closest one is about four hours driving away.

**Interviewer:** That’s not close.

**Interviewee:** Yeah, I even have … I have family in Florida. So we … some people … some of the family members we don’t see that often, so when we would get together, they would have a lot of questions like, “*Why does he do that?*” I found that the people that we … the people in our community were much more accepting of the things he did—probably because they saw him on a more regular basis, so whether it was at school, people who saw him almost daily, church people who saw him pretty much weekly. You know and so I had friends who would say to me, “*I know he doesn’t like to be touched, but he let me put my hand on his shoulder*.” He was probably about 14 or 15 and the secretary at our church said to me, “*I had a really nice conversation with him the other day and he didn’t look like I had backed him into a corner*.” Because she knew him and she knew that conversations were hard for him and she saw that as a positive step and she wanted to share that with me that she was able to have a nice conversation with him and see how he had … he was maturing and that he was reciprocating in the conversation. Not like, “*Oh, my gosh, someone’s talking to me: what do I say, what do I say, what do I say?*” And, like I said, you know, and people … I have … one of my friends actually, who’s known Antonio since we moved here. He was two when we moved to this town. And one of my friends, actually, she organizes the volunteers for the food pantry and she has noticed a lot. She can … she’s mentioned to me a lot of things that she’s seen him do over the years, like, you know, I know he didn’t use to want to be a part of the group, but now that he’s at the food pantry and he’s, you know, he’s really a part of the group and he’s willing to help out wherever. If we say, “*Hey, can you do this?*” he’ll jump in and do it, you know. So the people that see him on a more regular basis have seen a lot of changes. And people see him at the grocery store and say to me, “*Oh, I saw your son at the grocery store. Wow, he’s grown up and I had a conversation with him*.” So, and people pick up on that, you know, they might not have …. even if they haven’t seen him for a couple of years, like, he’s really matured and he’s, you know …

**Interviewer:** Yeah. That’s lovely. Would you say when he was younger was the community, like, more or less accepting of him and his sensitivities?

**Interviewee:** I had a few … it depends. I mean, in general, I would say no, but I had a few incidents when he was younger. You know, when he was … I said, we moved here when he was two. He was … I was in a group with some other moms and he was in … yeah, because he’s about a year and a half older than this other boy. So the other boy would have been about six months to a year old at the time, you know, like, really still an infant and my son was two and he was, like, getting too close to him. And I don’t … you know, and a couple of times the other mother got really, really anxious, like, “*What’s he doing? Why is he doing that?*” And she actually at one point said, she got … she actually sent me an email that said, “*I’m really uncomfortable with your son being close to my son and, you know, and maybe we can’t be at the same meetings or events together anymore*.” I had to bring that up with other people, because they were like, “*Well, there’s no way to prevent you from being at the same event*,” you know. I mean, the best I could do is say, “*OK, I’ll just try to keep him away from your son*.” The irony is that many years later, they ended up going to the same school. They were a year apart in school just because of the way their ages, you know … so, like, my son was in tenth grade, and her son was in ninth grade and they ended up singing together in the school chorus and they got along really well. But, you know, I told him later, I said, you know, “*When you guys were young, his mom didn’t want you around. She thought you … that you were not very safe around the other boy*.” Of course, the other boy ended up, you know … He was like, “*Oh, wow I can’t even picture that*.” And I said, “*Well, you are, like, a year and a half apart and so he was a baby and you were, like, this, in her mind, this big, burly two-year-old*.” And then when they were older, it kind of reversed because the other boy ended up being bigger than my son.

**Interviewer:** That’s funny.

**Interviewee:** Yeah, I mean, in hindsight, it was funny. At the time, though, it was kind of hard because it was like, you know … I felt rejected, I felt like somebody was rejecting him, you know. You know, in school I think there were a couple of incidents, you know, where he yelled at other kids, but this brought up … this is what … when the teacher … he had a very good preschool teacher, who, instead of saying, “*He can’t be in the school*,” said to me, “*There’s something going on*.”

**Interviewer:** That’s what the teacher should do.

**Interviewee:** Right. But not all teachers are like that, you know. It was something simple, like, they were playing a game with bingo cards and they were supposed to be using those markers to dock their cards, you know, and some of the students were doing it wrong. And in his mind, he said, “*You’re doing it wrong*.” And he got really upset, like, you know, way out of proportion with the situation. And I was … that’s … but that’s when the teacher said, “*You might need to have him evaluated*,” you know. So she was really good about it, she’s like, “*because this was, you know, this is just one example, but this is, you know, like … that I’ve known him for two or three years and this is just something that you should probably look into*.” You know, so there were times when he was younger, where people were like, “*Why does he do that?*” You know and, like I said, there was an extreme example where somebody said, “*We don’t want to be around you because* …” you know. And he wasn’t destructive. He wasn’t. He never actually harmed another child. And, you know, like, I mean, to be quite honest, his sister was a biter. I mean, if anybody didn’t want to be around us, it should have been because of her, you know. But, you know, it was kind of hard sometimes and I did have some situations with family. Like I said, we weren’t around them all the time and when they would say, you know, “*Why does he do that? Can you stop him from doing that?*” And I would feel very embarrassed because, you know, this is family. There was actually a time where one of my sisters said to … because her son came and said, “*He seems very insistent about why we, you know … the way we play the game*,” and my sister said to her son, “*Oh. Well, we talked about this, that he has these issues*,” you know. So it just felt like people were judging him, whether it was his sort of OCD tendencies in playing a game or some of his sensory issues, you know, like, spinning or jumping, or, like I said, you know. But on the other hand, you know, all the cousins with the kids would get together and he, you know, sometimes … we did have times when we were in the pool, and he would be swimming like a fish and, you know, really enjoying himself, you know. But I would say that, like, with my family, people … certainly gotten more used to the things he does and, in all honesty, a lot of things that he used to do have really been reduced. And I mentioned self-awareness earlier, that if I say to him, “*When you do this around Grandma and Grandpa or, you know, your aunts and uncles, they don’t understand why you do it*.” And just pointing that out to him. made him think, “*OK, I, you know … maybe I need to tone this down a bit*.”

**Interviewer:** Yeah. It sounds like self-awareness is a strength of his in a way.

**Interviewee:** Yeah. Well, I’ve always tried to be as honest with him as possible, I waited until I felt like he could understand it. When he was younger, I said, “*Your brain works differently than other people’s*.” As he got a little bit older, I explained his diagnosis to him and what it meant. But I also said to him, one time when he was in high school, I said to him … because I got very upset about something that he was supposed to do and he didn’t do and I said, “*Don’t you dare use Asperger’s as an excuse. It’s a part of who you are, but it’s not the reason that you can’t do certain things*.”

**Interviewer:** Absolutely. You just gave me so many awesome examples of, like, different community reactions and actions, but what about his job—is his job accommodating and accepting of him and his sensory sensitivities?

**Interviewee:** Well, I mentioned that his boss pointed out that if he’s late, he’s, you know … I think his job … when he was hired at the grocery store, they didn’t know his diagnosis. They never asked. I mentioned it to his manager later, he’d already been working there for a month. But his manager mentioned something, a couple things that he did and I said, “*Well, he has a diagnosis and that could have something to do with it*.” So his manager is very good. So I think his manager tolerates some things that he does because he has a diagnosis that maybe he wouldn’t tolerate from other people. I don’t know. Like, the lateness should probably be more of a problem than it is. But I think, knowing why … **[speaking to her son]** OK, that too. He is a nice guy. Go away. **[speaking to the interviewer again]** He’s outside the door, listening. He can only hear my side of the conversation, though. He … yeah, I mean, I think the job gives him opportunities because he works the front end of the grocery store. So he stacks groceries, and he goes outside to get carts and they actually realized that he’s really good at getting the carts out of the parking lot, like, he does it in a very efficient way. He is very conscientious about getting every possible cart back in the store. So they kind of, like, you know, like, “*OK, we’re closing, so you could, like, go outside and get all the carts*”—not as a punishment but because he’s good at it. And, you know, also, I think the physical activity helps him that he has an actual job to do, something to focus on. And even stacking groceries, he says he’s slow, but I think he’s also meticulous. So, yeah. And then, you know, with the job at church, most people were very understanding. I said, there was one complaint recently where somebody said, “*You weren’t here to do something and I expected you to be here and if you weren’t going to be here, you should have let me know*.” And I, you know that … but that’s unusual. I mean, he’s been doing this job for over a year now and that was really the first time I heard somebody complain. You know, they’re not asking him to do something completely … you know, like, it doesn’t have high expectations and he will actually go a little beyond the expectations in a lot of cases. So I think that, in general, most of the people at the church are happy with the work he does because they’re like, “*OK, maybe he didn’t do this, but he actually did that thing that I didn’t ask him to do*.” So some people are willing to forgive one thing because, you know, he’s going a little beyond in another area, you know, and it’s also … it’s a church setting, so I always hope that means that people will be a little more accepting.

**Interviewer:** You would hope.

**Interviewee:** Like I said, I mean, a lot of people in our church know him pretty well. Because once in a while I’ll say, “*I worry about him*” … I have talked to … I have some friends, you know, who are a bit older, I mean, one lady who’s even older than my mom, and I’ll say “*I worry about him because this and that and the other thing*.” And she’s like, “*No, of course you worry about him*” and even if I say, “*He did this*,” then she’ll say, “*Well, of course he did because that’s the way he is*.” Like, she … like, people are very accepting, like, you know, it helps me a lot when people say, “*Yeah, of course he* …” and even the school did that. When he was in school, a few times I said, “*Well, he does this*,” and they said, “*Well, of course he does—he has Asperger’s syndrome*.” And I went, “*Oh, they get him*.”

**Interviewer:** That’s awesome. That’s good. It’s really good for your son to, like … for anyone to be understood.

**Interviewee:** Yeah.

**Interviewer:** That’s lovely. Thinking again, a little bit more broadly: what hopes or worries do you have for your son in regards to how his community will react to his sensory needs in the future?

**Interviewee:** Well, I mean, based on our current experience, I hope that people will continue to receive him positively, but, you know, a lot of that … I guess a lot of it comes from people who know him. But if I use the example of the food pantry, he went into a situation where he knew only a couple of people—like I said, my friend who organizes the volunteers, he … basically the rest of the people were strangers to him. And he handled that really well, to the point where, you know, like I said, I encountered a bunch of people who were basically strangers to me, but they knew him and when I mentioned his name, they were like, “*We love him*,” you know. So that bodes very well for the future that, you know … sometimes I worry that he could meet people and they wouldn’t understand why he does the things he does. And he might do some things that will turn off some people. And he’ll also meet people who say, “*OK, he has some quirks, but look at the stuff he does*,” or “*He’s a really hard worker*.” So, you know, so those are my hopes. I mean, yeah, I worry that some people will focus too much on the things that … like all the weird things or the things he doesn’t do, you know, and that is a little worrisome. Like, if he gets a job and the employer isn’t understanding, he might not be able to keep the job, you know. So, you know, hopefully … and part of it, too, is that he’s learned to self-advocate. So I guess at some point, he’ll have to, you know … he should be speaking up for himself and he might say to his employer, “*I have some of these issues that I’m working on*.” So that would be one of my hopes is that he would self-advocate and say, you know, “*These things might be hard for me, but I’m working on them*.” Yeah.

**Interviewer:** Yeah, thank you. Shifting a little bit: in the, like, transition to adulthood, where do you see your son?

**Interviewee:** I don’t know. It’s hard. I think … I try not to project too much into the future because I guess I know from my own life that life doesn’t always turn out the way you plan. You know, I do hope that he could transition to living on his own and we’re working on that, you know, I’ve … you know, he’s the oldest of five children and I’ve said to all of them, they have to be able to do their own laundry, cook for themselves and do some basic sewing before they leave my house. You know, so these are skills that I’m trying to teach him, but also, you know, things like talking on the phone, managing his money and we’ve been working on those things. You know, he has a bank account. I’m the cosigner right now, but, you know, these are things that, as he gets older, he should be able to do independently. You know, so I see it as a transition and I think his transition is going to take longer than it probably will for his siblings. And, like I said, his sister’s already off to college and, you know, in four years, she’ll probably be, you know, she’ll probably be thinking, “*Oh, yeah, I’m going to get an apartment*,” you know. Knowing her, she’ll be like, “*My friends and I are going to get an apartment and* …” you know, whatever. You know, and I would hope within five years, he might be able to do the same. You know, the point is that, you know, the two oldest children, he’s 21, she’s 18. But in a lot of ways, I’ve seen them as sort of the same age, because, you know, developmentally, he’s always been a little bit behind. And, you know, so, you know, even when it was time for, you know … we got to the point where I had to stop hiring babysitters because they were basically the same age as he was at the time. But I needed his sister to be old enough to … because she was a little bit more responsible than he was. So he was old enough, but she was responsible. And, you know, so I left them … we left them alone with the other three, because I said, you know, “*The two of you can handle things*.” You know, but in a different … you know, if she had been the oldest child, we probably would have a couple years earlier. You know, so I just expect his transition to take longer and we’re in the middle of it, you know, like I said, you know, he’s working on jobs, he’s working on the bank account, he’s, you know … he started … he’s already started buying some of the groceries for himself, you know, because he lives at home, he could certainly put it on the grocery list, but at this point, too, I’m only going to the store twice a week. And sometimes he’s a little particular about what he wants: a certain brand or a certain type of thing. And I’ll say to him, “*Maybe it’s easier if you buy it for yourself*,” and he will.

**Interviewer:** OK, that’s great. What independent skills does he have—like, is he able to prepare a meal for himself? You talked about laundry, like, hygiene, things like that.

**Interviewee:** Yeah, like I said, the hygiene has gotten better. He seems to be a bit more independent with the hygiene. He just leaves some things probably later than he should, you know, for instance, he’ll have to work at the grocery store and he has to shave and he’ll … he has a shift that starts at two and he’ll shave at 1.15. Yeah.

**Interviewer:** He shaves.

**Interviewee:** Yeah, in general, yeah, the hygiene is good. He can cook for himself. He could probably prepare an entire meal, he can cook eggs, he can cook pasta, you know, he can … He’s probably working on some other things. But I mean, at 21, you know, I mean, unless … you know, I mean, at 21 there probably … he probably knows plenty of people his age who can’t cook at all. And there probably are other people his age who can cook better than he can. He’s probably above average, at least, in terms of cooking. He could definitely feed himself. I wouldn’t worry about that. If he gets, you know, when he transitions to living on his own. You know, I probably worry a little bit more about managing the money, I think he probably needs to work on that a bit more.

**Interviewer:** In what ways do you worry about that?

**Interviewee:** Well, he sometimes puts … because he has a savings account and a checking account and he has been known to let the balance in his checking account get too low. He actually almost bounced a check a couple weeks ago. You know, and at this point in his life, he doesn’t have that many bills to pay if he … when he transitions to living on his own, he’s going to have to take care of an apartment, a car, utilities, in addition to food. So, you know, so I’m trying to think what else—did you mention something else?

**Interviewer:** Like, laundry kind of, like, daily chores, household chores.

**Interviewee:** Oh yeah, laundry he can do … again, it’s just a matter of … that probably falls more into the executive functioning. Like, if he’s going to work on a Thursday, he should do his laundry on Wednesday, but no, he does it on Thursday morning. I’ve actually had him … you know, and one of the reasons that he’s late to work is that he’s washing his clothes and the shirt’s in the dryer. And, granted we live five minutes from the store, but he should be there, like … the shift starts at two, he should be there before two o’clock and at 1.53 he’s getting his T-shirt out of the dryer, you know, so … he can do the laundry. He just needs to work on the timing. You know, I would probably worry a little bit more about his cleaning skills because the boys are supposed to keep their own bathroom clean and, based on the condition of the bathroom … but he’s not alone in that. I think a lot of people move out and then they realize, “*Oh, goodness*,” you know, “*Mom’s not here to clean the bathroom anymore*.” You know, I’ve been more … I’ve been conscious of that with all of them, you know. I mean, and I don’t think this has anything to do with his sensory issues or his executive functioning. I mean, people move out from their parents’ houses all the time totally unprepared.

**Interviewer:** For sure, sometimes you just have to learn by doing.

**Interviewee:** He’s probably a little more prepared than most people his age.

**Interviewer:** That’s good. That’s awesome. Does he ever express interest in wanting to live on his own one day?

**Interviewee:** I don’t know. He hasn’t … not really. He’s never … like I said, at some point, his sister will probably say, “*Oh, when I get an apartment* …” He’s never said things like that.

**Interviewer:** Got you. What about his social life: does he manage one to some extent, does he have one?

**Interviewee:** It’s pretty minimal. You know, his social life is probably more centered around the church and things and, of course, the current situation doesn’t help at all.

**Interviewer:** No. It helps no one.

**Interviewee:** You know, he … but he didn’t have that much of a social life to begin with. I would say his social life is very centered on his siblings and church activities. You know, right now, the church activities are pretty minimal. In the past, there were things like potlucks and, you know, different things going on in church and he would participate in those and he would talk to people and be social at those events. And he likes to spend a lot of time … especially … his sister’s 18, his brother’s 16 now. They like to watch movies together and hang out together and sing together. He doesn’t have a lot of friends from school, high school or college. He kind of … I don’t know … I had to facilitate this, like, through high school because he went to … he changed schools from fourth to sixth grade. We didn’t move but he changed schools. And when it came time to celebrate his birthday, I, you know, would get in touch with his friends’ parents and say, “*Hey*,” you know, “*can we get the boys together?*” So there were a couple friends, even from elementary school that he stayed in touch with for a while. The good thing is that when he transitioned to the new school, he went with about four or five boys that he knew from his previous school, so in a sense that became his friend group. He didn’t end up making other friends in high school. He’s particularly close to another boy that graduated with him, but, interestingly, the other boy has Down’s syndrome. So he’s, like … he was, like, one of the most popular kids in their school. Everybody knew who he was and he and my son would just … they bonded over things like church and other things. And so they’ve kept in touch. They don’t spend a lot of time together, like, months will go by, but, you know, like, recently, the other boy’s dad contacted us and said … he asked if my son, actually, my son and my daughter, he asked if my son and my daughter could go up to their house. And my daughter at the time was getting ready to go to college, so she said she really wanted to go, but she had too much to do. So he went by himself. He drove up … we live in Billerica, he drove to **[name of town at 1:16:17]** and spent a couple of hours with his friend and his family. So he has a little bit of a social life.

**Interviewer:** Yeah, definitely. And then, thinking again to the future a bit—do you think he’ll be able to achieve more independence?

**Interviewee:** I think so. I see him, you know … because he keeps making progress. You know, when he was first diagnosed, of course, you know, I went online and this was almost 16 years ago, so the information that was out there was … you know, there wasn’t as much online and the information that was out there was interesting. And one thing I read says that people with Asperger’s syndrome will never be able to live independently, they’ll probably have to live in a group home, if anything. That was kind of depressing when, you know, you’re going through this with your five-year-old. And as he got older, I thought … as he got older and I looked at him and I saw that, whatever I read when he was five, that is not true. And the more … the older he gets, the less true I think that is. He could live alone. He could hold a job. I see that for him, you know, and he’s shown us that he can do those things. You know, he just needs a little more help getting there.

**Interviewer:** Sure. We all do sometimes. What do you think will help move him into adulthood more?

**Interviewee:** Well, I think probably what helps most people: trusting him and letting him make his own mistakes. You know, and that’s not always easy. I think it’s, you know … we’re going through that with his sister, too. She’s on campus and, you know, she told us some things last night and we’re like, “*Oh, really?*” You know, we might need to nudge him a little bit, though, because he’s pretty comfortable at home, so he … I could see where he could use a little nudging, you know, like, “*Hey, have you ever thought of getting your own place? You know, you’re, like, 25, and you’re still at home*,” you know. Although my husband is … my husband grew up in Italy. And of course, you know, they’re very comfortable having adult children living at home. So. Yeah.

**Interviewer:** Do you think there are particular …? **[crosstalk at 1:18:47]** I’m sorry.

**Interviewee:** No, go ahead with the question.

**Interviewer:** Do you think there are, like, services or interventions that could help with beyond, like, the parental kind of light push?

**Interviewee:** I don’t know. I haven’t really investigated what’s out there. I know that his neurologist has mentioned a couple of places that we could connect with, like—what’s it called?—the Lurie Center. You know, so that might be something … I did have … when he was younger, I had a membership to AANE and I know they offer some adult services. So I suppose it’s … to move him … to make him more independent, it would be good to connect him with those, so that instead of relying on us he can reach out to other people.

**Interviewer:** Absolutely. And now, putting these two things together—his sensory sensitivities and his transition to adulthood—how do they intersect for him or do they not?

**Interviewee:** I don’t know. I mean, like I said, you know, there’s some things that he can probably capitalize on like his auditory sensitivity—whether he will or not, that’s going to be up to him. Yeah. I think the fact that he’s learned to deal with a lot of them helps and the self-awareness that we’ve talked about, because if he’s aware of them, and he knows what triggers him in certain situations, he can either speak up or try to find strategies to deal with them. But, like I said, some of the strategies might rely on finding some services to help him and so, yeah, maybe it’s a matter of connecting him with some of those services so that he can use them as resources.

**Interviewer:** Absolutely. You kind of answered this in not so many words, but I have to ask it: would you consider his sensory sensitivities to be an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** Yeah, probably a bit of both. You know, like, as I said, you know, what … as I told him, you know, whatever he has going on is a part of him. And it can be an asset, it can be a challenge … he has to … and if it’s a challenge, he has to find a way to overcome it and deal with it, not just, you know, not use it as an excuse. You know, because that would probably be one of my biggest fears is that he would go out and say, “*Well, I have Asperger’s, so I can’t do this*.” I mean, like I said, he’s gone places … he goes … he went to work. He didn’t tell anybody. He went to the food pantry. He didn’t tell anybody. You know, so people met him on his own terms and said, “*Oh, this is what he’s like*.” And they didn’t know it was because he has a diagnosis. And it shouldn’t be.

**Interviewer:** Yeah, exactly. That was a great segue.

**Interviewee:** Thank you.

**Interviewer:** What do you anticipate as being challenging for him as he does gain more independence, in regards to his sensitivities?

**Interviewee:** In regards to his sensitivities, I don’t know … he … because I just see the improvements that he’s made. Because I would … if I look back, in the past I would have said a lot of those sensitivities were getting in his way and not so much, I can see where they might … they could get in his way in the future, especially if he gets in a situation that causes him anxiety, then maybe some of those sensory issues could come back on him and then start interfering with his own independence. You know, I mean, if he, you know … say, something like the handwashing, if he just, you know … the anxiety gets the best of him. And he’s, you know, he … say, he has a job and he’s in the bathroom ten times a day washing his hands. You know, and the current situation doesn’t help a lot with that, because, you know, he’s … at least he’s buying his own gloves and wipes. But, you know, it’s kind of got him a little freaked out about, you know, keeping everything clean and that could snowball on him if he’s not careful.

**Interviewer:** For sure. Especially right now, like you said.

**Interviewee:** So I guess it’s just a matter of keeping an eye on his sensory issues and not letting them snowball, not letting them get the best of him.

**Interviewer:** Absolutely. Do you think there’s anything that would particularly help him, like a service or intervention?

**Interviewee:** I don’t know. As I said, it’s not really something we’ve investigated for him as an adult, so, you know, I guess, I … we’ve certainly tried things as he’s gotten older. I mean, I … we had services through school. I also took him to a place in Lexington, where he took a course on executive functioning, for instance. We haven’t done as much with the, like, formally, with the sensory issues. A lot of what we’ve done so far have been things like executive functioning, getting organized. You know, and then … but sometimes it’s a matter of getting him to implement what he’s learned. So I know that from … you know, he took a class about executive functioning and getting organized. And then I said to him … afterwards, I said, “*Are you using any of the skills you learned?*” and he’s like, “*Well, kind of*.” And I’m like, “*Wait, so you went to the course for a week and you’re just kind of using those things you learned?*” Yeah. So maybe the challenge is getting him to apply any resources that he might have access to.

**Interviewer:** This may not be so relevant for you because you said you haven’t really, like, dove into adult services, but do you think there are gaps in the available services and interventions for kids like your son, adults like your son?

**Interviewee:** So, I was feeling like … that … I mean, you know, the transition from high school to college at least was … well, the college does offer some services. But yeah, I was like, you know, “*Where do you go?*” you know, when the school provides services and then, in the transition to adulthood, you have to seek these things out on your own as a family and as an individual, you know, and it’s not clear, like, where do you go, who do you talk to, how do you find these things? You know, so that path isn’t exactly clear. I guess, an organization like AANE might be able to help, you know, so that could be a resource that I could tap, because I know that they, you know … but part of it is too is his diagnosis that, you know, with AANE they always said if you’ve met one person with Asperger’s syndrome, you’ve met one person with Asperger’s syndrome because everybody’s so different. And he has met other people with Asperger’s syndrome, and he said to me, “*Oh, I met this person.*” He said,“*I don’t do that, do I?*” And I’m like, “*No, you don’t do that* *but you have other …*,” you know. So they can make suggestions, but we still have to investigate on our own because what works for one person isn’t going to work for another person because everybody’s so different.

**Interviewer:** Absolutely. And then, taking like another broad approach or, like, a broad thought: how do your son’s sensory sensitivities and sensory interests impact your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Well, I know at times, you know, we worry. I know my husband worries. He’ll say, “*How can he ever do these things on his own?*” You know, if he’s washing his hands too much or if he’s, you know, too distracted by sounds or whatever’s going on around him, you know. I guess I have some … you know, because he has a job and he looks at his work environment and says, “*I don’t know if he could do what I do*.” Because, you know, I think he sees a lot of … there’s a lot of sensory input in his job and he wonders if our son could handle that, you know. And I guess I focus on the positive: what he has been able to achieve so far. So I see that he’ll be able to achieve some other things as well. You know, a lot of that will depend on his motivation, which has always been a key. A lot of things in his life are dependent on his own motivation—whether that’s schoolwork or even getting a job. Like, I nagged him for quite a few months to get the job at the grocery store. You know, it was the summer after his freshman year, when he sat around doing basically nothing because in middle school they always had the summer packet to complete and so he had things to do. And then he got to ninth grade and said, “*Oh, there’s no summer packet, I just have to read one book*.” I said to him, “*You need to get a job because you need more to keep you occupied*.” But it took me months of nagging until I finally said, “*Listen, I’m going to put you in the car and drag you around to a few places in town and have you fill out applications.*” And he said, “*Oh, I was going to go to Market Basket*.” I said, “*Fine. I’ll take you to Market Basket*.”

**Interviewer:** Absolutely. We have one last very small chunk of questions so we’re almost in the home stretch. So, like, finally, like, 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:** Well, I mean, in a way, it’s similar to, you know, what it would mean for my other children, you know: that transition from living at home, depending on mom and dad to take care of certain things and then getting to the point where you live away from home and you take care of things. Now, it’s not a hard break for anybody, you know. In my mind, it is a transition. So there’s a period in between where, you know, like … my daughter’s doing it now because she’s living on campus so she has to handle a lot of things on her own. You know, for my son it’s different because we don’t have that transition where he’s living on campus, so we’re doing a lot of that at home. So for him the transition … I think I mentioned earlier, the transition is going to take longer. And it’s going to be more gradual and some things we’re going to have to sort of—not force, but, you know, we’re going to have to be sort of cognizant of the … “*Oh, he doesn’t*,” you know, like, “*he’s not on campus, doing these things on his own*.” So we have to sort of encourage him to, “*Why don’t …?*” Like I said, like, he needs something from the grocery store and I say, “*Well, why don’t you buy it?*” You know, that’s all part of the transition, just making him aware of, “*Hey*,” you know, like, “*Oh, yeah, I’m 20 or 21. I can do this. I don’t have to ask Mama for it*.” You know, some of it is still though … I see him still, you know … like, he’ll have something to do, he’ll ask a lot of questions and part of this transition is not just giving answers. Sometimes I’m asking a question back: “*But what do you think you do?*” You know, and I think, especially in his situation with his diagnosis it’s … yeah, I have to ask a lot of those questions. I really have to make myself step back more and say, you know “*What would you do?*”

**Interviewer:** For sure. Has this perspective changed over time for you?

**Interviewee:** I don’t know. For me personally, I don’t think so. I mean, maybe it’s just a little more awareness of … when he was younger, you know, was asking a lot of what if questions. “*Well, what if this happens? What if you don’t do your homework? What if …?*” you know, and it just … You know, in a way, it’s the same type of questions, but the situation is different, you know, and I think for me … I don’t know. I … maybe I took some things for granted. When he was 18, I said, “*OK, we’re going to the bank. We’re going to take the money from your young savers account and move it into a student account*.” You know, I mean, I just said, “*You’re 18 now. You can do this*.” He was a little bit like, “*Oh, oh, OK. All right*.” You know, like, he wasn’t certain. And he was like … but I wasn’t, like, pushing him off, you know, off the deep end and saying, “*OK, swim*,” I was saying, “*No, we’re going to go … you’re going to get an account. I’m going to cosign your account*,” you know. “*And*,” you know, “*you’re not … I’m not sending you out to do this on your own*.”

**Interviewer:** Yeah, it’s a deep end with floaties.

**Interviewee:** Yeah, you know, so. And the interesting thing is that, when I reassure him, you know, “*Well, you can do it*,” he just starts doing more things on his own. He’s actually surprised me, like, sometimes he’ll have some work to do at his church and then he’ll just sent me a text message saying, “*I’m going to go to* …” like, he said, “*I’m going to go to Walmart and look for that cable that I wanted to buy*,” you know. He … so the good thing is, he lets me know he’s not coming home immediately and he goes and he does … he takes care of his own errands. So because I started … he wanted to know if I could get the cable for him. I said, “*I don’t even know what I’m looking for*.” You know, so then he realizes, “*Oh, I should and could do this on my own*.” So that’s part of the transition is making him realize that he can and should do these things.

**Interviewer:** Absolutely. So what do you see happening in his future?

**Interviewee:** I don’t know. That’s a hard one to answer. Because I guess I try … right now. I’m trying to stay very much in the present. You know, I do see … I see possibilities because I mean, like I said … and I said this earlier, life can go in all sorts of different directions. I see the possibility of him living on his own. Probably not too far from us. So I would see him living on his own, but maybe not too far from home. I see him staying active in the church because that’s something that’s very important to him as well. You know, I can see possibilities where he has a job on his own, I can see other possibilities. You know, I can see possibilities where he would pursue something that would require more school. That’s a more remote possibility because … just because right now, the school thing isn’t going all that great for him so something that would require an advanced degree seems like less likely. But on the other hand, I could see him surprising us. If … like I said, if he’s properly motivated, I see him, you know, like, pushing himself finally and doing it, but I see that as a bit more remote and, you know, other things.

**Interviewer:** Absolutely. And then, final question: how have his sensitivities impacted this perspective you just articulated?

**Interviewee:** My perspective?

**Interviewer:** Yeah, like, on what it means to transition into adulthood.

**Interviewee:** Oh, OK. Well, I think that, you know, because … yeah, I have … as I said, when he was younger it was a little like, “*Oh my goodness*,” you know, like, “*we just need to get him through the school day*.” And then it got easier as he got older. It got easier. You know, we worked through a lot of things, he worked through a lot of things. And so I guess that in my perspective … it helped my perspective, because I told you when he was younger, and, granted, that came from a source that I don’t consider that credible, but the idea that there was a potential that he couldn’t live on his own. And, as I watched him work through these sensitivities and work through the challenges in his life, I saw that that wasn’t going to be true for him, that he could overcome certain things and he could be a productive member of society. So why can’t he continue on that track and live independently and, you know, transition to adulthood? As I said, I … so, you know, my perspective is still, it’s going to take longer so, you know, I got to keep that perspective. But he can do it eventually, in his time.

**Interviewer:** That’s what matters. So that’s actually all I have on my end. This has been wonderful. Thank you. Would you like to add anything else, any other thoughts?

**Interviewee:** I don’t know. A lot of the things came up while we were talking, so. And I’m sorry if things came up and I said, “*Oh, I should have mentioned this earlier*.”

**Interviewer:** No worries. As long as it was OK for you, it’s perfectly fine for me.

**Interviewee:** No, right now, I’m not thinking of anything else. **[inaudible at 1:36:41]** I’ll have to remind myself to go back and fill up those forms that you had for me.

**Interviewer:** Yeah. After this, once we’re done, I can send you an email with them again, that way it’s fresh in your inbox. But yes, as soon as those are done, I will send you a thank you gift card for all of your time and all of your effort and all of your thoughts. It’s been so valuable. We really appreciate it.

**Interviewee:** I hope it’s helpful.

**Interviewer:** Oh, it’s so helpful.

**Interviewee:** We’ve been very glad to participate in things like this over the years, because … I said this, “*Antonio*,” I said, “*If you go through some of these*,” you know, “*some of these studies and it can help them understand how to help other people*,” you know, “*with your diagnosis, then that’s great*.” So.

**Interviewer:** I like to think it will for this. I mean, from my perspective, there isn’t research on this. So learning about it does provide the groundwork for creating relevant supports. So, in my mind, you’re helping 100%.

**Interviewee:** Well, I certainly hope so because from my point of view, as I told you, when I do research, there isn’t as much out there as I would like as a parent. So if I can provide you with information that ultimately helps other families, then that … I would really appreciate that as a parent.

**Interviewer:** Thank you. We appreciate it, too. Do you know of anyone else who actually might want to participate in the study? It’s OK if you don’t.

**Interviewee:** In transitioning to adulthood, I don’t know. I mean, I know somebody whose son was diagnosed, but he’s much younger. He’s still in middle school. And you’re just looking for people … you’re looking for people on the autism spectrum?

**Interviewer:** Yeah, on the autism spectrum between 16 and just under 26, who live at home.

**Interviewee:** Yeah. Because I was mentioning that my son has a friend, but he has Down’s syndrome. So that’s a different consideration. I do know somebody else. I’m not sure how old her son is, I’d have to check with her. If he’s under 26 … and maybe I can … I do know somebody, her son is a little bit older than my son. So she might be somebody that I could connect you with.

**Interviewer:** Yeah. I mean, if you think she might be interested. If, you know, it’s not her cup of tea, that’s also perfectly OK too. I can send you our flyer again, if that would be helpful.

**Interviewee:** Yeah, that might be helpful. And then maybe I can forward it to her and see if it’s something that she might be willing to participate in.

**Interviewer:** That’d be lovely. Thank you. One unrelated but related question: you talked about looking into services for yourself, like AANE and things like that. I’m compiling a list that other participants have talked about. Would you like me to send you some things now? My goal is to send it to everyone when the study is over, but I could provide it earlier if that would be helpful.

**Interviewee:** Sure. That probably would be helpful.

**Interviewer:** Yeah, I can do that for you. OK. So, once we’re done, I will send you an email. It will contain those links for you, that flyer and also some hopefully relevant resources for you and your family.

**Interviewee:** OK. Thank you.

**Interviewer:** Awesome. Thank you. Thanks for taking so much time. It was longer than anticipated, so I appreciate it.

**Interviewee:** Yeah, that’s fine. It wasn’t a problem for me.

**Interviewer:** Thank you.

**Interviewee:** I’m glad to help.

**Interviewer:** You have helped very much. So thank you. All right. Well, I will send you that email and I look forward to talking to you in the future, hopefully.

**Interviewee:** OK. Well, thank you very much, Rachel.

**Interviewer:** Thank you. Have a lovely day.

**Interviewee:** You too.

**Interviewer:** Bye.

**Interviewee:** Bye.

**[End of interview]**