**[Start of transcript]**

**Interviewee:** OK. So I will be driving for part of our call, but not for a while, so.

**Interviewer:** No worries, whatever works for you. And, truly, if you need to head out, let me know. And we’ll just find another time, totally OK.

**Interviewee:** Awesome.

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

**Interviewee:** Very good.

**Interviewer:** Awesome. Any questions?

**Interviewee:** Nope.

**Interviewer:** Wonderful. If there are any questions that you don’t want to answer for whatever reason, that’s perfectly OK. Saying “*I don’t know*” is also a perfectly OK answer.

**Interviewee:** OK.

**Interviewer:** And if there’s anything that comes up later in the **[1:00]** conversation from earlier, feel free to jump in, it doesn’t have to be perfectly linear.

**Interviewee:** OK.

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

**Interviewee:** Yes. So it’s interesting, because even before we knew he was a person with Asperger’s, we would … we consider him super sensory. He has … even though he wears glasses, he is a perfect shot with a BB gun. He can hit a target from wherever—so he has super vision. Hearing … he can hear things. For example, my husband and I were on a camping trip in fifth grade and they were in the woods and everything was dark, and the sound of the cicadas drove him crazy. Cicadas are very loud cricket kinds of things, you know, in Alabama. And it was so overwhelming. It was incredibly overwhelming to him. So that, like, an Alabama football game is out of the question because it’s way, way, way too loud. Vestibular … so, like, for example, in a football game, if we go we have to sit on the floor. We … like, not on the floor floor, but we need a low seat because he does not like height.

**Interviewer:** Yeah,

**Interviewee:** Even now, he’s 6’2” and he still holds my arm on escalators, which is a little bit awkward for him because he looks completely normal. You wouldn’t know until you were engaged with him that he is a person with autism. Also vestibular … he … that, like, the bouncy houses that kids play in, he would just sit in the middle and put his hands on the ground and feel the vibrations. He never was into jumpy kind of things. When he played baseball, he would call time out if a helicopter was flying over for everyone to sit down because of the vibrations of the helicopter. OK, he was a little boy: that was like first grade. That was the only year he played baseball because he certainly was more interested in watching the helicopter from the ground than playing baseball. So that’s sight, sound. He’s very sensitive to cold. He does not complain about the heat in the summer and it will get up to ... it’s typically around 100 for six months here and that does not bother him. He doesn’t like the air conditioning in the house. And he’ll wear a sweatshirt in the air conditioning. He wears one sock. You know, when he goes to school he wears two socks, **[4:00]** but when he comes home he takes off his shoes and he will just wear one sock. He has … before I knew there were weighted blankets, I had done research on Amazon to find the heaviest blanket I could purchase, so it’s about 13 pounds. And he’s tried his sister’s weighted blanket. It’s too heavy. The one he has is just right. So he does like a heavier blanket. He does … he calls it his “*feels*” F-E-E-L-S with regard to clothing. He doesn’t like tags. There are only certain fabrics that he can tolerate, just because he doesn’t like the feel of it against his skin. So that’s … it’s limiting for him, clothing wise, although he’ll concede … like, we went out to dinner to a nice restaurant and he wore khakis and could not wait to get home and get them off, but he did wear them because it was my birthday. So, that being said, when we do go out as a family, we have to take all of these things into consideration. It needs to be a quiet environment, a place that will let him wear headphones, not a clanging pan type restaurant. If we can sit outside, we try to do that. We can’t be near screaming babies. Screaming babies and whiny children drive him crazy. Certain candles … like, he can tolerate earthy essential oil type candles, but ones that smell like, for example, men’s cologne he doesn’t like. Really strong fruity smells he does not like as far as scents go. Let’s see … bright lights … we have a very, very difficult time in certain stores at the mall and at Target. At Target, the floors are extremely buffed and shiny. It’s also like that in a couple of the major department stores here. That is just too much for him. And the bright lights are too much. He keeps his drapes drawn in his room. And our basement is, like, his man cave where he plays Xbox and the drapes are always drawn in there as well. It’s extremely stuffy in there, but that’s how he likes it because he’s always cold. So I did sight, smell … Taste … he does not do textures. Like, for example, in this survey it said “*cottage cheese*.” He does not do mushy food like oatmeal. He likes crunchy food, **[7:00]** cereal nuggets. He will make … I buy frozen, like, frozen bowls like Lean Cuisine bowls, just to have on hand and he’ll make those himself and eat those even though they’re casserole, like, something that would have, like, feta—not feta, goat cheese—like, that mushy kind of foods he will not eat. He has an aversion to brushing his teeth, which makes it difficult for him hygiene wise. That we have to basically take his phone and he gets it after he’ll brush his teeth. Mouthwash is … he does not do mouthwash no matter what flavor I buy. Even for … like, I buy him, like, the Clearasil face wipes and they’re cold on his skin but I force him to do because of his acne. I actually have to do it. He won’t do it. Because of his acne. But he wants me to do it. And will ask me to do it, but he physically can’t do it. He cannot—I don’t want to say he cannot—we do not make him load the dishwasher because, like, the leftover food residue on plates and dirty dishes is a tactile thing for him that he can’t touch it, although he does not mind having Cheez-It orange stuff all over his hands after he eats a bag of cheese balls. Let’s see: have I hit all of the senses?

**Interviewer:** Yeah, you did great.

**Interviewee:** Sight, sound, taste … sound, you know, hearing, vestibular stuff, sound … like I said, like, loud restaurants and football games we can’t do. I think that’s all of the senses.

**Interviewer:** Yeah. You were so thorough. I have a couple …

**Interviewee: [crosstalk at 9:06]** when we …

**Interviewer:** No, go ahead, please.

**Interviewee:** I’m sorry.

**Interviewer:** No, no. You go.

**Interviewee:** When he was … when we told him he had Asperger’s, we told him that he was super sensory and he was in third grade and really into superheroes. So we equated his Asperger’s disorder to that of a superhero where he just had these super … we told him they were superpowers and, even now, like, he’s so offended by the word ‘disability’ because he sees what he has as empowering and … although limiting, it’s … to him, it’s his super sensories.

**Interviewer:** Yeah. That’s awesome. I’m so glad he’s able to see those in a really positive light. That’s wonderful. Thank you. You were so thorough. I mean, I have a couple tiny follow up questions, but you really covered it all. **[10:00]** For sound: is he also bothered by, like, more mechanical noises kind of, like, from cars?

**Interviewee:** So, we hear a lot of lawn mowers and leaf blowers and things like that outside: that annoys him, but traffic and cars … the only thing about cars would be: the horn is very startling to him. I warn him before I’m going to vacuum because that … the sound is startling. Although he will vacuum for me. He will use a sander, he’ll use an electric drill. But I think as long as he is aware that there is a sound, a sharp sound coming, he’s OK with that. He does not like screaming or yelling, and has a very difficult time discerning what is speaking firmly … because he recognizes a change in tone when you’re speaking. So we actually … at his IEP yesterday, he and I decided that, at home, I will let him know when I’m going to speak firmly. Because he said that it takes him off guard. Like, if I need to correct him or be firm with him as a parent, he takes it as me yelling. And I said, “*OK, well, so I yelled at you three days ago. There is a difference between me speaking*” … and by ‘yelling’ not screaming but he had … I had a student and he had displayed some inappropriate behavior and then later that evening, I had to reprimand him verbally for that, so.

**Interviewer:** Yeah. Got you.

**Interviewee:** Sure.

**Interviewer:** Thank you for clarifying. And then, with his sensitivity to touch: you mentioned there were certain fabrics he prefers. What type of fabric does he prefer?

**Interviewee:** OK, like, the really soft T-shirts—almost like a dry fit, but not quite. I would say, like, a Nike. Well, it would be Nike or Under Armor dry fit, but not the cheap ones. He will also … so he had … when he was a little boy, he had a silky blanket. So he does like satiny feelings, like, mostly athletic … like, athletic shorts that feel satiny. He will … he also … I have a acupressure pillow that has spikes on it and he likes that and, like, spiky balls. So he likes really soft and really **[13:00]** spiky. He will carry a fidget, which is, like, one of … like, a squishy, like a slap … squishy kinds. There’s different squishies too. He has certain squishies that he likes that are, you know, very …

**Interviewer:** Can you say that again. You kind of cut out for that last sentence.

**Interviewee:** I think even … it’s hard … even, like, as far as underwear, it’s more **[inaudible at 13:31]** and more so than, like, Hanes underwear, like typical underwear that a man might wear, he will not wear. They have to be, like, a soft, brushed cotton, dry-fit, athletic type of … it’s actually … the brand is Spider, S-P-I-D-E-R. So I don’t know if that’s important, but …

**Interviewer:** No. All information is helpful. Thank you.

**Interviewee:** OK.

**Interviewer:** And then, for his sensitivity to brightness, is that also … would, like, sunlight … like, will he wear sunglasses when he’s out and about?

**Interviewee:** Yes. Yes, absolutely. And even in rooms, like, classrooms need … the lights need to be dimmed. It’s the overhead fluorescent lighting is really difficult for him. To him … he prefers, like, a side lamp or the dark. Like, he’ll play the Xbox with the lights out, the drapes drawn, the first … you know, in his room I’ll open the shutters and, you know, he’s … what do you call those little animals or that, like, “*Bright light! Bright light!*” like, it’s way … it’s just overwhelming to him?

**Interviewer:** Yeah, absolutely. Oh, nocturnal, is that what you meant?

**Interviewee:** Yes, yes.

**Interviewer:** Awesome. And then, last clarifying question: you said he had an aversion to brushing his teeth—do you know what about teeth brushing is just not OK for him?

**Interviewee:** He does not like how … he doesn’t … Let me think. So there’s a couple things. He likes the taste in his mouth and he doesn’t want to lose the taste of food in his mouth and when he brushes his teeth, he loses that taste. His oral hygiene is poor. He doesn’t have cavities, but he has … like, I take him to the dentist every three months to get fluoride treatments just to try to protect his teeth because his oral hygiene is not good. He will use those dental picks and, like, floss with the dental picks. He does not like the feeling. I bought him an electric toothbrush. He does not like the feeling of the electric toothbrush in his mouth. But he’ll tolerate the dentist. Now we’ve seen same dentist since he started … since he was **[16:00]** 18 months old and they know how to work with him. They’re wonderful and he gets rewarded heavily for dental cleaning, so.

**Interviewer:** Got you. Awesome, thank you for clarifying.

**Interviewee:** Sure.

**Interviewer:** You’ve kind of alluded to this, like, what you’ve been saying—but how does your son manage his sensitivities and strengths and how do you help him manage and cope with them?

**Interviewee:** So as far as food, we provide him with a variety to choose from and encourage him to try new things, which he sometimes will. We do not have … he does probably more chores than anyone in the home, but we do not make him load the dishwasher unless I will … if … when I want him to load the dishwasher, I will scrub all the dishes first and then he will load it—just because I think it’s important he knows how to load a dishwasher. And as far as … we do not … He manages the light and the heat. We have two thermostats in the house. So upstairs, he will run the air conditioning or the furnace however he needs to. It’s usually, like, 80 degrees up there.

**Interviewer:** Hot.

**Interviewee:** Yeah, I know. He … and his sister is opposite. I have one child at home, one … another child at home and she likes it cold, he likes it hot, but she’ll put the fan on to accommodate for him. As far as his … I only buy him clothes that he likes because otherwise it’s a waste of money and he won’t wear them. Typically, I will shop and bring everything home for him to try and then make returns. He will shop with me for school clothes, like, once a year we’ll go shopping for school clothes so that he can pick stuff. Let’s see … sounds … he has noise-cancelling headphones that he wears, but often he’ll just have his phone with the headphones in to drown out the noise. And it’s interesting, because he’ll put one earbud in and he can still attend to other things. Like, for example, we were at youth group and he took his Nintendo Switch and he had one earphone in while he was playing his Switch, but was also attending to the conversation and the video at youth group.

**Interviewer:** That’s impressive.

**Interviewee:** And I was shocked because I promise … I have volunteered in a **[19:00]** pinch and usually he doesn’t want me there and I promised not to get on him about anything and I told the other teachers, “*If you need him to put his stuff away, you have to tell him. I can’t. I promised*,” but he was able to attend, which shocked me. Yeah. And then, he knows when he needs space or quiet time and he will say “*I need some downtime. I’m going to my room*,” or he’ll say “*I’m getting overstimulated, I need to walk away*.” This is all … this is a new behavior in the … a new positive behavior in the last year. And he also … within his IEP, he’s allowed to take breaks when he needs to at school, if he gets overwhelmed. He will tell … he will ask people to blow the candles out or turn off their scent warmers or whatever. And do you have other questions? I can’t remember what all … what the other sensory things.

**Interviewer:** I think you answered that question very thoroughly. Thank you. You’re giving me wonderful answers.

**Interviewee:** Oh, there was one other thing: like, with regard to noise in loudness, there is … there are several mega churches here in Alabama and he was dating a girl—well, as much as you date at 14—and she had invited him to youth group that was loud, with bands and, you know, several hundred kids go. And I said, “*Are you sure you want to do that? It’s going to be really loud*.” And he said, “*Well, I have my phone, I’ll call you if it’s too much. And I can walk outside*.” And so, he’ll push through certain things that he wants to. He was able to stay at the youth group for about an hour and a half and he would just go in and out of the loudness. But he does not do pep rallies, he’s given the option at school for no pep rallies. He’ll go to football games. We’re fortunate: we have a trail system behind our home and we can just drive the golf cart. So he’ll take the golf cart, he’ll stay as long as he can tolerate it and then leave.

**Interviewer:** Got you. Thank you. And has your son received any specific, like, therapies or interventions to help him with his sensitivities?

**Interviewee:** Not specific to sensitivities. He does have occupational therapy for handwriting. And I would … you know, he has it for handwriting because of a poor or a weak grasp, but I would **[22:00]** say that holding a pencil and making his hand go that way is ... it’s more of a sensory thing for him. And his handwriting has improved. I don’t know … that’s not specific to ... it’s not like a tactile training kind of thing. But, like, with his Asperger’s specialist, she’s worked with handwriting and it’s more or less “*You are going to hold it and you’re going to write until* …,” you know, “*and I’ll give you breaks when you need*.” So she’s increased his stamina with regard to negative tactile stimulations.

**Interviewer:** So, for him, how is it, like, a tactile thing or how is it a sensory thing, writing?

**Interviewee:** I think just the fact that he has to hold his hand in a certain way for so long with a pencil. And, I don’t … he prefers, like, a squishy thing on the end of the pencil. I think it’s more just holding his hand in a certain way and not wanting to hold a pencil for that long. So maybe it’s not tactile, I’m not sure.

**Interviewee:** Yeah. I mean, it could be, you know, it’s … I mean, everything is kind of sensory. Like, our world is sensory in a way.

**Interviewee:** Correct. Yes.

**Interviewer:** How would … how have his sensory sensitivities and strengths, as you’re calling them, how have they changed over time, if at all?

**Interviewee:** He has become more tolerant. Yes, he has become more tolerant, I would say, vestibularly. He … so he was not able to learn how to ride a bike just because he did not like that feeling of balance, he does not like … on a two wheeler. But he did learn how to drive an electric scooter, which you still have to have balance for. So I think as he’s matured, they’re … a standing electric scooter—not like an old people one but the ones that you stand on. I think when he has a desire, he’s more willing to push through, or he’ll find a way to accommodate, so that he can achieve … like, he wanted to ride a bike like everybody else but he was more comfortable learning how to ride a scooter. He felt like he had more control. He’s also able to ride an escalator. He used to not be able to ride an escalator when … of course he hangs on to me. Let me think. He is … I think that mostly they’ve gotten better because he’s learned how to accommodate for himself. Like with earphones **[25:00]** or finding another way, like I said, for the example with the scooter. Foodwise, really hasn’t changed much. He’s not willing to try new things. I don’t … so that … I guess that’s really the only way that it’s changed is him finding accommodations: wearing sunglasses or a hat if it’s too bright …

**Interviewer:** Yeah, that’s awesome. Thank you.

**Interviewee:** … but him having more control over his own environment.

**Interviewer:** And do you think these changes are related to any independence that he’s gained over time?

**Interviewee:** Certainly, I think that the more independent he gets and the more understanding he has of himself, the better he’s able to determine what will make his life more meaningful to him and what will enable him to do the things he wants to do. So, you know, he’ll say, “*Mom, It’s cold*,” and I’ll say, “*Well, get a sweatshirt or adjust the temperature*,” or, you know … and he’s gotten into the routine that he’ll go into a room and he’ll darken the room, or he knows … he always has his phone, always has his headphones, and that’s more, I think, to drowned out … I used to think that it was to fit in and be popular, but it’s definitely to drowned out noise.

**Interviewer:** Absolutely. Thank you. So helpful. You have great answers. And, when your son is in a sensory scenario that is aversive to him, like, something that’s perhaps too loud or too bright, does that cause or increase anxiety for him?

**Interviewee:** Yes. So when he was … I would say, up until the last maybe a year to a year and a half ago, he would completely shut down, sit in a … sit … just go back and forth like that—I’m not sure what that’s called. Or put his hands over his ears. And that would be for … **[inaudible at 26:26]**

**Interviewer:** You cut out …

**Interviewee:** … lay face down in bed, right. We would need … Oh, can you see me now?

**Interviewer:** Yeah, you just cut out for a second. Hi. I just want to make sure I heard you correctly. I don’t want to miss anything. I heard you say that until about a year or like to be year and a half ago, he would shut down completely. That’s kind of all I heard. Is that correct? Did I miss something?

**Interviewee:** So he would shut down with … that would be for sounds and vestibular. He would sit on the floor, cross legged, hold his **[28:00]** knees and just rock his head back and … excuse me, rock his head back and forth. He would also put his hands over his ears. For sight: he would just leave the area and go to his room and go to sleep if it was too bright. So I would say he had significant meltdowns for his entire life. It could be … or screaming: he would just scream and scream and scream. But he does not … he’s learning alternate ways to cope now.

**Interviewer:** That’s wonderful. What are his alternate ways of coping now?

**Interviewee:** Well, he has words to express how he feels and he can communicate and say, you know, “*I’m feeling overstimulated*,” or “*The light is very bright. Do you mind if I turn the lights off?*” Typically, he’s kind, but if he’s really stressed out, he’ll yell it. “*Turn off the lights, it’s too bright in here*,” or “*It’s too loud. I’m out of here. I’m leaving*.” He would elope in the past. He does not elope anymore. He would elope from school and the home if it was … if, you know, if there was … honestly, if there’s been screaming in the house. Our family’s not perfect and if it would be too … my husband and I were fighting or whatever. He would elope if there was too much yelling. The same way … I’m thinking about noise. Like, it was almost like he had a fight or flight response to things, but now he’ll just … he’ll put his headphones in. Or, you know, at times he will refuse. Like, if he does not want to wear khaki pants, he will refuse. He’ll go to the extreme .. he would go to the extreme of making himself sick and, like, vomit, and to say “*I’m sick, I can’t go*.” But I think that he feels empowered now that he can adjust his environment or he can find a quiet place, if he needs to.

**Interviewer:** Yeah, that’s wonderful. I’m glad he feels that way. That’s such a positive thing to feel about yourself.

**Interviewee:** Yes. He’ll take … he wears an extra … he will wear an extra sweatshirt to school just in case it’s going to be cold. Because he ... if he’s cold, he can’t concentrate, or he always has an extra sweatshirt. He doesn’t like to be wet in the rain. So he carries an umbrella with him, in case it rains. He drives the golf cart to school. So that’s the … that’s his independence, you know, but he always has a golf cart, or always has an umbrella and an extra sweatshirt. **[31:00]** There are gloves in the golf cart, just sunglasses and a hat if he would need those to help with his sensory stuff.

**Interviewer:** That’s wonderful. And then, thinking a little bit more broadly—what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** I guess my goal would be that he can continue to be extinguished just by more exposure. For example, the vestibular things … like, it’s an issue. If we have to fly, I always have a prescription for him if I need him to … like, if he’s too worried about the movement of the plane. But I think that one of my goals would be for him to have a super meaningful life and be able to accommodate for himself, and just maybe expose himself to things enough that he can get more comfortable with them. And, honestly, to be able to find a job that he wouldn’t be exposed to the things that he hates. I mean, that’s what we all want in life is to have a job. I couldn’t work with people like **[inaudible at 32:36]** like the old talk shows and things. I wouldn’t be able to tolerate that.

**Interviewer:** May you say that again? Sorry, you cut out the last sentence.

**Interviewee:** I would hope that he would find a job that fits him, that he wouldn’t be in a situation or choose a job that would put him in a situation where it’s bright lights and loud football games, you know, that he could find something that would be in an environment that is comfortable, that he could wear his comfortable clothes to and have control over the environment itself, I guess.

**Interviewer:** Yeah, absolutely. Thank you. We’re going to move on to our next … oh … OK.

**Interviewee:** I had one more thing.

**Interviewer:** No, keep on talking.

**Interviewee:** And that was texture in food. This is a neat thing that he does. So he buys school lunch, doesn’t always like what the school lunch is and, in fact, has emailed the superintendent of our district to complain about the school lunch and the history curriculum, but … So what he will do is … I get a … like, a big box of Nature Valley crunchy granola bars from Sam’s with, like, 20 granola … and he carries it in his backpack, just in case there’s not an option that he would like at lunch. So he is learning to accommodate for himself. **[34:00]** I don’t know that carrying 20 granola bars **[inaudible at 34:05]**, though.

**Interviewer:** Awesome. Thank you. And it’s totally fine if you think of more things. Keep them coming. These are wonderful answers.

**Interviewee:** OK.

**Interviewer:** We’re going to move on to our next chunk of questions, but, again, feel free to add things from prior sections. As your son has grown up and aged a bit …

**Interviewee:** Pardon.

**Interviewer:** … how has his and your community reacted to his sensory sensitivities and sensory needs?

**Interviewee:** So his school community is very affirming to him. I would choose ‘good.’ Now, we’ve pushed it. I have an … he has an educational advocate. I feel like she’s mine too, but she’s also connected to an attorney and all of his sensory things are listed in his IEP and his teachers are now 100% on board that he’s not going to be in a bright class with offensive odors—or odors that are offensive to him. Within the home, it’s the same: that we all just … we live with each other and we do the very best that we can. I think that his sisters, as they’ve gotten older, they’ve become more accepting of his sensitivities. The community at large is difficult. Well, I would say, outside of our nuclear family … like, grandparents, they have a very difficult time. He has two grandmas. They have a difficult time accepting Will’s sensitivities because it’ll be … it’s … there’s … they sort of have the attitude, “*Suck it up and get over it*.” And they don’t realize that it’s not that easy for him. He’s involved in a youth group that is sensitive to his needs and … but … Oh, well, here’s another neat thing: he is involved in the Student Diversity Council at school, and there was an issue with his community education and the diversity team asked for a meeting, so that they could understand him better and understand and … so these, like, sensory things, but they were willing to hear and understand. And the first thing he said was, “*Idioms. I understand similes, but I don’t understand idioms*.” And they were interested in knowing about him. I guess **[37:00]** restaurants are pretty open when we ask not to sit by crying children. Our church has, like, a sensory-friendly service, but my son won’t go to church anymore because he had been hurt by … emotionally hurt by children at church, so he won’t go. But the church is open to making a … which is a Methodist church, but he was raised Catholic. He no longer identifies himself as Catholic—or Christian for that matter—although he goes to a Christian youth group, which is, you know … that’s where he’s at. And, you know, that’s who he is. I don’t really … that’s really the only involvement in community that he has. We were shopping for school clothes in an academy, which is like a Dick’s Sporting Goods here. And there were kids and ... with a family, who were mocking autistic people and they were, like, acting. There were tents set up and they were, like, “*Look at me: I’m autistic, I’m autistic*.” And, you know, my son … and so, typically, I would say, now, he would say, “*You know, what you’re saying is very rude. You don’t know who around you is autistic*.” And I think now he has the words to say that. But at the time he just started ear … I think it’s ear flapping, like when they … can you see what I’m doing, like? That’s what he was doing. And I would say, “*Come on, Will, we need to move. We need to go somewhere else*.” I mean, the folks were just ignorant. It wasn’t even worth engaging them. But community … we hope at this point the Office of Vocational Rehab is going to be involved with him at school and we’ll, you know, we’ll just see where it goes from there. But I would like him to have a job. He’s 16. I would like him maybe next summer to have a little part time job. And so we’ll see how the community is when they need Will. We’ll see, so.

**Interviewer:** Thank you, those are wonderful. Would you say that the community was more or less accepting when he was younger?

**Interviewee:** I would say that they were less accepting because we … he did not receive a diagnosis until he was in third grade. And so it was definitely … I would say they were more judgmental toward him and toward me and my husband and our parenting and, you know, it was like, “*All you need to do is*  **[40:00]** *discipline your son and he wouldn’t act like that*.” And that’s not the truth.

**Interviewer:** Yeah, not at all.

**Interviewee:** So now, I think it’s a little bit more obvious that he’s autistic once you start talking to him, that people are more understanding. And, in fact, my daughter’s … both daughters have a lot of friends who know that Will’s autistic and they try to welcome him and include him. That’s how he got into the Diversity Council, where, you know … they want him to be a part of it. And with the Diversity Council, he prepared a statement disorder and he went through his verbal … how he understands things verbally and how he reacts to things. And that’s the first time that he’s … that’s actually the second time that he’s been open about having Asperger’s, which is not … it’s not ever been a secret and it’s always been something that’s celebrated. But the girlfriend that he went to the youth group thing allowed … he told her that he had autism and she broke up with him. So, for him … because she said he lied to her, which was … stupid teenage girls … but he was concerned about … it’s … about others knowing because of being rejected because of it.

**Interviewer:** Yeah. Got you. Thank you for sharing those experiences.

**Interviewee:** Sure.

**Interviewer:** You’ve alluded to this, but again, thinking broadly: what hopes or worries do you have for how his community will continue to react to his sensory needs in the future?

**Interviewee:** I think that our community, though—at least the United States at large—is becoming more accepting. And my hope is that the community will be more accepting. You see more sensory-friendly things: sensory-friendly movies and our IMAXs and church services. So my hope is that he’ll be accepted in the community and will have a very meaningful, independent life, you know. I think that one of the things that he battles with … so he thinks that he’s gay and we’ve taught … we have several family members who happen to be gay as well and have talked to them. And I basically interviewed my cousin and her wife and said, “*OK, I need to know everything there is to know about being gay, being a lesbian. I just want to know because I don’t understand … I want to be able to* **[43:00]** *help him* *and, you know, he’s*” … Even though he’s had … he had a girlfriend and I said, “*Well, dude, I thought you were gay*.” And he’s like, “*I guess I’m bi*.” It’s, like, well, so he … in his mind, he can decide to be gay or not gay. And I think that there’s more stigma attached to being a homosexual almost, at least here in Alabama, in the Bible Belt, there certainly is. There’s more stigma to that than being autistic and having sensory needs.

**Interviewer:** Interesting. Yeah. That makes sense geographically. Thank you for sharing that. We are going to move on to our next chunk of questions. I want to be mindful of the time. I think we can get through the next chunk, and then maybe we can find another time to finish the rest.

**Interviewee:** Yeah, I’m enjoying this. So I agree. And I don’t want to be … we’ll do the next chunk while I drive and then we could schedule another time.

**Interviewer:** Perfect. Sounds like a wonderful plan. I’m glad you’re enjoying it. That means I’m doing my job right. In the transition to ‘adulthood,’ quote unquote, where do you see your son?

**Interviewee:** Not prepared at all.

**Interviewer:** OK. In what way?

**Interviewee:** Well, he really will not do any household chores without being asked, but he will ask for a list of chores. He has to be prompted and reminded for personal hygiene. If he’s not asked to take a shower, he will not take a shower for three or four days. He has the desire to have a job and live independently and have a family someday. But I don’t think that … if outside services help him … Can you tell me the question again?

**Interviewer:** Yeah. No, you’re doing great. I’m asking where in the transition to adulthood is your child and my follow-up questions were going to be, like, what you’re basically answering. So keep on going on your train of thoughts. Perfect.

**Interviewee:** OK. OK. So he has the body of a man, you know. I know that he’s shaving a little bit, although he doesn’t admit to it. I did buy him an electric razor. I think my husband has been—‘neglectful’ is not the right word—I think my husband has a hard time talking to him about man, teenager stuff. But I think that Will has the desire to be a man and to grow and **[46:00]** mature and I think that he has made strides to act more mature and to take more responsibility for his actions.

**Interviewer:** How is … so you mentioned that your son needs a list for things, how is he with, like, preparing meals for himself or, like, helping with grocery shopping?

**Interviewee:** He will help me with grocery shopping. If I tell him to go find stuff, he’ll find it from a list. From … I’m not going to have eye contact with you while I’m driving. So just tell me if that is OK. I need to get to where I’m going, if that’s OK.

**Interviewer:** Absolutely, absolutely. Drive safely. That is the most important thing.

**Interviewee:** OK. Yes. He’ll … so he’ll … when we grocery shop, all he wants to buy is candy and snacks and so, we will talk about meals and I’ll say, “*OK, so we’re going to have spaghetti, what do we need?*” you know, “*Pick out the type of pasta that you want*.” And I limit his snacks and I try to tell him “*OK, well, Mommy only has this much amount of money so you can have this or that*.” But independently, he can go into a store and if I say, “*Go in and buy me a loaf of bread*,” he can go in and buy me a loaf of bread. He has … he does not want to do that. He is not comfortable paying for things himself. I’m not comfortable with him getting the right change back and checking the change. He tries to tip … like, the last time we flew his aunt had given him $10 and he tried to tip the airline pilot $10 for getting us back to Alabama safely. So I think that he would give all of his money away. He wants to … like, at Christmas time, there was a Burger King inside the Walmart and he wanted to go to … he wanted to get Walmart gift cards for all of the Burger King folks because they don’t make enough … a lot of money. He has an extremely generous heart. But he does not recognize that he’s being taken advantage of.

**Interviewer:** Is he able to, like, prepare simple meals for himself?

**Interviewee:** Yes. He can make a sandwich. He can reheat leftovers. He can … with direction, he can, like, boil mac and cheese. I stock the freezer with frozen meals so that if he doesn’t like what we’re eating, he can make himself some frozen Lean Cuisine or whatever. He can read the directions and make that. He makes himself cereal for breakfast or **[49:00]** eats fruit or will heat up last night’s dinner. He’ll preheat the oven for me. He’s afraid to take pizza out, but he’ll preheat it and check it.

**Interviewer:** Got you. You talked about money briefly: how is he with, like, the concept of money and, like, the idea of managing money?

**Interviewee:** He likes money a lot. He is not a good manager of money, but he is interested in learning how to budget and that is one of his IEP goals. So he will be … he’s interested in budgeting. He receives an allowance for chores from myself and from my mother. And so his case manager is going to work with him on budgeting that allowance, as far as savings and candy and saving for things that he wants to save for. Initially, I think he’s … initially he told her to start with $33,500. And I saw that goal and I was like, “*What the heck?*” And she said, “*Well, that’s what he said*.” And I said, “*Well*,” and he said, “*Well, it was my birthday month*.” And I was like, “*Dude, you’re not getting three thousand bucks for your birthday, you know.* *You got, you know, $100, so maybe do $100 for birthday money*.” In the past, when he was more involved in youth group, he was tithing and he would tithe his allowance, but I had to encourage him to tithe 10% or 5%, based on what he had. And he had a desire to do that. So I feel pretty confident that if he was able to recognize the percentage to tithe that he would be able to recognize the percentage to save as well.

**Interviewer:** Totally. Absolutely. And does your son manage a social life to some extent?

**Interviewee:** He does not really have any friends. He’s been through the wringer at school. Over the last three years, he was targeted for both telling others … coming out as being gay and for having autism. And students … two things happened in eighth grade: someone falsely accused him of threatening to blow up the school. And so, of course, that was taken very seriously. Those children were proven wrong and it was, you know, proven that they **[52:00]** lied. But his reputation started then. It was sort of too late. And then last year, he did have a friend group and he started to have romantic feelings … I don’t know if they were romantic feelings toward the girls, but as a 15-year-old going through adolescence, I think that he may have been thinking about them sexually and expressed to them, you know, that … Well, they told him that they weren’t interested in him romantically. And he thought that because … and this is what he said … and so the backdrop to this is he … his oldest sister was raped last year and we … as a family, we all knew and we all were there for her. Unfortunately, that’s a difficult situation to have with all of your children. But my son understood rape as having sex, or someone forcing you to have sex that you don’t want to have sex with. And so when he was interested in these girls and having these feelings toward them, he sent them an email that said, “*I think that I want to rape you. I’m so sorry. I don’t know how to deal with this.*” But rape and violence was not what his intention was in the email. Unfortunately, that was a disaster and he was homebound for a year because he was accused of rape or of … he said that he wanted to rape them. And he didn’t, but it was … the email was already out. He was … I mean, that was proven to be a manifestation of his autism at a manifestation meeting in school …

**Interviewer:** I can’t hear you right now.

**Interviewee:** OK, how’s this? Can you hear me now?

**Interviewer:** Yes. The last thing I heard you say was it was a manifestation of his autism.

**Interviewee:** Yes, but unfortunately, not all kids and high school kids get that and so that significantly tarnished his reputation. So then he was homebound on … for school and he went to … his Asperger’s specialist has a facility and he was one on one with her until Covid hits, starting in January, and occasionally there would be another student there as well. So, since the kids are back in school, he’s told me … **[55:00]** Will told me that he feels like he’s rekindling his friendship with a friend named Ian, who’s been his friend since preschool.

**Interviewer:** That’s great.

**Interviewee:** It is great. And he’ll take Ian home from school sometimes on the golf cart. And he also … he was at the Asperger program and someone needed a ride. And he had texted me and asked *can he take his friend home?* And I was like, “*OK, yes, of course*. *You have a friend*,” you know. But, as luck would have it, he refused to do his work and had to stay longer … Will refused to do his work and had to stay longer to do his work, so he misses the window of opportunity, but that’s the first time he’s referred to someone as being his friend in over a year.

**Interviewer:** Well, that’s wonderful. I’m glad that he’s making positive progress. And thank you for sharing those experiences. I’m so sorry that happened to your daughter and your family. That’s really awful.

**Interviewee:** Thank you.

**Interviewer:** Yeah. How … so do you think your son will be able to achieve more independence in the future?

**Interviewee:** I do. I think he has a desire to drive, but I think he’s afraid to drive still, because of the … Honestly, I think it’s the vestibular stuff. We have to have a big truck, because he’s so tall so that he can fit in the back seat or the front seat. And I think that he’s afraid to drive the truck, but knows he needs a large vehicle. And I think that he is actively learning social skills and about inferencing. And he will look up idioms so that he can understand what they mean. And so all of those things will help him socially. And I think that his life will continue to improve as long as he continues to learn and grow.

**Interviewer:** Absolutely, absolutely. Do you think there are other things that would help move him into adulthood?

**Interviewee:** So I think that if he had a … I think that if my husband was more involved with him, that that would help him. My husband is an alcoholic, and … sober right now and has taken steps, he’s taking medication for it even. When my husband does well, he spends more time with Will. And the more time he spends with Will, the more empowered Will becomes and when he … when he sees positive male role models—and females for that **[58:00]** matter—that will … that would … that helps him. He currently has a male aide at school and I think that that is a … that is headed in the right direction to help him. He just went back to youth group at the Methodist Church this past week and there’s a male youth leader who used to be Catholic and has issues with the Catholic Church like Will does, and that helps him because they identify. So I think the more role models in his life the better. And as well as outside services, I am looking forward to the Office of Vocational Rehab. I think that if he can have a job coach when he starts working, and even to help develop a position for him somewhere. It is hard as an adult not to love him because he is so kind and funny and cool to be around and can have adult conversations about his favorite types of topics. So when he meets folks who are interested in the same thing as he is that’s empowering to him and that helps him grow and learn and become more independent as well. I also think that once … so his … the middle sister is a senior in high school and hopefully will get into University of Virginia.

**Interviewer:** Yay!

**Interviewee:** I know. And when that happens, I know he’ll be home with us. If you will excuse me, I’m going to have to … I’m coming up on a red light and then I’m going to have to put my Waze on just to make sure I’m turning the right way.

**Interviewer:** That is OK. That was actually my last question for this section, so we’re at a wonderful spot. If you want to finish your thought, you can. If not, we can finish up at another time.

**Interviewee:** Yes, let’s … how about … can you re-ask that question to me in our next meeting?

**Interviewer:** Absolutely. I will definitely … We’ll finish up here. Do you want to text later to reschedule? What’s easiest for you for rescheduling?

**Interviewee:** How about if I text you? Are you available today? I know I’m available. I don’t want to bother your weekend. But if you’re available today, I can most likely meet again today, like, around 4.15.

**Interviewer:** Yeah, that’s perfect. 4.15 your time is … what time my time?

**Interviewee:** I think … are you one hour ahead? I’m Central Time.

**Interviewer:** It’s fine. Don’t … that sounds perfect. I’ll figure out the time difference. We’ll do 4.15 your time, not a problem.

**Interviewee:** OK, that sounds great.

**Interviewer:** Wonderful. All right. We’ll use the same Zoom information and we’re almost … we’re towards the end, so we’re in a good spot.

**Interviewee:** OK, very good. Well, I’ll see you at 4.15 today.

**Interviewer:** Wonderful. Enjoy your haircuts.

**Interviewee:** OK, thanks so much. Bye.

**Interviewer:** Bye.

**[End of interview]**