**[Start of transcript]**

**Interviewer:** All right, 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 experiences. And I’ll be doing something called a semi structured interview, which means I have my planned questions, but I’ll be adapting them to fit our conversation so they actually fit for what we’re talking about and for your family.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** No, I’m ready.

**Interviewer:** OK, cool. And if, for whatever reason, there’s a question that you don’t want to answer, that’s super fine. “*I don’t know*” is perfectly fine as well. And if something pops up that you remember from earlier, feel free to say it. It doesn’t have to be super linear.

**Interviewee:** OK.

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

**Interviewee:** What it began or is it now?

**Interviewer:** Sorry?

**Interviewee:** When it began, or as it … what he has now?

**Interviewer:** I’ll be asking about past and present, so whatever it makes most sense for you to answer.

**Interviewee:** So I mean, as of now, observing him, loud noises irritate him. Yelling, fighting, things like that make him nervous. He’s … I noticed, maybe within, like, the last two years, he started actually getting into the headphones. So I noticed one day, like, he put … because he has two younger sisters, so if they’re talking loud or they’re fighting or they’re yelling, he’ll reach to put them on and he’ll walk away. So he does not like the loud, you know, noises. If you … he’s easily … you can easily … he’s easily startled. So if … you see, as careful as you are to try not to startle him, he’ll still jump, you know.

**Interviewer:** That’s me, all the time.

**Interviewee:** He’ll still jump. Even if you … you know, you call his name from downstairs, you’ll still hear him “*Ahhh!*” You know, so he’s, like, he’s always on guard. Luckily, he’s never been aggressive or violent or overly sensitive. You know that … yes … especially, like, if his feelings are hurt. He hasn’t done it in a while but he used to cry a lot. A lot. I mean, that’s pretty much … things like, you know, like the conflict, things like that, it makes him nervous. Other than that, I mean, he’s pretty good. He can watch loud TV, that’s not a problem. It’s just, like, sudden bursts of loud noises what really startles him. When he was younger, it was more like the fine motor, you know, meaning, like, he didn’t like to touch. I noticed very young age he didn’t like to touch grass, sand, things like that. Like when he was sitting we’d put him on the grass. He would use his hind legs to boost yourself up because he wouldn’t touch it, you know. He’s sensitive to touch with certain, you know, certain solids. Other than that … **[crosstalk at 3:00] [3:00]** No, he actually does a lot of slime making. A lot. And I think that that texture’s helped him a lot. You know, I mean he has his own little experiments out there **[inaudible at 3:17]**. But he loves that, he loves the slimes and the little beads. That doesn’t bother him. When it comes to food, he will—I mean, God bless him—he will eat everything and anything, things that I won’t even touch, like muscles—you’d be surprised, right?—clams, things like that. I wouldn’t touch it. To me it’s like a wet booger. But he will eat it but, ironically, up until about a year ago, he was OK with, you know, like, French fries. home fries, but he would not eat mashed potatoes. Within the last year, he started eating them. He will not eat corn—popcorn yes, but he will not eat corn. I mean, he’ll eat carrots, you name it, any kind of vegetable. The only vegetable he will not eat is corn or peas. He will not eat them.

**Interviewer:** Do you know if that’s a flavor thing or a texture thing?

**Interviewee:** Honestly, I don’t know because … I think it might be the mashed potato was definitely a texture because I was even making them … I was trying to manipulate it, so I would make a dish that had … Like, for example, something I made … oh, you know, like, how the can has … canned chili. He won’t eat beans. And that’s one thing that, as Hispanics, we pride a lot is our beans. And he won’t eat them. I’ll put the juice from the beans on the rice, fine. He won’t eat the beans.

**Interviewer:** Is it all beans? Oh sorry, go ahead.

**Interviewee:** All beans. If he doesn’t know it’s there, he’ll eat them. If he knows, he won’t. It’s like his whole demeanor will change. And, like, the canned chili that comes with the beans, I get the no-bean one. But one day I kind of wanted to see, like, a little test the theory, you know? So I gave it to him and he was like, “*I like these*.” So, with the mashed potato it definitely was the texture. The corn, I think it’s the texture because, I mean, he eats, I mean, certain vegetables I wouldn’t eat, but he eats them, but he will not touch corns and he will not touch peas. Other than that, this kid will eat any seafood, you name it, there is, but he won’t. Like I said, he just recently started eating mashed potatoes. You know, now he loves it, before he couldn’t stand it. He ate home fries, French fries, you know? Not even the baked potato. He wouldn’t touch that. Now he does. So I think it is definitely a factor even with the guacamole. A very little bit. He’ll say, “*Just a little bit, very little*.”

**Interviewer:** So it seems like **[6:00]** he doesn’t really like those kind of more mushy-ish textures?

**Interviewee:** Yeah, yeah. Yeah. But that’s pretty much it. I mean, sensory as far as … I mean, he’s just, like I said, it’s sound definitely sounds, you know, sensitive to, like, basically his environment. You know, it’s, you know, we have to always make sure that … If he sees something, a conflict, loud noise, like I said, he’ll move away. You know, but other than that, I mean, that I can think of and so maybe I’ll think of something else, but that’s pretty much it.

**Interviewer:** For noises, you talked a lot about, like, voices or, like, yelling—what about non-human noises, do those bother him?

**Interviewee:** Not so much bother him, they more like will startle him. So like, we have a dog. And if he’s just sitting there and the dog barks, he’ll jump, but then he’s like nothing, he’ll go back to whatever he was doing. And we’re a loud family. So, I mean, he’s pretty used to it, I try to knock him out a routine. You know, he’s got two little sisters. You know? So I mean, it is what it is.

**Interviewer:** And what about, like, cars or sirens, things like that?

**Interviewee:** Like I said, he can tolerate it. But if it’s something where it just comes out of the blue, he’ll say, “*What the heck is that?*” You know, which I’m OK with, because if he knows how to use that word, then I’m OK with that, you know.

**Interviewer:** Absolutely, for sure. And then, does he have any sensitivities to, like, any visual stimuli?

**Interviewee:** Light. He has this thing. He’s very fair skinned, so he’s … he will not go outside without his sunglasses. It’s to the point where, like, even in the summertime, he’s super, super careful with him, because, like, I think this kid probably hasn’t really had any sun in so long, because he burns, you know, most of the … He loves the dark room, you know. I mean, but I think that’s, like, a lot of … that would be, like, a teenage boy thing where they have their dark shades. And I don’t … I’m not seeing that as, like, an abnormal thing. But it does … when he is outside, he does use his sunglasses, because he’s, I guess, so much in the dark. Other than that, I don’t think, like, medically that he has an issue with, you know, sensitivity to light. It’s just he don’t like it, he doesn’t like it.

**Interviewer:** That’s fair. And when he is in his dark room, will he, like, dim his screens or just turn off lights?

**Interviewee:** Actually, he has … we try to keep … at least, I try to encourage him to have some kind of backlight so he may crack, like, the blinds, or he’ll use, like, the screen from, like, the computer or the TV because, you know, he watches TV a lot, too. So, or he’ll play his games, so. But he’s not in, like, full dark, only once he’s sleeping. Yeah, that makes sense.

**Interviewer:** Thank you. And what about smells: any sensitivities towards smells?

**Interviewee:** No, not that I can think of. I **[9:00]** mean, he has a pretty strong stomach. Yeah, he does—stronger than mine, so.

**Interviewer:** And so how would you say his sensitivities have changed over time?

**Interviewee:** Well, he definitely touches more things now than before. Like I said, you know, the whole **[inaudible at 9:21]** textures … he’s not afraid, actually, to kind of like … to do things. Like if you ask him, “*Hey*,” you know, “*let’s make some something from scratch*.” And you have to get in with some dough or something. He’s not going to be bothered by that, you know, because he actually did a cooking class at school too. So that has changed. Like I said, the other thing at this point is just trying to figure out how to help him with, you know, like, with the noises pretty much. That … I mean, that has changed too. It has progressed. You know, because when he was younger, it was like, he went through night terrors. So he would just, you know, he would scream for literally hours and hours and hours and hours and hours at a time. We couldn’t take him out in public. He would scream and scream until he threw up and would pass out. So he has come a long way. You know, he didn’t speak. He wasn’t speaking until he was maybe seven or eight. So he’s definitely … it is changing, so.

**Interviewer:** And when he was younger, was he more bothered or more startled by sounds?

**Interviewee:** Yes, definitely. He was socially incapable of adapting to his surroundings. So we literally … when he started to show signs and develop the PDD we were basically homebound for at least a good three years before he actually was able to go back into the world. You know, we … he literally lived in the pool the whole summer. We had the TV outside, you know, all we have is, you know, the third one with Spanish soap opera. And that’s actually how I learned how to speak Spanish was watching him in the pool and watching the soap opera, it was the only time I could get. Yeah, but he … it was really bad. It was really bad. He actually … we had kind of, like, our own … he spoke jargon. So we had our own little lingo, you know? “*Ninininini*,” **[imitates her son at 11:20]** and then he started to speak, you know, and then … Sorry, I lost my train of thought.

**Interviewer:** That’s OK. I asked youif you thought that his sensitivity to sound … if that had also decreased over …?

**Interviewee:** Yes. Yeah. So he would we would go into the store, we would literally have to … that’s when it first started, we would literally have to run in and run out. It was so bad, to the point where he would … the moment we would walk in somewhere and he was in the surrounding of too many people, he would scream bloody murder. I mean, you know, you always have people that will look at you. And there were some people that, of course, they had comments, but we just, we learned to ignore that. And then there were others that they heard that that cry was, **[12:00]** like, a cry of pain. He was, like, mentally and physically in pain because he could not be in an environment where there are too many people. So that we were just … we didn’t go anywhere. The first time that he broke out of that was … he was my, mine you, a little bit before the 18 months was when he started to develop the issues. When he was about—I want to say maybe four—we took a chance to come to Chuck E. Cheese, because you know, there are a lot of sounds and lights. He clung on to us. But he let us walk him over to where they had, like, you know, the stage area. So we took him back again, the only thing that he was allowed to do … allowed us to do for him was take him literally straight back into the stage area so he could see the lights. He would not budge from the chair. We did that for months. And he already knew when he saw the Chuck E. coming just to keep going, you know, and all of that mouse came nowhere near him and it was fine. One day out of the blue, he got up and started running around out of nowhere. I was crying in Chuck E. Cheese because I think that was such a progress from this little boy, we literally would just have to run straight to the back, sit him down for his pizza and go. And he just … he wouldn’t … he didn’t care about the games. He was just running around. And that’s how it started. And at that moment, I knew that he was going to be all right. As a mother, I said to myself, “*If he can tolerate this and he’s doing this* …” That was a very young mother and I knew he was going to be OK.

**Interviewer:** That’s wonderful. Thank you for sharing that. Thinking about the changes in his sensitivities: do you think that’s related at all to any independence that he’s gained over time?

**Interviewee:** Absolutely. And I think it’s very important, especially if parents don’t know or understand, you know, autism, that they keep encouraging it. And you get a lot of, “*Oh no, they’re never … they’re not going to be OK, they’re never going to be able to do it*.” You know, and they can, and it’s not that they can’t do it—they just do it differently. And a lot of parents don’t understand that. They think that their child is going to be dependent on someone for the rest of their lives. But, I mean, you can see any bit of progress from your child, just from sitting in the chair to getting up, then they’re going to be OK. Yeah.

**Interviewer:** And, for your son, how do you think his independence has related or, like, has facilitated this decrease in sensitivity?

**Interviewee:** It’s all about routines, you know, with these kids and for him. I think what helped him was, when he was a lot younger, he was … he had a lot of … more OCD. He still has that now but it’s not as bad and he would get really irritated if I changed his routine and I didn’t care. I fought him tooth and nail and I would take him out of his routine and he would get **[15:00]** mad at me, but I would do it. And as I was doing it, and I saw he was adapting, I said, “*Oh, forget it. This definitely*.” So I think by taking them out of routine, you know, and finding a way to modify things—so simplify, I should say, not modify—simplify things for them can definitely help decrease that. Like, for example, people said, “*Oh, he can’t get his driver’s license*.” He doesn’t have it yet. But he did take the driver’s ed course while he was in school, which, obviously with the COVID, he can’t do anything. And people say, “*Well, aren’t you worried that, you know, you may startle him, he may get startled* *and crash the car?*” Like, listen, I seen this little boy, we have the amusement park, get into those adult-size go-karts. Granted, I know, it’s not the same thing. But this boy was whipping those go-karts around that track, OK. And these are loud machines that are coming at you. So, with that, I know, there’s no modification for that. But I think within time and him, you know, slowly learning how to drive and getting … being taken out of his element, he can help it. And I thought of ways of doing it by, you know, well, maybe, like, safely in a parking lot while we’re … if he’s driving, you know, like, scream at him while he’s, you know, got the wheel see what he … just kind of jolt him, you know, things like that. So I’ve definitely got a plan in mind for when things eventually get back to normal, we can start doing that. But yeah, I think taking them out of their routine, showing them a level of discomfort to see how they can handle it is definitely something that is very vital to their pacification **[inaudible at 16:42]**.

**Interviewer:** That’s awesome. Thank you. And then, when your son is in a scenario that is aversive to him: like, where it’s too loud or lots of startling noises, does that cause or increase anxiety for him?

**Interviewee:** Sometimes yes, depending on the situation. And, like I said, we’re a loud family. So, like, his dad teases him all the time and they have their own situation. And he’ll seem like he’s mad at him but it’s more like a thing. It’s an act between them two. If he sees that the two little ones, like, really loud, he’ll excuse himself and go upstairs. He’ll just, “*Oh OK, time to go upstairs*.” Still he removes himself from the situation. But I start to see him, you know, he’ll get off, he’ll start to pace a little bit, you know, he’ll … his head is kind of going like *this* and his eyes are twitching a little bit. You know, and he … when he walks, he still walks with his hands turned like this a little bit in the back. You know, he’s got broad shoulders. So he’s, you know, he doesn’t flap as much as he used to when he was younger, he did a lot of flapping. Not as much anymore. Now, it’s more like the hands are just inverted, like, turned, you know, back while he’s walking. Other than that, he, like I said, he removes himself from it.

**Interviewer:** And did it use to cause more anxiety when he was younger?

**Interviewee:** Yeah, yeah, it was bad—to where, you know, I mean … **[18:00]** not that he, you know, it was … I think it was more like, if he was outside in public, that was where the anxiety was at. Because, you know, it was like, whether it was, you know, five people near him and talking. He was like … his brain was on fire. You know, and he would … like I said, he would cry and scream until he threw up and he would pass out. But yes, it definitely has changed.

**Interviewer:** Yeah. So, like, it’s decreased over time?

**Interviewee:** Yeah. Oh, absolutely.

**Interviewer:** And you’ve alluded to this before, or so far, rather, but how does your son cope with and manage his sensitivities or how do you help him manage and cope with them?

**Interviewee:** Well, sometimes I’ll … like, if I see his face starting to change—you know, sometimes he has that RBF and then I’ll say, “*What’s up? What’s going on?*” Like, I’ll kind of, like, I’ll joke him back, because sometimes if I see, like, he’s getting an attitude, you know, and it’s not something he shouldn’t … you shouldn’t be getting mad about, like, you know, I’ll try to be empathetic to the situation, depending on what it is. And I’ll ask him about it. “*Oh, nothing, everything is fine. I’m OK*.” I’m like, “*Does this … let me know, does this bother you?*” So he’s not afraid to convey what’s going on, how he feels. But if I feel like, sometimes he gives me this attitude. I’m like, “*Listen, excuse me, don’t talk*.” “*I’m sorry, Mom*.” You know, because I don’t … you can’t hold them either. Because then they’ll develop that, “*Well, I can talk however I want,*”you know. And so it’s … sometimes it may cause him … I see where a lot of the conflicts are at, especially if you have more than one adult involved in the child’s life. So, for example, like, parents and grandparents, obviously, the grandparents, they may not understand that the enabling is actually going to harm them, you know, and they worry about their future. I get it. Trust me. I was always worried about my son’s future. I’m not anymore. That fear … I lost that fear right shortly after high school, when he started doing things that people said he couldn’t do, I knew he was going to … he’s going to be fine. And my thing is, this is a cruel world. He has to learn. Because if I’m not with him, I can’t always be with him forever. You know, he has to learn. And I’ve had conversations with him. And I’ll say to him, “*Do you know what it means, someone that takes advantage of you?*” And he can tell me what it is, you know. “*And what would you say to them?* **[inaudible at 20:23]**. You know, so, they know, it’s just we don’t give … some people don’t give them credit, enough credit. You know?

**Interviewer:** So you’ve talked about him using … Well, thank you for sharing that, first of all. You’ve talked about him using headphones or, like, walking away from a loud scenario.

**Interviewee:** Yes.

**Interviewer:** Does he use any other techniques sometimes?

**Interviewee:** No. Well, he talks to himself. He’ll talk to himself and he’ll say, **[huffing and puffing noises at 20:52]**. He rants, you know, I can hear him from upstairs stairs. I can see him. But that’s about it. He doesn’t, thank God … Go ahead.

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

**Interviewee: [21:00]** Thank God, you know, he doesn’t, you know, destroy the home, he doesn’t punch, he doesn’t … he’s not aggressive. Like I said, he’s like a big gentle giant.

**Interviewer:** That’s wonderful. That’s really great. That’s helpful.

**Interviewee:** Yeah, no medication. He’s never been on … I refused medication when they suggested that at seven, so he has never been …

**Interviewer:** Got you. And has he received any specific therapies or interventions for his sensory sensitivities?

**Interviewee:** Right. So, right before he turned three, he received a few months of the early intervention at home. And then in the district that we live in … **[addresses someone else at 21:39]** Turn that back on, please. The district that we live in, once they turn three, obviously, they have, like, a half day disabled preschool in the traditional school district. So he’s been in school since he was three. So from when he’s in preschool—not from his school—he received speech, occupational, he received that from pre-K, oh my God, all the way up to high school, minus … The occupational stopped a little bit early, I think it stopped—I want to say maybe in middle school, it stopped in middle school, but he had the speech up until he graduated from high school. He actually had his … an updated psychological evaluation that was done by the high school, so that he could start college. So that one’s up to date. Other than that, that’s pretty much it, just a standard, you know, therapies that they offer in school. I did, I took him, you know … he did the whole neurological evaluation when he was younger. The last one that I did, he was pubescent. And that was the reason being because there were certain questions I had, because of that stage in his life. I wanted to make sure that things were normal and not—how do I say?—excessive **[inaudible at 23:05]**. So I actually spoke to my sister, she works for the neurologist and we’re going to be looking into taking him over there for another assessment as an adult to see what level he’s in at this point. But that’s pretty much it.

**Interviewer:** And the speech and OT he received in schools, do you think that helped his sensory sensitivities?

**Interviewee:** Absolutely. You know, being in groups with the kids, you know, having the speech therapy absolutely. You know, obviously because with IEPs you can read the progression. But, you know, I think also with them taking him … They had, like, a life skills program, which I think is very, very important. You know, like, they had, like, a little Cartman setting, they showed them how to wash clothes, brush their teeth, they took them grocery shopping. They actually had, in his middle school because, **[24:00]** luckily, the district that I work in … well, we have a very high number of autistic children. So pretty much almost every school is equipped for children with challenges. Yeah, no, it’s a very good district. And, in the middle school, they … he started the life skills program. And they even had the other children that are general education involved with the children, so that way they can understand and they can, you know, obviously grow with them. Yeah, they’re a very big part. And he did all types of things. They had a little school store that only the children in the special needs classes ran, like, making coffee and things like that. So he was able to get a lot of experience in school. **[inaudible at 24:49]** Yeah, in the high school as well. They also had the programs.

**Interviewer:** And you feel like those experiences helped him decrease his sensitivities?

**Interviewee:** I think so, especially since, you know, in … even in the school setting itself, you know, it’s not just them, it’s everybody. So they’re going to … they’re involved in all of the activities, you know. So you did know when they had activities done for, like, even the parents to come, the children who were more, even more sensitive, they have their own **[inaudible at 25:20]** with their ears covered. So they were all … they’ve met their needs, you know, for … yeah.

**Interviewer:** And now, thinking more globally and more broadly: what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** I mean, I guess, like every parent, I just want to make sure that he’s productive and that … Self-advocacy is my biggest thing. You know, hoping that there … I mean, there’s a lot of things we could hope. But I mean, at this point, even with the experience of college, like, he’s on his own, like, I’m the one sitting there, literally, simplifying, modifying every assignment with him. Because if not, he I mean … not that he can’t do well, but the help that he’s supposed to be getting right now, they’re not giving it to him, and I get it, but I don’t want to see him fail. So I think, just him … at this point, just making sure he takes care of himself. I know, you know, he shaves, he knows how to shave, I know he can learn. Just, you know, I want to make sure that he makes the right decisions, you know, if that makes sense.

**Interviewer:** No, for sure. And how does this self-advocacy, in your mind, relate back to his, like, auditory sensitivity or even some, like, texture stuff for food?

**Interviewee:** Basically, knowing when to speak up for himself or when to ask for help. He has shown improvement, like I said, at the beginning of the semester, you know, I just kept drilling and drilling and drilling, “*If you don’t know something, ask the question*.” And I started **[27:00]** off by writing the questions down. And then there were other questions that he thought of, and I knew he grasped it, because then he came back to me and said, “*Mom, guess what? I remembered this question and I asked her and she said I did a good job*.” So just … you know, I think they just need to be reassured, you know. Focus, you know, he needs to focus more, you know. And then again, I have to look at it, he’s—excuse me—he’s still kind of like a teenage boy, because, you know, teenage boys, they’re messy and lazy. And he has a little **[stretch? Inaudible at 27:29]**, so I can’t knock him for that, you know.

**Interviewer:** Absolutely. We’re going to move on to our next chunk of questions. We’re going to shift gears a little bit. As your son has grown up and aged a bit, how has his and your community reacted to his sensory needs?

**Interviewee:** I just lost my earpiece. Sorry.

**Interviewer:** No worries. That happens.

**Interviewee:** So, like I said, in this, in our town, autism is very … it’s … we got a lot of it. So the community is very active with people and children with challenges. I don’t know if you are familiar with Eric LeGrand, the Rutgers football player who is a paraplegic. He got hurt. He’s from Rutgers University, he’s actually from the area. So they, like, did a bunch of parks in his honor. Like they do a lot of, you know, foundations and fundraisers and things like that. So it’s very noted. Actually, a friend of mine, who was a volunteer firefighter, since they were quarantined, and we felt … he kind of got gypped because he finally gets transition and he has a little graduation. So what she actually organized the fire trucks to do, like, a parade for him. Yeah, it was awesome. So I mean, it was just, like, people that knew what he went through in his life—you know, friends, family, you name it. They showed up for him and participated. It was, like, there wasn’t a dry eye because they knew the struggle. This boy was like, you know … You have the people, “*Oh, he’s going to go to college. Oh, he can never drive. He can never … What are you going to do? And how are you going to …? How is he going to survive? And who’s going to take care of him?*” Like, that was all I heard his life, you know, and the fact that they came together to recognize … I had friends that we had, you know, babies the same time and their sons dropped out or weren’t going to do anything and I’m, like, so proud to see that this boy who they said that he could not have this opportunity, you know, succeeding and, you know, put their kids to shame. You know, so it was definitely a good feeling, you know, and people definitely, you know, they came together for him.

**Interviewer:** That’s wonderful. That’s really beautiful. I’m really glad he had that experience and you did too.

**Interviewee:** Yeah, yeah.

**Interviewer:** Would you say the community was less or **[30:00]** more accepting when he was younger?

**Interviewee:** Less.

**Interviewer:** Yeah, how so?

**Interviewee:** Absolutely. Definitely, when he started developing was right before that surge started spiking, you know, but I think at the same time we got lucky because it was more … it was … there were more children being classified. So that kind of helped versing maybe even two or three years prior to that some of those children. And I know this is weird to say, but those children are kind of stuck in a trance, if that makes any sense.

**Interviewer:** What do you mean by that?

**Interviewee:** I have a theory and, depending on the level, obviously, because there are children that have all … they have all different types of capabilities. But I think that is so crucial within that, between that, like, two years to, like, five years old, it’s really important to really get that therapy for them. Because that can make or break them that’s … I’m not a doctor, you know, but I’ve seen many parents in denial. You know, “*My kid can never do it*.” I’m like, “*My kid was the same way*.” You know, you just kind of push, you just got to give them that chance. So it was definitely less accepting when he was younger, because you had more negativity. Now it’s like, “*Oh, yeah, my cousin’s brother’s father’s daughter, they* …”like,all of them are autistic, so it’s nothing. But back then it was like, “*Oh my God, you poor thing*.” Like, “*How are you going to handle this?*” So yeah, the stigma is very, very different. Yeah.

**Interviewer:** And then, thinking about community in a kind of … as a large concept: are there specific spaces or places that are more or less accepting of him? Like did you see school as being really positive for him, for instance?

**Interviewee:** Well, I noticed … OK, so if this makes any sense, he … maybe because, in the high school he went to, when he went out for algebra senior year, it was a very small class. You know, when I had a conversation with his math teacher during the IEP, he said, “*Let me tell you something*.” He goes, “*I had my doubts*.” And they all said the same thing, “*I had my doubts with Alexis. I didn’t think that he was going to be able to do it*,” because they didn’t know what they were walking into. They didn’t … it’s a chance they take and that’s the problem, that if the parents don’t fight, they don’t know what these kids are capable of doing. I mean, there really isn’t much to modify algebra. So he says, “*I don’t know how he did it. He got the answer. I don’t care how he got it. He got it. I don’t know how he gets it*.” But the kids in his class … there wasn’t many, but they were like his cheerleaders. So I think the good thing is, is that, as there are more and more classifications and the general education is going up in this population, that is definitely helping. And it will help because the majority of our future are going to have classifications. So I think that it’s almost kind of, like, it’s intertwined. **[33:00]** So there … it’s going to be more accepting. In the future, it will be because there’s so much … there’s so many more children that are coming out as classified, right. And even in the college, when he first started, I noticed in his screen, and—not that I want to judge them—but based on their body language and their demeanor, you can tell that there are, there were several students that have learning disabilities and it was, like, the teachers were pretty much, you know, they were supportive. And the other classmates, I could see it, you know, as far as I mean, obviously, you’re always going to have your … The negative stuff was more when he was younger or if you … if I have a conversation with someone and maybe they don’t understand how autism works. I don’t get mad at them for not knowing. So I just try to educate them, you know, and explain the different levels of autism, of the spectrum. And … but, by now, most people know, you know, they can just Google, but back then, like, it was a lot different, you know, but yeah, I mean, he is more accepted now. You’re always going to have the negative Nancys. But I mean, you can’t change everybody’s minds, you know.

**Interviewer:** That’s very true. Thank you. And again, now thinking globally and towards the future: what hopes or worries do you have about how his community will react to him and his sensory needs?

**Interviewee:** The … I think the one thing that worries me is my son, he’ll … I don’t know if I mentioned this before. He will have, like, outbursts of laugh, will suddenly laugh. And it’s because he watches so much TV and funny jokes that he’ll think about something even if it’s a day later, and he’s hysterical. So my fear is, you know, what if he’s on the bus one day and he just starts laughing and the person thinks he’s laughing at him, and he, you know, wants to get physical? I mean, my son’s a big boy, so you’d have to be kind of crazy to want to, you know, get into a little tussle with him. But he’ll have, like, these outbursts and he’ll just laugh, you know, but I mean, that was probably, like, my own fear that I had of that is, like, the outbursts. But it’s not like a Tourette state where he’s, you know, cursing or “*Urgh*,” **[makes noise at 35:17]**, you know, doing a thing. It’s just, he’ll think about something funny, and he’ll just start laughing and you’ll hear him up there laughing for hours at the TV, you know, but that’s pretty much it.

**Interviewer:** That makes sense. Thank you. And do you have any worries about ... related specifically to his sensory needs or just kind of more generally?

**Interviewee:** No, not really. Because if he’s uncomfortable with something, he’s going to stay away from it. If he … like, I, what I do is, like, I’m trying to teach him. You know, like, if, as he gets older, he’ll be able to fend for himself, like, you know, food wise, even if he doesn’t cook. You know, I’m telling him, “*Look, they make these frozen P. F. Chang dinners, you know, or these healthy meals*,” **[36:00]** like, I know that if he has to eat a TV meal, TV dinner every day or go to a restaurant, I know he can take care of himself, you know. Because he stays home by himself. He loves it. He loves it. When we leave with the girls or the girls stay at my mom’s for the weekend, he has the whole house for himself. And he’s got an old soul. He’ll jam up the Earth, Wind and Fire and he’s just rocking by himself. So he loves it.

**Interviewer:** That’s good. It’s good to know what you like.

**Interviewee:** Yeah, no, yeah.

**Interviewer:** It’s really important. So we’re going to shift gears again, we’re about halfway done. So in this transition to adulthood, quote unquote, where do you see your son?

**Interviewee:** In the sense of, like …

**Interviewer:** Like, do you … where … do you think he’s approaching independence? Do you think he’s halfway there? Do you think he’s like his peers?

**Interviewee:** Well, he’s definitely not like his peers. I can tell you that. Approaching yes, developing yes, just from the fact that his dad taught him how to shave. Well—a couple years ago was it?—a couple years ago—because my son’s very hairy—his dad started talking about him shaving, he does it. I just got to keep reminding him because now he developed, like, this dermatitis and a mild psoriasis. So I’m teaching him now how to make sure … and he gets lazy, like any teenage kid, so I would say he is a little bit behind, but he’s getting there. You know, he’ll definitely—trust me—will not starve. He will make himself something to eat. He won’t touch the stove, you know, unless, like, we’re together. But like, he’ll use a toaster oven, microwave, make a sandwich, TV dinners, things like that. He’ll make a fruit salad. He’s pretty independent. If he had to live on his own. Yes, I just, you know … making sure in his future that he has a way to work. You know, that’s why we’re doing the college thing because he’s never had a job in his life before. You know and—obviously not now because what’s going on—but we’re trying to set it up. So that way in the future, if he can profitably work from home, maybe a computer job, that’d be great. You know, because it doesn’t have to be too much in the scene with too many people. So that’s kind of what we’re going for, you know.

**Interviewer:** Does he want a job?

**Interviewee:** Yeah, oh he wants to make money. His goal was having an RV in the future, he wanted an RV? But he was like, “*Oh, if that doesn’t happen, then, you know, even if just a little apartment*.” So he does want to live on his own. You know, I think we’ll know. When we finish, we might hit that subject, so I’ll wait to get there.

**Interviewer:** No, that was one of my questions: does he want to live by himself, so you answered it.

**Interviewee:** Yeah. Because with … like you said, well, when it comes to … are you going to touch about, like, resources and things like that?

**Interviewer:** Kind of, but you’re welcome to bring it up now, if you’d like to.

**Interviewee:** So yeah, like, my thing is … Oh God, I’ve just lost my train of thought again.

**Interviewer:** That’s OK. OK, no

**Interviewee:** Well, we’ll get back to it. Go ahead.

**Interviewer:** No worries. Thank you. You talked about him preparing a lot of, like, pre-made food for himself: is he able to go shopping for those types of foods on his own?

**Interviewee:** Oh absolutely, if you give him a **[39:00]** list. So what I do is, when I go shopping, he loves to shop with me because the kid, he saves money and he gets money for all types of holidays. So he’s got a little something saved. So if I go to Walmart, if I go to ShopRite, I’ll say, “*All right, you go get this; I’ll get that. Go get that*.” He goes, “*Do you need me right now, Mom? I’m going to go and get my stuff*.” He goes and gets his stuff. So he knows how to shop.

**Interviewer:** Yeah. Does he understand saving or does he just not like to spend money?

**Interviewee:** He does. The only thing he really … he spends his money on is the stuff that he gets for his slime creations. That’s pretty much what he spends his money on but he … You know, like, I … the plan was to open up a bank account for him and all that and then COVID did and I said, “*You know what, I just haven’t gotten around yet, haven’t had a chance, you know, but I want* …” That’s our next step is opening up a bank account for him to start putting some money away, you know. Because he likes to say that he has it hid in his small, little safe.

**Interviewer:** And how is your son with, like, taking care of himself physically or helping with household chores?

**Interviewee:** He washes dishes, takes out the garbage. I don’t have him do, like, the heavy cleaning of the chemicals in the bathroom, but I’ll tell him, like, you know, “*If the toilet seat’s dirty, wipe it, you know wipe your spit the same*,” you know, things like that. “*Clean up after yourself*,” you know, like typical teenage boy. Like, we’ve got a teenager, but, yeah, he’s nineteen, you know, things can get a little messy sometimes. And I’ll say, you know, “*Listen, you don’t get in there … Grandma’s coming in there*.” He hauls butt and he cleans it up. So he knows how to clean it, you know. He does … he’ll go on his own, he’ll clean the dishes, take out the garbage for us, you know, and his room. Other than that, like, the heavy stuff with the chemicals, I don’t want him to, you know, mess too much. But he knows to clean after himself. Yeah, he’s considerate. He is.

**Interviewer:** That’s great. That’s wonderful. And does he manage some sort of social life to any extent?

**Interviewee:** There really isn’t anyone really around here within his age group because, like I said, we actually, we moved his senior year to a different neighborhood in the same district. And, honestly, the peers of his class, in a self-contained class before he was transitioned, he really didn’t like them very well. Because my son, when it came to school, he was very respectful he was that student that everybody praised and loved, he was so calm, and just right to the point. And, you know, some of the other children were a little more hyperactive, if you may, or their challenges, you know, exceeded their behavior a little bit more, and he wasn’t like that. So **[42:00]** he didn’t like that. And then they were like, “*Alexis, Alexis, Alexis*,” and he just hated that. So, you know, we tried a couple times to, you know, link up with some of the kids, you know, play dates, things like that, and he just didn’t like it, you know, but if we’re, if we go to a gathering or a party and someone starts a conversation, he’s all for it. He’s not afraid to converse with anyone. You know, but other than that, he’d just rather be by … and he’s a loner, but then again, his birth dad is like that: very antisocial. I think … his family actually thinks that he may have had undiagnosed classification. So, from what I was told, so it makes a lot of sense. So, yeah.

**Interviewer:** Got you, thank you. And then, do you think your son will be able to achieve more independence in the future?

**Interviewee:** Oh, absolutely. I mean, just the fact that … just last semester was a success. You know, like I said, I only helped him with one of the classes to really modify and he got a, what a 3.8 or 9 or something like that.

**Interviewer:** That is hard. That is hard in college. It really is.

**Interviewee:** So right now he has, he’s doing business the, you know, the regular, the Business 101. He’s got his last English course. And he has two of his major courses. So we … my thing is with him, I have to keep on top on him. Because he’ll get lazy and I’m like, “*Did you do your homework?*” “*Yeah, I’m going to do it*.” Like, right now he’s working on, it’s, like, a four-panel comic strip he has to create for class for tomorrow. So he’s working on that. But I make sure … I have to be on top of him. I have to. He’s come this far. Right now there’s no one coaching him, like I said, or giving him the services that he needs. So I have to do it for him as for now, you know.

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

**Interviewee:** Just constant redirection. And, like I said, the self-advocacy and just the experience. He definitely needs experience, you know, not these—and I don’t want to mock it because they’re not **[inaudible at 44:26]** to each his own—but these programs that some of these schools have, like, we have what is called the Rise Program and where they don’t … technically don’t finish high school when they graduate, they go on till they’re 21. That, to me, that wasn’t for my son. I felt like, based on experience that I’ve seen with other children, other parents, it is basically a babysitting situation until they’re 21. Then what do you do? You know, and I initially began thinking about trying to see if he could transition. He was **[45:00]** in his sophomore year and I said, “*Listen, give this kid something. Maybe he could do something*.” So then they ended up letting him do … he did a Spanish class. It was, I believe, in his junior year. He got a B in that class. And the teacher barely made any modifications. So then I said, “*OK, let’s try something else*.” So we did a cooking class. And when it came time for that IEP, the baking teacher wasn’t a very nice person. Thankfully, she retired. But she said to me that my son was never going to be a chef. He would be the one sweeping the corners in a bakery. And I had to remember everything, every ethical bone in my body to keep from jumping across that table and yoking her up. And I basically professionally told her that she was a POS and that my son was going to be successful. Of course, you know, she apologized, because she realized that she said something horrible, you know, but that conversation and what she said to me stuck with me. And I said, “*Oh, no. I’m not putting him in this program. Because what are they going to do for him? What are they going to do? They’re going to, they’re going to … it’s going to be like* …” He wanted to get the heck out of school then and I didn’t force him to go to college. I had a conversation with him, you know, in his junior year and I said to him, “*Listen, you know you’re going to be a senior. What do you want to do?*” I gave him the option. I said, “*Do you want to do this program? Do you want to get a job? What do you want to do?*” He says, “*I want to go to college.*” And I … that was the moment. That was the epiphany. That was the moment when I said, “*Oh my God, my son can do it*.” And I said to him, “*Why do you want to go to college?*” He says, “*Just because*.” And I said, “*Well, tell me, so I can prove*.” And he wouldn’t say it, though. Only, “*What do you mean, ‘so I can prove?*’” I’m like, “*So you can prove that you can do it?*” “*Oh, yes*.” So I knew. He himself was telling me that he wants to prove he could do it. He just needs to be constantly reminded because he forgets to do his homework, you know. Other than that, when you … Yeah, yeah, that’s all right. But that was the moment that I said, “*Oh my God*.” Like, I had a belief, like, this burden that I had sitting on my shoulders for all these years when … Parents need to try, we need to give our kids a chance, even if it’s fighting that school tooth and nail it … even … Going into that sophomore year, let them try another class. It’s easy to dump these kids in a self-contained class. And just, my son was so bored in there because he was one of the highest, at the highest levels in there. Because it was just … everybody was at a different level so he was bored. He went … and even in the senior year, he was completely transitioned. He still had the **[48:00]** IEP, obviously, so they … for the college thing. But he was completely transitioned from senior year. He was doing the … you know how and now they’re doing the career services in high school. He did all that: the financial class, he did all that. You know, so.

**Interviewer:** Besides this wonderful experience that you are articulating, do you think there are other services or interventions that could benefit your son in this transition?

**Interviewee:** Absolutely. I definitely think that there should be more resources or services for social life, you know, things that are … places that they can maybe group with people of their own, you know, experience, situation. You know, definitely I know that there are a lot more companies that are hiring, you know, more challenged and disabled, folks, you know. **[inaudible at 49:01]** Quick Check, things like that, but there needs to be … this particular age is rough. Because it’s, like, “*Where do we go now?*” You know, a lot of people get stuck in transition homes and that will never be for my son. It could never be. He can’t live with anybody. I wish, like … when I first heard about this study years ago, like I said, you know, I was so, you know, interested in it because I wanted to share my experience. I always wanted to advocate and then just … time just kind of flew by and I never got the chance to do it. And then I saw it again. And I always said that if I can share my experience, you know, maybe—trust me, there’s nothing more that I would love to do than take my life experience, education and work in this type of field. I just don’t know where or how or what to do, you know, or how to get into something like this. You know, but if … even if just sharing this with you guys can maybe help. You know, I know at least I did my part, you know, or, at least, you know, in society. Because these kids need, they need social, they need to interact. That’s the part that’s missing. That’s the element, it’s the socialization. They have buddy ball. They have a whole program here in the district where they do sports, all types of sports for the children for free. But it’s not the same thing. You know, granted a lot of … you know, they may … certain towns may have other … Some may have more activities than others. But there’s a gap. There’s a gap. And it definitely has to do with socialization. Like, even, like, I know they have chats and websites and things like that, but that scares me. Because what if there’s predators out there looking for kids like this? You know, and you don’t know. You know, and some of them will want a girlfriend. You know, we’ve had the sex conversation, you know, from very early age. And I **[51:00]** think when he first started talking, I think he was about maybe eight years old, and he accidentally caught a glimpse of—do you remember when *The American Dad* started? It was a very nasty show. I didn’t know what he was watching, so I heard something and then I changed it. And one day, we were out in public somewhere and he looked up at me and said, “*Mummy, what’s a virgin?*” Yeah. Luckily, I was actually taking human sexuality at that time in college. So I was able to say, “*So what do you think it is?*” You see these little blue eyes looking at me. So I said, “*Well, Mommy and Daddy, they fall in love, get married, have a baby. You want to know anything else?*” He was like, “*No*.” And then he went about his business. You know, but we had the whole sex talk. Like I said, I took him to the neurologist when he was pubescent because I just wanted to make sure that he was, you know, normal and doing his thing because I know that’s all normal. And, you know, he had to talk to his dad. And I know he looks at, you know, stuff that he shouldn’t be looking at. So, you know, but he’s a growing boy, I just … I had the conversation. “*But just be careful what you look at*.” Only because I worked in law enforcement and I … as P.O. and I had, you know, mentally challenged defendants that had no fault of their own, you know, they were cognitively 17, even though they were, like, 25. And they saw something they weren’t supposed to see. And they were sitting in jail. So that scared the hell out of me. So I had to make sure I told him that, “*If anybody ever sends you anything, don’t open it. If you ever see anything with children, you don’t open it*.” And so we’ve had, you know … Though, that’s another scary part is the part about that situation that, as they become adults and they may not understand the law. So what do we do to prepare them? You know, so that’s why I, you know, I constantly have those conversations with him. Those are things that parents maybe don’t realize is consequences, you know, consequences of the law, you know, they don’t have the same understanding, you know, as someone else their age,

**Interviewer:** And they have adult bodies with adult needs.

**Interviewee:** Exactly. Exactly. So.

**Interviewer:** All good. Thank you. That was wonderful. So, in this intersection of sensory sensitivities and this transition to adulthood, how do they intersect for your child’s?

**Interviewee:** Meaning?

**Interviewer:** Like, do you feel like his sensory sensitivities to, like, loud noises perhaps or, like, sudden noises, do you think that impacts his ability to transition into adulthood?

**Interviewee:** A little bit not major. Had he not had the same experience or, you know, had he had a different **[54:00]** upbringing maybe. He’d probably just be like a bump on a log. But because of all the costs and pushing and fighting and, you know, changing a routine, definitely, it helped him. He is … does have issues. I’m not going to say **[inaudible at 54:17]** that he doesn’t. He does. But he’s capable of recuperating and capable of adapting to his surrounding. He is capable. Yeah, definitely. Had it been a different situation and had I raised him differently or shielded him, I think he probably … Those children who are shielded a little bit more, coddled, definitely will have an issue. If they didn’t, they don’t receive the same amount from as early age as possible. And the signs, from my experience and from other people’s experience, the signs are there very early, very, very early and it’s very, you know, it’s very common and parents are very in denial. “*No, my child is normal. I don’t make children like that*.” And they’re only doing a disservice to themselves because it’s going to prolong the recovery. That’s all it is. We always have issues, of course. And I look at a lot of things. Even Daryl Hannah. She’s autistic. You know, I read her backstory. Amazing. What her mother did for her, you know, very amazing story. I don’t know if you’ve ever read her story?

**Interviewer:** I don’t. I’ll have to look it up after this.

**Interviewee:** Yeah, very amazing. Yeah.

**Interviewer:** Back to the idea of, like, sensory and this transition: do you feel like his sensory sensitivities are an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** Probably both. Definitely, you know, because he’s going to have to learn how to manage them. Because I tell him sometimes when he gets nasty, you know, he’ll get, like, you know, he’ll catch attitude. And I’ll say to him, “Listen, just suck it up. Hey, this is the world. Listen, you know what, you don’t like it …” And then he’ll bring him … you’ll see the demeanor change. So it’s all about jolting them, you know, you have to call their crap when they do it. Don’t … you can’t baby them, you can’t. You can’t feel sorry for them. You really can’t.

**Interviewer:** In what way do you think it’s a vehicle for him?

**Interviewee:** Well, he has to learn how to … socially, he has … basically he has to know how to drive his life, you know, without us, you know. And I know that there are things he can do and there’s things that he still has to learn how to do. And he’s young. He’s 19. I know, even though he’s 19, you know, he still has another—what—six, seven, eight more years for his brain to grow. So I know he’s not at a 19-year-old level. If I had to guess, I’d say he’s anywhere between maybe—I don’t know—**[57:00]** 16 to 18 years. Only because there’s … when we talk about certain words, he can break down the root and know … he knows what the word means. And then if I ask him a question, he’ll give me an answer that maybe someone in high school gives me. So I know he’s not completely there. But he can do it. You know, he just has to learn how to … he has to figure out how to live his life. He really does. You know, so there’s definitely obstacles. But he’s got to be in control. You know, he has to learn to say, you know, when something’s bothering him, you know … And he does, he’ll say, “*No, please*,” like, you know, “*don’t bother me*.” Or “*Please*,” or “*Stop*,” or … he’s saying it. He’s already saying it. So I see him driving it. He’s hitting a couple speed bumps. But he’s there, if that makes any sense.

**Interviewer:** It does. Thank you. This question may not be super applicable, given a previous answer, but what do you anticipate as being challenging for your son as he does gain more independence, in relation to his, like, sensory and, like, sound sensitivities?

**Interviewee:** Meaning “*Do you think it’ll improve?*”

**Interviewer:** Do you think it’ll make something hard for him in the future?

**Interviewee:** Maybe. Maybe like by driving, for example. That might be a challenge. That’s why, honestly, like, we don’t know when it gets to that point what it’s going to be like in that situation, you know, because you have people that are … that road rage, that will use their horn at you, you know. What if he gets into a car accident? What if he gets to step on the wrong gear? Things like that. But we won’t know until he tries and he even told me, you know, even back when I asked him if he wanted to try to go for his permit. “*I don’t know. Do you think I can do it?*” You know, like, a lot of self-doubt. Well, because it’s the stuff that he’s hearing from people. Of course, he’s going to doubt himself. “*Yeah, I don’t know if I can do it*.” I’m like, “*Well, you’re not going to know unless you try*.” You know, “*Well, what if I can’t?*” “*If you just try, if you can’t do it, then you can’t do it and you have to learn the bus*.” But I want him to, not to just short change himself, you know. But definitely he is always going to have issues. You know, he just … he’s learning to manage them, you know. And they just … they really need honesty. Honesty is very, very important with these kids because they’re not stupid. They really, they’re not. Because I’ll ask him like, you know, “*Do you know what autism is? You know you’re autistic?*” “*Yeah, I know. I know what it is*.” I’m like, “*What does that mean?*” “*It just means I do things differently.*” You know, not that you can’t. You do them differently.

**Interviewer:** We all do things differently, though.

**Interviewee:** Yeah.

**Interviewer:** And then, again, not super … maybe not super applicable because you don’t think his sound sensitivities will be super impactful, but do you think anything could help him with that at this intersection?

**Interviewee:** Like I said, it’s more of, like, the socialization part of, you know … **[1:00:00]** Once he actually gets into the real world, like, I know he’s going to be able to have a job, you know. He just needs the proper training and guidance, but my thing is mainly just him socially, trying to connect with people. And that were … those were things that they worked on. Even, like, with speech therapy, they would give him a task: “*OK, I want you to go in and start a conversation with two strangers that you don’t know*.” So I’d be … I try to kind of, you know, “*We can’t do that now*,” you know, but … Well, actually, no, that’s not true. I shouldn’t say that. You know, with the whole college thing they have the discussion boards, so they’re required to have to post and critique or comment on their peers. So I’ll say to him, “*OK, well make sure you, you know, do your post*.” And then I’ll say to him, “*OK, remember to critique. You have this amount of people to critique. Don’t say,* ‘*Oh, great job, buddy. Oh, that’s really nice.*’” I’ll tell him “*No*.” And I had to explain to him what critique meant. And tell him really, “*Oh, I love your painting, the way you use the black with the brush*,” and, you know, trying to be a little bit more creative with his words, you know. So he’s been doing that. So I’ll tell him, before each class, “*Don’t forget, make sure you ask a question. Don’t forget, make sure you connect with someone from class*.” So that part he’s still working on remotely. But yeah, he’s been doing it like that. But he definitely needs socialization.

**Interviewer:** Other than these, like, opportunities for socialization, do you think there are, again, specific services or interventions that could help him more or additionally?

**Interviewee:** It could be, you know. Like I said, maybe, you know, resources that, I mean, you know … I don’t know, maybe get them together, you know, create maybe, like … have sites, you know, where they can, you know … I know that there are some out there, but those pertain mainly to children. We actually have a brand new building they put in our township that’s like a sports complex, but it’s mainly, like a recreation place, but it’s mainly for children or for kids that are in high school, you know, or in this program they have till they’re 21 They need a community. They need something for them, you know. Maybe there’s a place they can go to, you know, that they can meet people that are in a situation they are, you know, maybe have some kind of peer group for these particular kids that are in college, you know or even, like … I don’t know. I think they just … they need something, a place to go that their own that can help them, connect them to, you know … Like, I know that they have them, but it’s kind of hard because it’s depending on the state that you’re in. Like, Jersey, it’s kind of hard, like, we have the **[1:03:00]** DDD, but waitlist is astronomical. You know, they … luckily, I mean, I can navigate through the system, but there really isn’t anything for him like that. I mean, they have a booklet with hundreds and hundreds of services, but by the time you actually get through to somebody, it’s … like, you know, I wish there’s something like a, like, if he was to, let’s say, I don’t know, if there was, I don’t know, let’s just say, hypothetically speaking, a house, House of Heroes, I don’t know, it’s just a name or something. And this particular house can … has different services for maybe group homework, you know, like, tutoring, or maybe, like, a social event, like having a dance, you know, for these kids or maybe, like, a date night or mingle, single mingle, you know, for these adults of a certain age, you know, or maybe have, like, job fairs, which I know they have them, but it’s sporadic. And it’s not always geared for them. You know, like I said, even the college too, they have … they’re supposed to have the services for him, but they have not helped at all. You know, I don’t do the tutoring for him. I do it for him, you know.

**Interviewer:** Absolutely. And it’s going to be a bit of a gimme question, but do you feel like there are gaps in the available services and interventions for folks like your son?

**Interviewee:** Yeah, absolutely. They’re the forgotten group, they’re definitely the forgotten group, you know, because they … what I and I want … I’m not trying to knock any of these … I know, there are a lot of, you know, there’s a lot of help out there. But here in Jersey, you know, for the younger kids, great, you know, they do have transition home. They have a lot of that. I will say that. But what about those kids that don’t need that? What about those kids that can actually do something with themselves when they’re older? How do we help them to set that platform? Maybe he doesn’t want to live in the community like himself. Maybe he doesn’t want to be bothered with any of that, you know. They are definitely forgotten in my opinion.

**Interviewer:** Yeah. Well, I’m asking your opinion, so that’s all that matters right now. Looking back again to sensory a little bit: do you feel like your son’s sensory sensitivities have impacted your goals, hopes or expectations for him as he has navigated adulthood?

**Interviewee:** Yeah, absolutely. Positive and negatively. Negatively, you know, as, in his younger years, I worried. I thought that, you know, he would … I was scared. Oh my God, you know, I was a single mom for a long time, you know, and then, you know, I was lucky enough, fortunate enough that, you know, I had two more girls. So that kind of gives me a sense of relief, not that I’m trying to push them to have to be his caretakers, but I know that, with them being younger, that they’re going to take care of him **[inaudible at 1:05:58]** and make sure he’s OK. **[1:06:00]** So I feel a little at ease with that, that he’s not the only child anymore. That was a big concern. As he gets older, I just … I hope that he’s able to live healthy and take care of himself when he has an issue. Because, I mean, there were times where, for example—and I don’t know if this may help—but he had a situation where he had had an ingrown toenail and never said anything to me. And he would just go through the pain and go through the pain. And I didn’t know this. Luckily, you know, they were able to just only to have to take off the nail, but he lived with that pain probably for a couple of weeks. And, even when he had, like, this … he started developing, like, this psoriasis. He had really bad ones on his back and he didn’t tell me anything. Luckily, we were able to … it’s all gone now, thank God. But these were the things where I had to tell him, “*Listen, you know, as you get older, I’m not going to be around forever, you got to take care of yourself. If something hurts, you got to go to the doctor, you got to get medical attention*.” So that’s one thing. That’s another thing that does concern me is that he takes care of himself, you know, and I think, as he gets older, and the more he does it, the more practice, he’ll be OK. Because, like, when it was time for the medication, I was doing it for a while and then he was showing me that he was doing it. So he was consistent. When I start to see him slack off. I’m like, “*You’re not putting your medicine, because it’s starting to get red again.*”“*I’m going to do it*.” And then he’ll go back and do it. So it’s the consistency. But then again, that stems from … he’s still got that teenage brain, boy brain so it’s kind of hard to tell. Like, “*Wait, can he do it or can he not do it? Because is he being lazy or is it because of the challenge?*” That’s kind of, like, a conflict that a parent has throughout an autistic child’s life. But as they grow and they do and I know that as long as I know he can do it, he’s **[inaudible at 1:08:00]**.That’s the constant battle.

**Interviewer:** And these worries that you have, is it more related to him as, like, a whole individual and less related to his, like, auditory sensitivity?

**Interviewee:** A little bit of both. Because I know he’s taking a shower every day. He knows, like, I have to tell him, “*Change those sheets*,” because he started getting that psoriasis, each time it started to look like a snowstorm that had broke. So I’m like, “*Roll up them sheets*. *Change them. It’s very important*.” So it’s just a constant reminder, you know. It’s just … I just hope that as he gets older, he, you know, he maintains the same cleanliness because he knows like, “*Listen, nobody likes stinky people*,” you know. But then again, that stems from the laziness of being a boy. You know, but every day he showers, thank God.

**Interviewer:** Thank you. We’re going into our last chunk of questions. We’re almost done. Homestretch. So finally, as a caregiver, as a mom, as a parent of someone with autism, but also a little bit of **[1:09:00]** sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** Definitely anxiety. For me, in the sense of—I don’t know if you’ve ever heard this before, I don’t know if it’s just me, but you kind of develop the challenges with them in the sense of well, me, meaning when I hear certain loud noises or I myself, I feel like my brain is on fire. I’m not classified. I kind of developed some of the stuff with him as he was growing, you know, but as a caretaker and seeing his capability, he is, I mean, reached far more expectation than myself or anyone can imagine. You know, like I said, I know this world is a cruel place. You know, my experience with him, like I said, you know, I was raised by a single mother and then raising a child as a single mother, especially with challenges, was extremely difficult. Very, very difficult, but he was also rewarding. You know, I guess things happen for a reason, you know, and for a long time, I blamed myself as a caretaker, you blame yourself. You know, “*What did I do to make my kid like this?*” You know, but then, as you get older, and you realize that stuff is genetic is not in your control. But as his caretaker, you know, I know that I have an obligation for him. And right now, you know, I still support him financially, you know, emotionally, you know, until I know he’s ready to be on his own. Then, you know, I’m not worried about him going, I’m not. I don’t foresee that anytime soon, obviously, because he has a long road ahead of him. I just want to make sure that he finishes school and that he gets a job that, you know, support himself. It is, it was very exhausting. You know, I think, the relief finally kicked in, kind of like, into, like, the preteens to the teenage years was when the relief starts kind of to kick in a little bit. You know, like, when I saw that I was expecting for my older daughter, he cried. He was 12. He cried and he wanted us to take her back. But then, when we had … were expecting the second one, and we were afraid. We didn’t know how to tell him because of the reaction for the first time and it was different. It was, “*You’re having another one!*” So we saw the maturity in him. So it’s little things like that that, as a caretaker, you realize it’s going to be **[1:12:00]** OK. It’s just the simplest things that he says or his reaction towards things, you know. And it’s weird, because one moment you’re talking to your child, and he’s in la-la land. And then the next minute, it’s like, this little switch turns on and it’s like you’re having conversation with a normal person. You know, like, “*Well, that was weird*.” So it’s like, “*I know you’re in there, you know. It’s pulling you out*.” And so they need that stimulation. They do. They need those honest conversations, those grown-up conversations, you know, so.

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

**Interviewee:** His or mine?

**Interviewer:** Yours.

**Interviewee:** Mine? Well, I definitely … I don’t take anything or anyone for granted. I don’t sleep what a person’s capability, what their capabilities are. Their potential is amazing. I mean—just to, you know, just to share something with you—when he initially started coming, developing his challenges, there were certain places that I could take him to. One place was … my uncle had a, like, a little newspaper stand, pick-it store, little candy store for many years. And there was one place that I could take him was there. So, you know, there were times I had to take him because the little bit of money that I had, I was working for my uncle, so I’d bring him with me. And he … the only way that we would keep him calm … my uncle had a lot of, like, old … the circulars. My son went through a phase for a few years where he would take the circulars or any kind of paper newspaper and rip it from the very beginning to the top. You know, to get that straight line, you have to use scissors. My son didn’t need scissors. It was like an art for him at two years old. He could take that paper and rip it. I mean, you’d be there for a long time. Rip it, rip it, rip it, rip it, very slowly. And people would just stare at him as he’s ripping this paper. And the moment that one little, little crease or a little tear went the wrong way, he would freak out. And we’d have to run and get him a new one, or he’d start and he would make straight lines as if he was cutting scissors this paper. That’s hard to do because you get all the little bevels and the ridges, the sweepy lines, as you know. The moment if that paper did not come out straight, he would freak out and run and we had stacks and stacks and stacks of paper. So then it turned into an art for him, up until he was in middle school, he had … my mom had, like, this fake floral arrangement on her table. And the whole thing was just spilled, his papers just dripping down. **[1:15:00]** Then eventually he started making dinosaurs, like, monsters, creatures out of paper, paper and tape, paper and tape. And he has a couple of them still left around. But it was just amazing just seeing this child create art or use this tool out of just ripping paper straight. I mean, there were no imperfections in this paper and they’re … it was amazing.

**Interviewer:** It’s really impressive. And it’s really hard to do.

**Interviewee:** Yeah, no, it is.

**Interviewer:** And what do you see happening in your son’s future?

**Interviewee:** I’m hoping that the course that he’s taking in school, he seems to be interested in it, it’s **[inaudible at 15:42]**. So he has a lot of, like, arts programs right now. And he’s starting to gravitate towards the drawing right now. He really likes it. So I’m hoping that he can find a job, that he can work from home or at least part time from home. That’s my goal for him is finding a job in his comfort. And I know there’s a lot of companies that are doing that—excuse me—like, major companies that are hiring children with special needs because of their brain. And I’m hoping that that’s the case for him. I just want to make sure that he has a job where he’s comfortable. That’s it. That’s probably my main goal for him.

**Interviewer:** And do you see him finishing his college program as well?

**Interviewee:** Absolutely. And it’s funny because, right now, I don’t … I didn’t sign him up for winter courses. I don’t plan on signing him up for summer. So one of the advisors, you know, right before the first semester and it says, “*Well, you know, he’s got to take the summer so that he can graduate for the two years*.” I said, “*Ma’am, we’re not in the rush. It’s not a race*.” It’s OK if it takes him three years, four years. The fact that he didn’t have to take any remedial courses and went right into his major, that’s going to cut classes alone. So I said to her, “*We’re not in a rush. He’s going to take … he’s going to do two semesters a year and that’s it. If he wants to go on, that’s fine. If not, he only needs, he’s only going to need … What’s the three years, so what? At least he’s doing it. And we’re supporting him. I’m not … I don’t have a timeframe where he has to move. I’m not kicking him out, you know. You know, he’s with us. He lives with us*.” You know, I just … and the other thing, I think the … one of my main concerns is I need to—obviously, with a pandemic going on—work on making sure that I do something with the courts in regards to, you know, his … because he’s obviously, he’s an adult. I am his proxy school. So that gives me some kind of wiggle room. But legally, I’m limited. So that’s something I have to work on. And I think that’s an issue that maybe some caretakers don’t have. They don’t know what steps to take to make that happen.

**Interviewer:** Do you see him moving out? I think you said that, right?

**Interviewee:** Oh, yeah. Yeah, oh definitely. Not **[1:18:00]** now, eventually, because we’re actually working on, you know, getting a bigger place. Because this was just a temporary move because they were demolishing where we lived at before. So we had to kind of just take whatever we got. And then pandemic hits. So we’re just waiting a little bit and then we’re hopefully going to look into maybe getting a house of our own. So even if, let’s say, it’s a multifamily and then we get something else. And maybe he can … my goal is that he has his own apartment. And, no matter where it is, if we are fortunate enough to get a multi and eventually another home, he will always have that apartment for himself. That is another goal that I have: making sure that he always has something of his own.

**Interviewer:** Yeah. And do you see him one day having a family of his own to some degree?

**Interviewee:** Honestly, it’s kind of hard. I mean, he’s never had a girlfriend. And that’s the problem. Like, there’s no social events. I don’t want to say that he may never. At this point, he’ll get to, you know what, if he has any kids. He says, “*No, Mom, I’m never going to have a girlfriend*,” because he gets embarrassed. But I think, as he develops cognitively, that might change. Because I know he likes girls and we’ve had the conversation if he likes boys or girls, you know, at a younger age. And he says … he didn’t really say anything. I’m like, “*You know, it’s OK if you like either or. I don’t care*.” And I said to him—just to kind of see where his head was at—I’m like, “*Would you rather see a girl naked or a boy naked?*” He was like, “*Definitely a girl*.” We’re like, “*OK. He likes girls*.” So yeah, so I think another thing is very important for caretakers to do is definitely have conversations about sex ed. Especially right before they hit that. Because people think that it’s not necessary, but it is. We did have an issue in the middle school that I had to kind of get in them a little bit, you know? And they didn’t realize that he should also need it. And right after this issue occurred, they’re like, “*No, we need to start talking to these kids too*.” Because what I guess they don’t realize is that children who have challenges, their change in puberty is a lot different. And even, like, for females, you know, that they’re more aggressive because they can’t control their hormones. So they’re … they don’t realize they’re a little more aggressive than boys. But they don’t really realize that they need that talk too. They understand.

**Interviewer:** All individuals need that talk. Everyone changes in that direction.

**Interviewee:** And you see the cliche, like, the parents are like, “*Oh, they’re not going to understand what I’m talking about*.” I’m like, “Hello, how else are you going to explain why they have hair in certain places or why they’re touching themselves **[inaudible at 1:20:53]**? You know, that’s very important, is that conversation because you have kids doing inappropriate behavior, you **[1:21:00]** know.

**Interviewer:** Absolutely. Thank you. I have one last final question and then we’re done. Again, this may not be super relevant to you and your family, but this perspective you just described about, like, what it means for your son to transition—did his sensory sensitivities impact that perspective?

**Interviewee:** What do you mean perspective, which one?

**Interviewer:** Like,you talked about how … what it means to transition for your son is kind of like, he can reach a potential that others didn’t think, but it also means some anxiety for you. What … how much did his auditory sensitivities play into that perspective?

**Interviewee: [addresses daughter at 1:21:41]**. I got it honey, right here. So wait, I’m confused. You said … I heard anxiety and then auditory.

**Interviewer:** Yeah, I’ll say it again. So my … so you just articulated your perspective about what it means for your son to transition and, when describing that, you talked about how he can meet a potential that others didn’t think he could meet, but you also talked about your own personal anxiety. And my question is, did his auditory sensitivities impact that perspective?

**Interviewee:** Yes, absolutely. Absolutely. I seem … sometimes I get a little frustrated. And I know more human. A perfect example is college right now. You know, there are times where I’m trying to explain something to him, he may not … I don’t know if he’s registering it or if he’s just tuning me out or if he didn’t get enough sleep the night before. And so sometimes I get frustrated and you … have to redirect myself, you know. Because it’s … “*You have to remember he’s got issues*,” you know, “*you got to remember*” … I’m talking to myself at the same time, you know, so that it does, you know, and this is unprecedent. So it’s not like, where he’s in school and then he’s coming home and I’m just reviewing something with him where I’m like, “*OK, you don’t understand this. Go to Sutton Hall and go, you know, sit down with your counsellor, your social worker and have them help you*.” We can’t do that. You know, so, yeah, it’s … sometimes it can be frustrating, or if, you know, when it gets his little attitude, but that, I guess, it’s just any kid, you know. Yeah, definitely, with this whole school thing. It’s kind of, you know, definitely challenged me with that.

**Interviewer:** I’m sure. Thank you. So, actually, that’s my formal questions. Would you like to add anything else?

**Interviewee:** I guess just, you know, parents with children in this age group, just keep fighting for your kids. You know, and don’t take no for an answer, you know, challenge them. Definitely, you know, there should be some kind of resource for these children. You know, I would like to, hopefully, in the near future, maybe **[1:24:00]** kind of start some kind of support group for parents, you know, so they can see that this is … there’s hope, you know. But these kids definitely, there’s something missing. This gap needs to be filled. It really does. It does.

**Interviewer:** Yeah. Thank you. I … this has been so wonderful. It’s been invaluable to hear and learn from your perspectives.

**Interviewee:** Any time.

**Interviewer:** Your knowledge really will make a difference. So, thank you so much for making time in your busy schedule, especially at such a hard time right now. So thank you.

**Interviewee:** Yeah, well, they got a snow day today, so they’re enjoying it. So, if you ever hear, like, of any, you know, like, any kind of, like, research programs or things like that, like, I’m always up for, you know, sharing this information because hopefully me sharing this can help open up something, you know, something better, you know, or I can contribute to something. Because, like I said, I really want to focus. You know, right now I’m on leave from work until March, but it’s really what I want to do so I’m trying to focus on something in this area for him, you know, and use my experience to, you know. And we’ll see, right.

**Interviewer:** There are a couple other studies, so I will send them to you. And, hopefully …

**Interviewee:** Yes, please.

**Interviewer:** … they ring true to you and you want to participate. But if you’re not, that’s OK, too, always voluntary. Do you know any other families who might want to participate in this study?

**Interviewee:** Let me think.

**Interviewer:** It’s OK if you don’t. I ask everyone.

**Interviewee:** Yeah, I mean, if I do, I’ll let you know definitely, because, like I said, there’s a lot of … I mean, the parents … I knew the parents from school, but, you know, he really didn’t want to have friends.

**Interviewer:** Yeah, no, that’s super fair. Don’t worry about it. **[inaudible crosstalk at 1:25:49]** Can I do anything else for you? Can I answer any questions?

**Interviewee:** No, you … it was very delightful. Like I said, if you know, if you have any other studies, I don’t mind because the more knowledge shared the more, you know, resources that could potentially be created for—I don’t want to say kids because he’s not a kid—but, you know, adults in this genre.

**Interviewer:** Yes, absolutely. I’m not running any more studies. But I know some other folks who are doing similar work. So I’ll send that to you. And hopefully, it fits for you. But as soon as this … we’re done chatting, and as soon as this video is done rendering, I will send you a follow-up email. It will include a gift card as compensation for all of your time and effort because we do so appreciate all the time and effort you are giving us.

**Interviewee:** No, trust me, I’ve been wanting to do this for a long time. So I appreciate you guys, you know, because it will help. Even if he’s, you know … he doesn’t get the grunt of that at least someone else can benefit from that.

**Interviewer:** Absolutely. Your insight is invaluable and ethical.

**Interviewee:** Just keep fighting, these parents need to keep fighting. And if they say no, don’t take no for an answer. Just keep fighting. Your kid can do it, they can do it, you know, **[1:27:00]** even if it just takes that one class. You know, and the school will tell you, “*Oh, I don’t know how we can modify that. I don’t know how we can change that.*” You don’t have to. Just give them the extra time and let them sit, in let them observe. All they need is to see.

**Interviewer:** Makes sense. Absolutely. Well, thank you. This has been wonderful. I won’t keep you from your evening anymore.

**Interviewee:** Thank you so much, Rachel.

**Interviewer:** Thank you. It’s been a pleasure. And if you need anything, you know where to find me. Feel free to reach out whenever.

**Interviewee:** Stay safe.

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

**Interviewee:** Bye bye.

**[End of interview]**