**[Start of transcript]**

**Interviewer:** No worries, not a problem. All right, so we're recording now.

**Interviewee:** Okay.

**Interviewer:** And so I'll be asking you questions about your perspective about 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 a set of questions, but I will be adapting our conversations and changing…adapting my questions to follow our conversations that way it actually makes sense for us.

**Interviewee:** Okay, you don’t mind the cat’s tail?

**Interviewer:** No, cat’s totally fine.

**Interviewee:** He’s tryingto sit on me.

**Interviewer:** It's okay, all of my **[00:36]** have cats and them, you know, it's not a problem one bit. Do you have any questions before we begin?

**Interviewee:** No, no questions.

**Interviewer:** Okay cool. And if any questions are uncomfortable, you don't have to answer them.

**[speaks to someone in the background].**

**Interviewer:** So for the first question, could you start off by telling me a bit about your son’s sensory sensitivities and interests?

**Interviewee:** Let's see. His sensory sensitivities would be, he has an aversion to pickles really bad. Like he doesn't want it on the plate, near the plate, he doesn't want to smell it. Other than that, loud noises bother him. So he tends to close…covers his ears. He wears earphones most of the time, when we're in and out and about, but not you know, with the COVID, not so much. He also has an immune deficiency problem, so we haven't been able to let him go out too often. Usually it's to the grocery store and back home or to the doctor and home. Other than that, he's here. We just moved, so we moved someplace with a balcony in case this is long term. So like I’m thinking it's probably best for all of us, if, you know. We can at least go outside and I have to go outside with other people so.

**Interviewer:** Absolutely! We talk about it all the time, we wish we had our own personal space, so that makes complete sense.

**Interviewee:** Yeah.

**Interviewer:** You mentioned… **[02:01 crosstalk]**

**Interviewee:** I’m sorry

**Interviewer:** Oh, no go ahead.

**Interviewee:** No, but I'm hanging up on a call.

**Interviewer:** No, it's fine. If you need to make something else let me know, I can pause the recording. You mentioned aversions to pickles, are there any foods that he really is interested in?

**Interviewee:** Oh, he loves…French fries is his main go-to. Chicken wings and **[person speaking in background]** the Japanese, yeah.

**Interviewer:** **[Laughing]** it's a good choice. Are there particular loud noises that he also dislikes or…? Yeah.

**Interviewee:** Like trash trucks, or any big moving vehicles, you know, 18-wheelers, things like that tend to bother him if he's if he doesn't have his headphones.

**Interviewer:** Got you. And similarly are there any sounds that he does like or is interested in?

**Interviewee:** Oh anything dealing with Sonic. He has all the music memorized bygame, episode **[03:03 crosstalk]**.

**Interviewer:** So like Sonic the Hedgehog, right, that's what we're talking about?

**Interviewee:** Yes Sonic.

**Interviewer:** Okay.

**Interviewee:** Yes, that’s his obsession, has been since he was probably five. He was still a little young and yes, that's been his major obsession. He's had others here and there but that one has been there the longest. Right now, it’s **[03:20 crosstalk]**

**Interviewer:** What else?

**Interviewee:** It's electronics.

**Interviewer:** I'm sorry?

**Interviewee:** Anything electronic. Phone, tablet, computers, video games of course.

**Interviewer:** All those sounds or like just kind of topically?

**Interviewee:** No, he's obsessed with everything.

**Interviewer:** Got you **[chuckles].**

**Interviewee:** All of those things, but Sonic is always number one.

**Interviewer:** Got you. So you mentioned other things kind of changed throughout time. What else has been an interest historically?

**Interviewee:** He used to collect the little Hot Wheels cars, he had over probably 300 at some point.

**Interviewer:** Wow, that's a lot.

**Interviewee:** Yeah, when he was little. The other thing he would collect was…I’m trying to think. That's the one that sticks out the most.

**Interviewer:** Yeah, totally.

**Interviewee:** Yeah, that's the only right now. I'm sorry.

**Interviewer:** What about…no don't be sorry. No sorries here. What about the taste and sounds, has that changed over time at all?

**Interviewee:** The sounds has been the same. He's also been diagnosed with APD – Auditory Processing Disorder. So we noticed it when he was about five, you know, anything loud came by, he covered his ears. At first we thought it was just a fear of the truck, we didn't realize it was the sound…

**Interviewer:** Got you.

**Interviewee:** …until later. Because we tried getting him to go to the trash truck and have the guy show him how it works. He was fine, but he was holding his ears the whole time. So, then we **[04:48 crosstalk].**

**Interviewer:** Got you

**Interviewee:** *“Oh, it's not the truck, it's the sounds.”* His taste, he's pretty…he will pretty much try anything at least once.

**Interviewer:** Okay, yeah.

**Interviewee:** And then make up his mind, yes or no. Like hates broccoli. He doesn't want it all this plate either. If it's there, he'll pick around it, won’t eat it. But he won't like throw the plate away. If there's a pickle on there, the plate, the whole plate has to go!

**Interviewer:** Has that…has he always been…has he always disliked pickles?

**Interviewee:** No, I think it was somewhere around nine or ten when that changed, because his sister’s a big pickle eater. And I would say I remember him eating pickles with her up to a point and then all the sudden an aversion to it.

**Interviewer:** **[05:32]** Absolutely. And so this question may not be super applicable to your son, but I have to ask it for consistency purposes.

**Interviewee:** Okay.

**Interviewer:** So, do you think any of the changes you've noticed, so like you mentioned change, now he dislikes pickles, or any other changes in his sensory sensitivities and interests. Do you think that’s related at all to any independence that he's gained over time?

**Interviewee:** Yeah, I mean he's a boy scout, so yeah, I would have to say yeah, because he got into scouts in third grade. That was around nine, eight or nine. So that's probably what had a lot to do with it, because that was his first time being part of a group, other than going to therapy of course and yeah, that was his first time. And I think he tried different things because the kids were trying different things. And we went camping at least once a month every month for even the summers with this, with the pack we had joined.

**Interviewer:** Oh.

**Interviewee:** So he…it helped him come out of his shell of, you know, not wanting people nearhim or joining in. As a matter of fact we are waiting on his Eagle right now.

**Interviewer:** Oh, that's awesome! That's so lovely. And so you mentioned headphones as something that he does to help him kind of manage his sensitivities to loud noises. What are other things that he does or maybe you help him do to help him?

**Interviewee:** He will listen to music instead, it’s usually Sonic music. If he doesn't have his headphones, he will put on his hoodie and pull it up over his head or he will find a quiet spot. He will locate one. He was good at that at school, they said, he would just…he’d find hiding spots or he’d find a teacher the he could befriend so that he could be away from the noise, like he didn't like being in the cafeteria.

**Interviewer:** That makes sense.

**Interviewee:** He would get his food but he would vacate as soon as possible **[chuckles]**.

**Interviewer:** No, that's fair. Cafeterias are really noisy when I think back to high school and middle school too. These coping skills, and kind of like management strategies that you're talking about, how did…like where did he learn them? Were there particular interventions, or like therapies where he learned these?

**Interviewee:** Some of them were therapy, because he’s had all of it. He’s had a pals group where he was trying social skills out in like different scenarios, and playing things out. He was in a group of what, I think like eight and then it dwindled down to six. And one of them he still keeps in touch with, they still communicate by texting and email. Also, once he gets to high school here – because we moved from Florida to here at ninth grade, which was probably not our best thing. But I would say after going through all four years, it probably was because it forced him to be more independent. I think we didn't know he could do a lot of things once we got here, like he can…of course DC's Metro driven, he can get on the train and can go anywhere. He's better at it than me and his dad put together **[interviewer chuckles]**. He’s not too great with the buses, we just let him download Uber onto his phone and Lyft, so he can get a car.

**Interviewer:** That’s great.

**Interviewee: [09:03 inaudible].** So, the city has forced him to become more independent because he had to.

**Interviewer:** Totally.

**Interviewee:** We lived on one side of town and school was on the other side **[chuckles]**.

**Interviewer:** Is he okay with public transport with all the noises and everything, because it can be so loud?

**Interviewee:** He puts his headphones on.

**Interviewer:** That’s great.

**Interviewee:** Which I don’t like, but I mean, it’s a double edged sword. Either he puts them on so he can concentrate and figure out what he needs to do or…but if he's crossing the street, I would say 50% of the time he'll take them…at least pull one down so he could hear if somebody’s blowing at him, but only about 50%.

**Interviewer:** Okay, better than nothing, right? **[chuckles]** Would you say that his sensitivities cause or increase anxiety?

**Interviewee:** Yes.

**Interviewer:** Yeah?

**Interviewee:** Yes, definitely.

**Interviewer:** How so?

**Interviewee:** The noise tends to make him jittery if he doesn't have his headphones. Now if he has his headphones, he's fine. It's just if he doesn't have them, he tends to be short-tempered, I want to say he's ready to get moving, he does want to stay there long, he wants to just be gone. So he is very short-fused. Anything else? **[thinking]** That's all I could think about as far as if he doesn't have his headphones.

**Interviewer:** And would do you say that he uses his headphones to help him manage that anxiety.

**Interviewee:** Yeah, yeah. He spends a lot of time in his room listening to music.

**Interviewer:** And how has anxiety changed **[10:34 crosstalk]**

**Interviewee:** Oh, go ahead.

**Interviewer:** Oh, I'm sorry, I didn't hear you, go ahead please.

**Interviewee:** It's worse. I would say it's worse now because of COVID. I think because he’s worrying about, you know, family. We've had one scare, my daughter was exposed but thankfully her, and no one else in her family got sick. But others who were close to that family did, their whole family got sick. The mom, the grandmother, the daughter, a friend but not her dad or her family, and they had all been together like two weekends before.

**Interviewer:** It must have been really scary.

**Interviewee:** Yeah, it was because she had to go get tested and everything. So he was freaked out. We've had a death in the family, my husband's father passed, not from COVID, but during the same time in April. So, he's had some bumps in the road, so he’s…one of his things that he does when he's anxious is he picks his skin, so he’s got some really bad scarring right now. And also from him wearing the headphones so much, it causes him to get these little ear cysts, that blow up in his ear. So like now he's going through treatment of antibiotics and we have to go see an ENT specialist because they keep coming often, but there’s nothing else we can do. We've gotten away from using the ear-buds because those really made the ear, like blow up. But we even opened the ear once, I think it's just too much moisture, but trying to get him to realize that that's a problem is, it's hard. So hopefully the doctors will tell him, *“you to stop wearing them all the time.”*

**Interviewer:** **[12:08]** Yeah. Well, I'm so sorry to hear about your father-in-law. There's so much going on right now, I'm so sorry you have to deal with that too.

**Interviewee:** And we haven't had a funeral. So when all the protesting happened and they were having funerals online, and the first thing he says was, “*if they’re having a funeral why can’t we?”* And it’s hard to try and explain, you know, that was an exception because the world needed to see that happen, I think, in order to have some type of closure, but we're not allowed because Pennsylvania's pretty much closed down right now we can’t…we’re not going to do anything. So, it's been rough.

**Interviewer:** Yeah. I'm so sorry that…Zoom funerals are not…they do not lend the same healing and that's really hard.

**Interviewee:** Yeah.

**Interviewer:** I hope your family can heal together.

**Interviewee:** Oh, thank you. We're working through it, we’re trying to keep mom on the phone. So we try to call at least two, three times a week, check on her and see if she needs anything, so far so good.

**Interviewer:** That's good. Glad to hear that. Circling back a little bit if that's okay.

**Interviewee:** Yeah, it’s ok.

**Interviewer:** So you mentioned that he does get anxious with loud noises, so he does use the headphones. Has that anxiety changed over time specific to his sensitivities?

**Interviewee:** Yeah, it's gotten worse. He's more…when he was younger, he wouldn't demand the headphones, I would usually slip them on him if I knew we were going to somewhere loud. Once he got accustomed to the area or what was going on he can he can expect, or knew what to expect then he’d take the headphones off himself. Now he wants to live in them, pretty much.

**Interviewer:** Got you.

**Interviewee:** All the time.

**Interviewer:** Absolutely, that makes sense, okay.So what are your goals and hopes for Stephan in regards to his sensory sensitivities? Did I say his name right?

**Interviewee:** Yes, Stephan?

**Interviewer:** Okay, cool.

**Interviewee:** It’s Stephan, but he answers to both.

**Interviewer:** Okay. I just wanted to make sure **[chuckles]**.

**Interviewee:** Better time management overall with wearing the headphones so that he'll realize that he's missing a lot of things in life with wearing them all the time. He's in the process of getting ready to do a summer internship at a school out in California.

**Interviewer:** That’s exciting.

**Interviewee:** We're trying, with ABA, him becoming more independent faster, sooner. And he's liking right now, mainly because the school is in California and that’s the school he wants to go to, and the only way we can do it is we have to make sure that he's going to be safe.

**Interviewer:** Is this for college?

**Interviewee:** Well, it’s a school…an ASD, for ASD students in California who are interested in the arts, like filmmaking, commercials and that type of thing. But they just added game design and that's really his big thing, **[15:00]** and it's a three-year program versus a four.

**Interviewer:** That sounds awesome.

**Interviewee:** And they don't do the academic part. He can do the academics, it’s not going to be a problem, but I think he just needs to go ahead and get his skills, he seems to like the curriculum that they have going on. So he's supposed to be taking an internship with them this summer to make sure it's what he wants, before we spend all that money.

**Interviewer:** **[Laughing]** I mean, that’s great though.

**Interviewee:** And send him that far away

**Interviewer:** Yeah, it is far.

**Interviewee:** Because a lot of kids on the spectrum, if they're left to their own devices, they will do one of two things, I think. It’s mostly game all day long, and not get enough sleep and eat because they will be just gaming.

**Interviewer:** Yeah.

**Interviewee:** He's proven it to us time and time again. We've experimented with us being gone, like overnight, a weekend, just to see what he would do on his own, did not end well **[laughing].**

**Interviewer:** He wouldn't eat right without you guys?

**Interviewee:** We were gone one weekend for 21 hours, from the time we left the house to the time and came back, so overnight he gamed 20 of those 21 **[chuckles]**. Because I could see the records, because we have that kind of app that shows what’s goes on. He didn't eat, didn't shower, nothing.

**Interviewer:** Mm-hmm.

**Interviewee:** That was about a year ago. Last time we left him I think was…yeah another day, he did a little bit better.

**Interviewer:** Okay.

**Interviewee:** The house was still a disaster, he still gamed a lot, but I want to say he did get at least five hours of sleep.

**Interviewer:** Well, better than no sleep **[laughing]** so, you know, progress is progress.

**Interviewee:** Yes, so, yeah.

**Interviewer:** That's good. Shifting slightly, so as Stephan has grown up and aged a bit, how has your community reacted to his sensory sensitivities?

**Interviewee:** Oh, now that was a fight!

**Interviewer:** Oh no!

**Interviewee:** He just graduated in June.

**Interviewer:** Yeah, I saw.

**Interviewee:** His school, let's just say they…it's not the school I wanted for Stephan, but…

**Interviewer:** It was not the school you wanted?

**Interviewee:** No, I did not. I wanted him to go to a computer school that was here in DC. He was accepted at an art school in Florida right before we moved, and he was upset and thought he would never get into one. And just by happenstance they save about 10 percent of their spots for people who move into the area, he actually got into an art school here. I don't know if you’ve heard of it, Duke Ellington School of the Arts. But the problem with the school is they're great for kids who are already independent, but not so great with kids who need assistance with things like time management, or making sure he has all his homework and, you know, studying for tests, or know that a test is coming, because he is very forgetful.

So they weren’t that…you would think with them being an art school day would be more inclined to help him, but they weren’t, they just didn't have the skills. A lot of it I had to do myself, like contact all the teachers when he was behind on what's left to be done, and it's a lot of running around. Also half…I would say half the teachers didn't understand his sensory thing or why he was constantly putting his headphones on in class. Most of the teachers didn't have what I would call, *control* of their classrooms, so a lot of times it will get loud and out of…I’d say *chaotic* almost. And he would just check out, he’d put his headphones on and they would just think that he was being rude or whatever, and it would take me a while to convince them that this is his way of one, not reacting badly, so he wouldn’t go off and started yelling, throwing things because people are invading his space or it's too loud, he can't comprehend or deal with it. So he puts his headphones on. If you have a problem with it, then we need to get your classroom close, you know, calm down before you tap him to say take off his headphones, otherwise, he's just going put it right back on.

**Interviewer:** Yeah.

**Interviewee:** And then you have some teachers who just didn't buy into the autism thing.

**Interviewer:** What do you mean?

**Interviewee:** One of them told me she didn't believe in autism, she said that she thought that the kids were just lazy. Oh yeah, oh yeah, I had those kinds of things deal with **[chuckles].**

**Interviewer:** That’s insane! I'm so sorry.

**Interviewee:** Yeah, it was rough.

**Interviewer:** That's horrible.

**Interviewee:** But we made it through all four years. We did attempt to try to get him a half a year, his junior and his senior but his grades were so good, they wouldn't go for it. But he would’ve really benefited from an extra year in high school to, I don't know, to get his stuff together as far as like, you know, working on his planning and time management and stuff like that, but it's okay. We’ll go on a different route.

**Interviewer:** Yes he will. I'm sorry. So, you mentioned that some of the teachers were not accepting or accommodating of his sensory sensitivities or even of him in general, which is well, such a shame and not really acceptable personally **[chuckles].** But was this different when he was younger? Were people more or less accommodating of him?

**Interviewee:** Middle…elementary was fine. We did have one or two teachers, the first two teachers, I think it was first grade and second grade teacher, he had the same teacher two years in a row. Don't ask me how that happened. And she was just, oh my gosh! She's probably the one who made me realize that I needed to fight for my son more. So…and be more vocal, because the first year he was with her, I tried to be nice. And I've learned when you have a special needs child, whether it’s autism or something else, you can't be nice all the time **[chuckles]**.

**Interviewer:** Yeah.

**Interviewee: [20:49]** So by the second year, I was a pain in her side. And justifiably so, because she was…she wouldn't do any of the things that therapy was suggesting, like removing him from distractions, don't sit him in the…or sit him in the front of the class near the board. She’d put him in the back of the corner because she didn't want to deal with him and you know, those types of things. *It was rough*. But after that, once…we changed schools because she was going up the grade again, I said, *“I do not want…”* and I finally said, *“you know what, I don’t even want her to ever to look at my kid.”* So, we changed schools and that was the best thing I ever did, because he flourished in third grade, fourth and fifth.

Middle school was a little rough, sixth grade, just adjusting to class changing and that kind of stuff. They called him a little baby tornado, and he was, he would unpack everything looking for one thing, type of thing. But after we…during that time we started doing, I think occupational therapy and speech therapy, that helped a ton, because he had a little cheat sheet he could use to put on his backpack, that says, you know, don't forget your coat, your backpack, your lunchbox, your homework, do you have your folder? But it was little pictures instead of words. So he would just have to look at it and he could just look around and say, *“oh I got everything,”* that helped. But once he got to high school, it was like starting all over because he tried to throw *everything* he'd learned, out the window because, “*I'm a high-schooler.”*

**Interviewer:** Mm-hmm.

**Interviewee:** Whoa! Ninth grade was another. Whoa! That was rough! And then moving on top of that, you know, from Florida to DC was rough. But he's made it to the other side, so I can see him being very successful as long as he finds a job that he loves. It's got to be something he loves because otherwise he will lose interest and he will eventually get fired, because he didn’t show up or he forgot he needs to go to work, those type of things.

**Interviewer:** He needs to like hone into what he likes.

**Interviewee:** Yeah, but he's got to like it. And that's what I found out about the schools. In middle school, I let him pick his middle school. We went and saw like five, and he picked the school he ended up going to and it probably was the best fit for him. High school, I did the same thing, but now I'm kicking myself, I think I should have held my ground and said, *“no you need to go to the computer school.”* But he's done it and he's finished. My problem with art is that it's a little too much…it's too fluid, I think he needs something more rigid. Like you know, how do you fix a computer? You put these pieces together plug, plug and you're done.

**Interviewer:** Yeah.

**Interviewee:** Art allows him to be more creative, but it can also be what I call a rabbit hole for him. Like he can just keep going and keep going…

**Interviewer:** Oh, yeah,

**Interviewee:** …and keep trying to perfect it and keep trying to make it perfect, and he was always turning in everything late because it just wasn't right yet. It's not right, so.

**Interviewer:** No, I did a bunch of art in high school and I totally know what you mean, like everyone was like weeks late on projects and that was just how it happened and it doesn't seem like it would teach him the same structure that you were talking about, that you wish he had.

**Interviewee:** Yeah, right.

**Interviewer:** **[23:57]** So you talked a lot about school in relation to like his community and how they were accepting or not so accepting. What about other parts of his community, like your family, things like that?

**Interviewee:** Family has been somewhat…his sister is his biggest advocate, she's his what I call his cheerleader. She's a special Ed teacher. She just, she's been certified now about 4 years, 5 years. She has patience with kids, because I think she…last year she had three of them, three ASD students. So they were shocked that she knew exactly what to do with them, like you know, find their own special spot and they have their own separate things and you know, she allowed them to do other things that other kids can't do, but it was because she knew that's what they needed. Like my son, a lot of his teachers figured out if they gave him something to do like, let's say a special project or something, he would finish up his homework so he can go to the special project and his work will be turned in on time. It's the teachers who didn't take that extra time to figure out what made him tick that he was struggling.

English didn't come around for him until his junior year. The teacher he had was awesome. She nurtured his creativity side. The two before that, oh my God! 9th and 10th grade year, I'm surprised he made it out of there with Cs, I really am. Because they just…they wanted it a certain way and they couldn't understand his brain was wired in a different way, that you need to explain things a little differently so he understood it. So, it was a struggle, but his third…as a matter of fact the third year and the fourth year, they got it. They figured out that you know, they needed to have little sidebars with him and give him extra examples and then he would go…and the he got it. I tell people all the time when I'm talking about him that, *“he's a black and white kid, don't give him grey, because if you give him grey, he gets stuck in there. You can say yes or no, do this or do that, don't give him too much freedom if you want something completed on time. Now if you want him to be creative and you don't care when you’re getting it, then okay, but you remember you opened up the flood gates.”*

**Interviewer:** Yeah, absolutely.

**Interviewee:** The apartment we used to live in was awesome with him. We had a shuttle bus driver, he knew Stephan, he would wait for him, he would pick him up if he saw him walking. They were very accommodating with him, the staff in the building, even the maintenance guys, they would tell me if they saw him and if he was doing something bad or if he was questioning, you know, like, *“we weren't sure if you knew he was doing this.”* *“Okay, thank you for telling me, I’ll go jack him up.”* Even a couple of the neighbours even looked out for him. So we just moved here, so it's going to be interesting. I've only told one person who works here that he's on the spectrum, we'll see how that goes **[chuckles]**. But the apartment we lived in last was for three…I think we were there for almost three years, yeah, three years, and it was awesome **[27:00]**. It was better than the first apartment. In the first apartment we didn't really know our neighbours, we didn't know too many people in the building, we didn't really know the staff really well, it was just a very clinical situation. The last place we were at was more like home, everybody knew everybody and hung out. And when the COVID hit, it was a big shock to most of us.

**Interviewer:** Yeah.

**Interviewee:** Isolating.

**Interviewer:** Well, I hope this new community becomes that similar community for you, once COVID is over and you actually can do that **[chuckles].**

**Interviewee:** And the other community I guess I talked about is scouts. He's been doing scouting since third grade. I think he started in 2010, so he's been doing it for 10 years. We're trying to encourage him to stay in it, because he can stay in as an adult and start teaching other adults training and that kind of stuff. He's 18 so he can go to either venturing crew until 21, or he can join like the training crews. He's right now in OA, which is the Boy Scouts equivalent of Honour Society.

**Interviewer:** Oh, cool!

**Interviewee:** He got in that I think about a year ago, he's still active with them. But as far as Boy Scouts itself, he can't stay with the troop unless he's an adult leader because he turned 18. And like I said we’re waiting on Eagle. We had to unfortunately change troops three times, let’s see 100, 198 **[28:29 inaudible].** Yeah, we started out at 606 in Florida before we moved here. My husband started that troop because of my son, because he wanted a unit that would be more inclusive so he wouldn't be bullied, and that kind of thing. So, most of the boys he was in a pack with came over to the troop, so that was a good environment for him.

And then we had to change troops when we got here, now it was rough trying to find the right fit, where you know, he wasn't being bullied, he was allowed to speak out, I guess, and be heard and given time…extra time to make missteps and adjustments to figure out how to fit in because he's with new people. But we stayed with the first troop for almost a year and we just figured out it wasn't the good fit, so we transferred to a different troop and that was a better fit. The kids were close to his age and more tolerant of his diagnosis and they also figured out that he knew more stuff than they ever knew in a million years because my husband made sure he was very skilled in life skills, so like building fires and all those things, my son can do all of that. He can I think light a fire like 10 different ways without using a match.

**Interviewer:** **[29:47]** Way better than me. I know zero ways.

**Interviewee:** He can tie all the knots from memory. So, he has really good recall with certain things that are attainable like that. That's why I said, I thought computers would be better for him because he can, you know, one and one equals two, type of thing. Whereas art to me is. you know, it's just not that rigid, but we'll see. Hopefully he’ll get to do what he wants to do, and that’s just going to be the thing, you know, I'm hoping that he gets a chance to do it and say, *“yes, I it did it.”*

**Interviewer:** Absolutely.

**Interviewee:** Even if it didn't like it but…I think he’s just going to find it hard to meet the deadlines that's going to be required with things like that. That's just going to be his problem. I have to have a very…I guess understanding boss, or leader, or person who will take the time to nurture him and get him on the right track, that's all.

**Interviewer:** Absolutely. So, you've talked about like a nurturing, understanding boss or leader, you also talked about a job that you hope he really likes. But what else are your hopes or worries about how his community will react in the future, as he does gets more independent and he does like enter into adulthood more.

**Interviewee:** As adults we’re not allowed to make too many mistakes. That's going to be the biggest worry for me. So, how is he going to get over any mistakes? Like I said, his sister is his biggest cheerleader, but I have made it quite clear for her, once we get him independent and in his own space, if something was to happen to us, she's not to take him in. She could help him all day long, but I don't want her to take him **[31:31 unclear word].** She can help him get his own place, whatever. Because I feel like she will get stuck with taking care of him and I don't want that for either one of them, mainly because it won't help Stephan either, if he's constantly being taken care of.

**Interviewer:** Yeah.

**Interviewee:** As a matter of fact, we're hoping to try to get him in his own space, in with a roommate. We're working with a company here, an organization that helps teens who are…who have a disability and want independence and they will help them get roommates.

**Interviewer:** That’s awesome!

**Interviewee:** So, we're hoping that in a year we can get him in a good place and then he'll be ready to go to that school in California.

**Interviewer:** That’s super cool though, that’s such a great organization.

**Interviewee:** Yeah, so as a matter of fact, I think she calls tomorrow. No, Thursday.

**Interviewer:** I hope it goes well

**Interviewee:** Yeah, me too. It will be her second interview with him by phone. A lot of times it's hard when people don't get to meet you face-to-face to really gauge your personality, but I think she gets it, because she interviewed me first before she interviewed him. So she wanted to see you know, if…I guess if he was on the same page, but.

**Interviewer:** Yeah.

**Interviewee:** He held his own, she was surprised, she said he was a lot more…what's the word, articulate and vocal about what he wants.

**Interviewer:** That’s great!

**Interviewee:** So that's a lot of training, and I will have to definitely give to the ABA **[33:00]** because we've had that for about two years. I didn't even know they did teenagers, I was shocked! Because in Florida we could never get ABA, there was always a waiting list, like I mean as long as arms trying to get him any services like that. So we ended up having to go to clinics and do whatever they had there, but we could never get ABA. And most of them only wanted to deal with, like elementary only. Once you get to middle school, they don't want to deal with the ABA, so it was totally different here, when we got here.

He's had the same therapist for, I can't…I don’t know what they're called, I guess therapist. Now, we've had three different BCBA's, the people who oversee the whole program. But the person that he deals with every day, it's been the same person and I'm glad we haven't had to change from her. Because she has patience, and she's young, she's like 24, so she's close to his age somewhat and if she can remind him about things that you know, she had to deal with too like, you know, first time she moved out and that kind of stuff. So that helps that he has someone that he can talk to other than us.

**Interviewer:** Yeah, and has like the relevant experience.

**Interviewee:** Yeah.

**Interviewer:** That’s great.

**Interviewee:** As a matter of fact, she's living at home right now because of COVID, and she broke her ankle and other stuff. And she's like, *“hiccups happen,”* and she's saving money, trying to you know, to move out again, and I think she said this will be our third move out **[chuckles]**.

**Interviewer:** I mean it happens, you know, I mean I did the same thing, moved out for college, came home after college, moved out.

**Interviewee:** Yeah, me too, I did the same thing.

**Interviewer:** Yeah. So it's actually a great segue to my next set of questions. So, in the transition to adulthood, like as a concept, where do you see Stephan?

**Interviewee:** I see him working at a company he likes. I see him living alone, eventually. Not at first. I think his first couple of years out, he needs to have someone around, mainly because he does the little things like forget to turn off the stove. He may forget to feed the cat if he has one. He keeps saying he's taking mine, I'm like, *“no way!”* He'll need someone to be his backup, but I think once he's gets all of this under wraps, like, you know, figured out his schedule, and work, and having a job on top of going to school and…‘cause I've told him, I said, *“you’re going to have both, you can't just go to school,”* and he's like trying to figure that out. And I’m like, *“that's why they make weekends, you work on the weekend, you go to school Monday through Friday, and that's how people make ends meet, but you're going to have to earn your way.”* But that's something we've always taught him, even when he was doing scouting, he had to raise money or earn money to help pay for scouting. I never thought that we should…we paid for everything, that's just not, you don't learn anything from that. So he's always had a summer job every summer since moved up here because they have those, they have something called the Marion Barry Youth Work Employment Program, where they pretty much find a job for the kids and then they can make money. I mean most of them have been a joke, but he did love working at the radio station, that was his first job. He went back there the third year because he loves it so much, he didn't…he took an art class, he took an art job. And the second year, the 10th grade summer, hated it! And I'm like, *“dude that's what you…”*

**Interviewer:** You like art **[chuckles].**

**Interviewee:** Yeah, because at first at the radio station, he tried to get out of it, he’s like, *“I don't want to be there mom, this is not art.”* And then I’m like, *“it's a different kind of art. It’s still a medium,”* I said, *“but you're use your voice and your personality,”* and he fell in love with it. So we'll see, that may be his back-up plan. He met a lot of people in the industry and met Donnie Simpson and at least two others, who told him, *“hey, if you want an internship just let us know.”*

**Interviewer:** That's awesome!

**Interviewee:** That’s a backup plan, so we’ll see.

**Interviewer:** That's great. So he doesn't have a job right now?

**Interviewee:** No, he did a six-week internship after…right before school ended, and that was more like teaching him like how to balance check books, opening stuff, you know. They talked about making sure you know your medical history, and all that type of stuff. But those are things we were working with the ABA, all of it, anyway. So he's had a bank account since…I want to say since seventh grade. Yeah, seventh grade, we started it in middle school.

**Interviewer:** That's great.

**Interviewee:** So he's always had an account. He may have, I think right now and probably has over a thousand in there because he also qualified for the stimulus check, so he got the full amount.

**Interviewer:** Great!

**Interviewee:** Because he was 18, so.

**Interviewer:** Yeah.

**Interviewee:** That was a shocker, because I’d filed his taxes just so that…because we're not claiming him this for 19 and let him be independent so that he can qualify for more programs. So, that's where we are with that.

**Interviewer:** Yeah. So, for the jobs that he has had, like does he like know he needs to save his money for like the Boy Scouts or put it into his account, yeah?

**Interviewee:** Yeah, yeah, we've stressed that. That's one of those things I wish my mom was better with me with money, like my daughter, she's a miser. Oh my gosh, she hates spending any pennies. I'm serious, she's tight on the penny *man*. But she's 27, no 28, 28. She just bought a new house. I would never, I had her at 26, there was no way I would have been ready to buy a house or anything else. She’s a lot more…

**Interviewer:** That’s amazing.

**Interviewee:** Yeah, she’s got her head on right. I guess I did something right. I don't know.

**Interviewer:** Yeah, you did. Is that Emily you mentioned, someone in your demographics form?

**Interviewee:** Victoria.

**Interviewer:** Okay, sorry.

**Interviewee:** It’s his sibling, his sibling. They are two years apart.

**Interviewer:** I have a big sister too **[39:02 inaudible].** Does he…how is he with like cooking for himself, or like caring for himself in that way?

**Interviewee:** We're doing that as well, we're backing off. The only meal I supply for anyone in this house is dinner, everybody else fends for themselves for breakfast and lunch. I figured out that if I provide all the meals, he will never do it. So he will eat when he's hungry, like he’ll fix a grilled cheese sandwich. He loves my air fries. I know that's probably first thing going with him when he leaves, he’ll put anything in that. He loves it to reheat food as well, he says it's better than putting it in a microwave, so he loves the air fryer. He'll cook grilled cheese, he'll put anything in there. He's figured out how to do desserts in there and stuff with…put an aluminium foil in there so you don't have to leave a mess, so he's pretty comfortable.

**Interviewer:** That's great!

**Interviewee:** He knows how to use microwaves. He learned how to cook really at camping. That's one of those things the Boy Scouts did, that you have to master so. He's not the *cleanest* cook in the world, but.

**Interviewer:** You know, he can cook, he can feed himself.

**Interviewee:** Yeah. That's what I said, he can feed himself. We’re working on the laundry right now. It takes him three days to do three loads of the clothes which I'm like, *“dude that's got…you’ve got to get that down to one day.”* That’s because he won't set alarms for himself, to remind himself, even when the alarm is going off on it, he won't set another alarm to go change the clothes from the washer to the dryer, those types of things.

**Interviewer:** Mm-hmm.

**Interviewee:** We have to do…we do a lot of reminders, we're trying to move towards Alexa on his phone, just reminding him like taking a shower, or did you take your meds? Those type of things. He has to have a lot of memory reminders.

**Interviewer:** Totally. You’re giving me great segues. So other than reminders like that perhaps you're giving him. What else do you think would help him get from like where he is now, into the place where he is living independently like you talked about or like having that job that he loves, like what will help him transition to that spot and in your mind.

**Interviewee:** He would have to listen to the alarms. If he did what they say to do when they go off, he would be fine.

**Interviewer:** Got you.

**Interviewee:** But that's the problem, if he's engrossed in something that he's obsessed with, like he's playing a video game or he's drawing something, he won't, he will just ignore them. So, therefore that's how he gets off track. And now we're trying a new thing where he has to…we kind of, we had a checklist that didn't work. We had a thing on the phone, checklist that didn't work. So now we're going back to the basics where we have these little *pictures* that he just moves on from one side to the other and it's just one day at a time. It’s not a whole week, it’s not a whole month. It's just, *“put this over here when you've done it.”* So we started on Monday, Monday he just didn't do it. But today,I can say at least half of them have been moved over, so.

**Interviewer:** That’s good.

**Interviewee: [42:04]** We said to him, *“if you want to not have the kiddie board, you’ve got to do the pictures first. You’ll start doing those then we'll change it to words and then we'll go put it on the calendar and then you can go check offs,”* or whatever, but we’ve got to figure out what works for you.

**Interviewer:** Yeah, absolutely.

**Interviewee:** So we have to find that one. And we're going to no switch for the video games until the weekend, because it’s so hard to get everything back from him, it’ just a fight and causes too much stress in the house, so we just started that as well. He's not happy about it, he’ll be all right.

**Interviewer:** He will be alright, absolutely. So now, kind of putting these two things together, like sensory sensitivities and also transitioning to adulthood, how do these two things intersect for your son?

**Interviewee:** He's just got to learn when the time to do it is, because I've told him before, it’s like, “*if you’re going into a meeting with your boss, you can't put your headphones on if you're in a meeting with your boss and anybody else, it's just that's inappropriate.”* So trying to get him to realize when it's appropriate when it's not appropriate to do that. Like, *“if you're at your desk, you’re chilling, and you don’t have anything scheduled, okay, you can pop your headphones up, but make sure…”* you know, I would try to keep one of them caught. We did meet a gentleman who said he kept his headphones in, but he used buds. He's on the spectrum, he was…I would say *27*. He said he grew his hair long so he can cover them up. He kept them low enough that he can hear anyone talking to him. But his music stream – 24 hours. He said he even slept with them in, but he said he made sure his hair was long enough that he covered them and that he kept it low enough.

And now if my son can figure out what he needs to do, to do the same so that he can have his safety net but not miss out on anything. Because that's the biggest fight that him and his dad get into, it’s my husband constantly having to repeat himself or constantly telling him to do something because he didn't hear us because he had the headphones. So that's going to be biggest fight. After that, it's going to be time management. He's got alarms, he's got to pay attention to them, he needs to do things when it goes off, not later. And getting up on time, because we still haven’t mastered that either. I bought him an alarm that shakes the bed.

**Interviewer:** Oh I’ve heard of this.

**Interviewee:** Yeah. And it also has a fog horn but because we live in an apartment here and use fog horn because we’re like, *“oh the neighbours will really love us,”* but it's 50/50 if he'll get up with the shaking of the bed, so it just depends. That and med management, he's got to learn he…we’ve tried to go off the meds to see how he would act or behave or how his grades were, and we figured it out quick, *“dude you do have to have the medicine so that you can calm down long enough to…”* Of course his sister's ADHD. She didn't do well with the meds, so she stopped taking them and I told her it was her fault…her choice, *“but at the same time you still held to the same [point], A's and B's, no C’s No D’s, or you have to go back on the meds if your grades dropped,”* and she was able to keep hers up. Stephan’s grades dipped really, really bad because he wasn't able to focus, so he definitely needs the meds. Right now he's only on Adderall, XR and his anxiety meds and everything else is for his allergies.

**Interviewer:** **[45:31]** It totally makes sense.

**Interviewee:** We’ve dwindled it down.

**Interviewer:** That's good. Perhaps you answered this already, but again I have a question, I have to ask them. Would you say that his sensitivities and also interests are an obstacle, a vehicle or both towards his independence?

**Interviewee:** Both, both.

**Interviewer:** Yeah, how so?

**Interviewee:** Just, if he could channel that tunnel vision of, *“I'm doing this right now,”* into the thing that he's getting paid to do, he’d be great.

**Interviewer:** Yeah.

**Interviewee:** We call scout mode, when he's in scout mode, get out of his way. He will floor any adult and impress anyone because of the things he can do. It’s his downtime that seems to get him in trouble because he doesn't know what he should be doing with himself. So usually then he will start doing inappropriate things, like he’ll start watching videos that are too mature for the other kids you’re around, making inappropriate jokes or things like that. So if he can learn to channel that into whatever he's doing to get paid, he will be fine. But that's going to be biggest downfall if he doesn't learn how to control that.

**Interviewer:** Got you. So you said, like that's the biggest challenge for him as he does get independence?

**Interviewee:** Yes, yes. He's got to be able to stop whatever you're doing, the fun stuff, to do the stuff you have to do. That's what my husband was saying to him, he said, “*Look you always want to do the stuff you want to do, never want to do the stuff need to do.”* So.

**Interviewer:** Absolutely. And like learning how to stop so that he can channel this into that kind of the right or socially appropriate direction, quote-unquote. Like what do you think would help your child, like would help him get there?

**Interviewee:** He needs to be out of our house, he needs not to be here. We're too much of a crutch, I think. I think he sees us as a, *“oh they’ll remind me, they'll tell me what I need to do, they'll…”* we've already tried that as soon as he turned 18, I stopped reminding him of his doctor’s appointments. I said okay, “*we need to sit down for the week, put out all your scheduled…the appointments in your schedule so you…”* It did not go well **[chuckles]**. So people call me, *“he didn't show up, he didn't call, he didn't call in.”* Well, *“it's supposed to be on him now, so you know to call him.”* So he is doing that with this therapist, his cognitive behavioural therapist. He's only seeing *[him]* by himself now, so that's a good thing. But at the same time, he's not being told totally…I don't want to say dishonest or lying but he’s just not being totally truthful about his situation right now, like…

**Interviewer:** With the therapist, or with you or himself?

**Interviewee:** With the therapist. He tends…I tell people, *“Stephan sees everything through rose-coloured glasses, everything is great, awesome.”* But if he gets feedback from someone who's dealing with him, like his ABA therapist or me or his dad, it's not so rosy. He did this but he didn't do this, this, and this. Those are the things he's not telling his therapist, because he's just telling him the highlights, you know, *“I did all this.”* What about the stuff you *didn't* do **[48:48 inaudible]**?

**Interviewer:** Got you.

**Interviewee:** You know, but he's new also, so. I think he's only had two visits with him, and he's supposed to have a new psychiatrist, which is going to be a nightmare. As a matter of fact, I think tomorrow I'm supposed to call and try and make an appointment. So everybody's going to be new right about now.

**Interviewer:** New is hard.

**Interviewee:** It changes every six months which is…because he goes to the Children's National, which is a teaching school, so the doctors rotate out every six months.

**Interviewer:** Mhhh, got you.

**Interviewee:** Yeah, so.

**Interviewer:** So, you just talked about **[49:23 crosstalk]** Oh, I'm sorry.

**Interviewee:** No, no. Go ahead.

**Interviewer:** Oh okay, sorry. So, you just talked about how you think him moving out and not being able to rely on you will help him before he was able to move out. So you know, maybe a couple years ago or even a year ago whenever. Did you feel like there were gaps in the services or interventions that you wish he had that would help him now?

**Interviewee:** Oh, yeah. Oh, yeah.

**Interviewer:** Tell me more.

**Interviewee:** I think once these kids turn 16, they should have a home for them to move to so that they can learn these skills independently, because my son spent a night at a homeless shelter. He had a big blow out with his dad in front of the doctor and the doctor said, *“well, I need to remove somebody from the house and I don't think your dad since he pays for everything, he needs to leave, you need to leave.”* So he made a reservation for him to go a teen homeless shelter. In other words, give me a reality check **[chuckles]**.

**Interviewer:** Sure.

**Interviewee:** He flourished there! They fell in love with him.

**Interviewer:** Really? **[laughing]**

**Interviewee:** You know most people would say, “*I never want to go there again*!” He was fine, I mean he complained about the bathroom, he said it was really bad because there’s a bunch of guys being guys. And I’m like, *“that’s one of those things you have to do with if you have a roommate,”* so…but they really need…once they turn 16 they need to push them into experiencing what…if they're planning on going to college, definitely they need to do that, because they need to experience that living alone type thing. Being **[50:45 audio cuts]** alone, you know what I mean?

**Interviewer:** Yeah.

**Interviewee:** I met a lady who went to… I go to pretty much any seminar that goes on around this area that's for people with disabilities and autism, or just anything that I think would help him, I’ve joined a couple of blogs, groups and also joined a group that's about a Rockville. One of the best ones I went to was about college and it was for adults, it was for the parents only, she didn't want any kids in there and we found out why, her son passed away. He was this rock star athlete in high school, straight A's, the whole nine yards, got a scholarship, the whole…somebody you would not think would have a problem at school. He didn't even make it to his freshman year and he killed himself. And she said the biggest problem was that he went from her home where she did everything for him, you know, meals and laundry and she said she wished she'd realized he needed that extra time before he went to college. And how to say, *“I need help”* or *“I’m struggling”* or…

**Interviewer:** Yeah.

**Interviewee:** But because he was this rock star athlete, he thought he was expected to be able to handle anything, and of course it was about a girl, because he was not allowed to have a girlfriend before he went to college. So it was his first…it was just, I'm sitting in there boohoo crying.

**Interviewer:** Yeah.

**Interviewee:** Okay, I heard her and I took…and I told my husband I said, he cannot go until we are sure he can handle it, and he knows who to call if he has a problem or an issue, and then until then we can't let him go to that school. So that was the biggest eye-opener. And then the second one was, we went to the seminar, I took him with me; he didn't act like he got too much out of it, but when police officers were trying to advise them on how to act with police officers like, you know, do not put your hands in your pockets, do not reach for anything, ask before you go to get your phone.

As a matter of fact, he has a bracelet right now that has all his information on it. So, he does not have to go to his phone, he can just say, *“this is my bracelet, my ID, you can call, they’ll give you all my medical information, my parents information, everything.”* That was another one because with my son being as the world is today, being a male, a black male and then an autistic black male, it's just like a triple threat right now. So I was really, really glad we did that, and they were very, very insightful and got down on their level so they can they can understand what they were saying and understand what…from their point of view, not only just from the kids, but from the officers’ too and so it was eye opening. And then the third one was meeting adults on the spectrum, who are somewhat successful. One had like six doctorates and everything, but he lived at home **[54:00]**.

**Interviewer:** Six doctorates?

**Interviewee:** And he said he can't do anything at home. He said he forgets to eat, he forgets to feed the dog, the cat. He pretty much wears almost the same thing every day, because he doesn't like making choices. There was one who was 24, who’s closer to my son's age, he said he almost flunked out his first year mainly because why? He threw everything that he learned, how to deal with things out the window, said he thought that he could recreate the wheel. And then there was a girl and another guy, who I don't remember too much about him, but he didn't talk much, he was very, very quiet, but they had four adults there, which I think it’s something they need to do also.

They need to pair these kids when they're about 14, 15 with an adult on the spectrum. I think it’d be great if they can find them a mentor who's willing to talk to them. I just think I found one for Stephan. And of course, he hasn't made the phone call, but I reached out to someone and he's willing to talk to Stephan and answer any questions he has. He just finished college, has not found a job yet, but he said he's willing to talk to him 101.

**Interviewer:** That’s awesome.

**Interviewee:** And I think that’s another thing, they need a mentor. They need someone who's already been through half the stuff, they've been through. They need to get out of our homes as quickly as possible, sooner than later, especially if they’re planning on going to college. If they’re nonverbal, I think even they can be out of our homes to try to get some independence, because a lot of times we make a lot of decisions for them, and sometimes we forget to ask them what they want, what's best for them. And my son and my husband just got into a fight right now, that's why I know that's one of the things he needs, is to be able to make decisions. But at the same time, know that the world doesn't end if you make a mistake.

That's my other biggest problem with him, sometimes he's an all or nothing kid. He is either…it’s either not going to bother him at all that he made a mistake or he's going to fall apart, like the whole world is going to end right now, so. **[55:59 inaudible]** until we get to that grey area.

**Interviewer:** Yeah.

**Interviewee:** That's what you know, that's why we have all these things in place for him. His previous cognitive therapist has told him, *“dude, your parents go* way *of beyond what most parents.”*

**Interviewer:** Sounds like it.

**Interviewee:** He has everything, I mean thankfully, we have great insurance that mostly pays for everything he's getting.

**Interviewer:** That’s awesome.

**Interviewee:** And they're fighting right now, as a group, there's a bunch of them, parents who are trying to get the insurance company to keep them on our plans longer. **[50:36 inaudible]**. Some of them need to be on there probably until we are not on there anymore. So they're working on that right now. And as…I would say that too, that **[56:49 inaudible]** will keep the insurance as long as possible, because it takes them longer to get these skills under wraps. Medicaid pays for some things, but a lot of times oncethey become…he has Medicaid now, we just got in the last year, but once you get Medicaid, a lot of your opportunities go out the window for you because there’s only so many places that will accept it, then you get restricted. So that's why I think they need stay on private the insurance system as long as possible so that they’ll have more opportunities and options out there. So how many did I give you, three or four? **[57:28 inaudible]** what you needed.

**Interviewer:** You gave me plenty!

**Interviewee:** Did I answer alright?

**Interviewer:** Yeah, you're good. That's the beauty with qualitative data, anything you tell me is great. There's no bad answers here **[laughing]**. So, kind of like taking a step back, and thinking…like having a broad picture. How do Stephan’s sensitivities and interests…ooh, are you frozen? I thought you froze for a second.

**Interviewee:** No **[57:52 inaudible].**

**Interviewee:** How do his sensitivities and interests impact your goals, hopes, and expectations specifically as he navigates adulthood?

**Interviewer:** Wait a minute, maybe I missed something.

**Interviewee:** Yeah, I’ll say it again. Absolutely, it's kind of a doozy of a question. How do your child’s sensitivities and interests, impact your goals, hopes, and expectations for your child as he navigates adulthood?

**Interviewer:** Oh, slows everything down **[chuckles]**.

**Interviewee:** Yeah?

**Interviewer:** It's baby steps. We were just talking about that the other day. It seems like we take five steps forward and then seven steps back. So it's a slow process with him, getting him to be consistent. We tried to make that the word of the of the year – *consistency*.

**Interviewer:** Yeah.

**Interviewee:** Hoping that he'll learn it and grasp it, and realize he needs to do that in order to be successful. I haven't worked since he was born, except part-time here or there. Last job was in Florida, I haven’t worked since we've been here, mainly because it's a full-time job just finding out all the programs he needs to be in, fight with the doctors and the school, it's just full time. I'm hoping to go back to work because I miss it. I worked in the medical field as well, medical billing. What I don't know if my son realizes is that us pushing him is not because we're being mean, but it's because we know the world is going to push him and if we push him first, he'll be ready.

**Interviewer:** Yeah.

**Interviewee:** That's the hard part, trying to get him to understand the world is not a nice place, especially for, like I said, black, male, autistic. You’ve got to be ready for a lot of hard knocks and trying to get ready. Because he says sometimes I'm really mean. I'm like, *“no, I'm trying to get you ready. You claim you want to move, you want to be on your own, well dude, there are something’s you got to master before you can do that. Time management is one of them, not everybody's going to be accepting to the fact that you're late, every day or everything you're assigned you’re turning in late.* *Yes, school allowed it, I hated it, but you know, it's what we had to do at the time. But now it's time to put on your big boy birches, and get with the rest of the program.”* And he said, *“Why are you always forcing me to act like others?”* *“I want you to assimilate pretty much, try to, try to be like others. If you need extensions be able to ask for it, but at the same time it shouldn’t be every time you get an assignment.”* After all, everybody understands life gets in the way. But if they can find someone who's not ASD, who's going to turn in the stuff on time or even someone who is on the spectrum that can turn in stuff on time. They're going to find that person and let you go, and that's what it boils down to. It’s, *“these are the things you need in order to keep a job and be independent for the rest of your life.”* So that would be my biggest takeaway, I wish he would understand that we're not being mean, we're just trying to get him ready for the world, which is *really* mean.

**Interviewer:** **[1:00:59]** Yeah. It sounds like you're trying to give him like all the tools he needs to handle whatever comes at him.

**Interviewee:** Yes.

**Interviewer:** Which may not be an accommodating, nice thing.

**Interviewee:** Yeah, I mean because there’s people out there like I said, who do not believe in the spectrum, they think it's all made up, that you know, it's just an excuse to get a kid another, what is it, another…

**Interviewer:** Accommodation?

**Interviewee:** Star, I guess I don't know. But yeah, that's my biggest thing is for him to realize that we're not doing it to be mean, we're doing it because we want him to be successful, we want him to be happy and we want him to be as independent as possible.

**Interviewer:** Absolutely. So, now we getting into like my last set of questions, we’re on the home stretch.

**Interviewee:** Okay.

**Interviewer:** As a caregiver, as a mom, as a parent of a child with ASD and sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** Success, is it all worth it? All the therapy, all the…oh my gosh. I mean me and my husband, we tried to add up what we think we spent on everything on this kid, oh my gosh. Probably could have bought two houses by now **[chuckles]**, I'm pretty sure. I mean, because it wasn't just his ASD, because he didn't get diagnosed until 17. We always suspected since I think third grade, but in Florida we really didn't have to get that diagnosis in order for him to get the services he needed, so we didn't do it. Because there they don't like labelling kids, but here I had to because the school wasn't going to do anything without it. I think, yeah, that would be my biggest thing, it's just him being independent.

**Interviewer:** Yeah, it makes sense, absolutely.

**Interviewee:** It’s all worth it.

**Interviewer:** I'm sure. I mean it sounds like you’re doing a fabulous job.

**Interviewee:** I'm trying. I mean a lot of people probably say I'm probably doing too much, at least that's what Mr Smith his last IP coordinator said,but I told him I said, “*Well, when you get your kid that's on the spectrum talk to me again.”*

**Interviewer:** **[laughs]** Right!

**Interviewee:** And I left it like that.

**Interviewer:** That’s all you can do sometimes. Has this changed over time for you, like this definition?

**Interviewee:** Oh, yeah, yeah. At one point I thought he’s going to live with me forever. Oh, yeah.

**Interviewer:** So it changed into a positive direction.

**Interviewee:** Yeah, yeah, definitely

**Interviewer:** **[1:03:22]** What made you…what was that shift? How did that happen?

**Interviewee:** I think it was once moved here. And like I said, I saw the things he could do, that we never in a million years would have thought he would have been able to do, even navigating the Metro. That was the first…he nailed that in three months, and I was like, *“hey, wait a minute, he can do that? Maybe let's see what else he can do.”* So we just started, you know, testing him and pushing him and seeing what will happen. So I can see it. It's just that he…like I told my husband, he's going to have to want it more than anything else and then until he gets that drive…because I'm one of those people, don't tell me I can't do something because I'm…oh, my gosh, I’m going to prove you wrong. He doesn't have that, his sister *has* *it* and she told me, she said mom, *“I got that from you and unfortunately and that’s not a good thing.”* **[1:04:10 inaudible]** she said, *“yeah, but I take everybody like I'm fighting now.”* I'm like, *“well, sometimes that's what you got to do, because a lot of people dismiss women, one, and then black women, two.”* I said, *“so you kind of…”* She said, *“oh, is that why you think…”* I said, “yeah.” At least she grew up the 90s, I grew up in the 60s! I said, *“I was born in the 60s,”* I said, *“it was rough!”* And she was like, *“I never thought of it like that.”* *“See how everything you've taken…things that you're able to do now you've taken for granted, we had to fight for,”* I said. So yeah, I have that don't tell me I can't do something because I'm going to do it. I wish he had a little bit of that in him, if he had that I think he would, I probably wouldn’t worry about him.

**Interviewer:** Got you. What do you see happening in his future?

**Interviewee:** He’s the luckiest kid on the planet, my husband says this all the time. It's like, like I told you when he went to the homeless shelter, we were thinking, oh, he's going to come back home saying, “*never send me there again*!” He flourished, they loved him. Matter of fact we just went over there a week ago and dropped off some bed sheets because, I asked, it was like…he went in, I think he went in February? Or was it January? Anyway, he went in one of those months

**Interviewer:** Sure.

**Interviewee:** And because the coronavirus shut down…and they closed the one in DC but they kept the one out in Heights, but we don't have a car. So I told my husband, I have some stuff to drop off, I'll just wait till you guys open this one back up and I'll drop them off. I think they thought yeah, okay, whatever. We showed up with the big box of like seven sets of sheets and socks and underwear, and things I just picked up that was on clearance racks and it's just for whoever needs whatever. She said, *“oh my god, I can't believe you bought, oh my god it’s the kid we fell in love with! Oh my God you should have told me you’re going to bring stuff.”* I said, *“I would have brought them, you know, a while ago,”* but because of COVID and everything. And he wanted to come with me so I had to make sure we were at a point where, okay, it’s okay for you to go and stop by and drop stuff off. We didn’t go inside, we just dropped them at the door. But that was very, I think satisfying for him is that they remembered him, one, two, that, you know…but he's had other things just fall in his lap, like I said the job with that radio station.

**Interviewer:** Yeah.

**Interviewee:** Meeting all these famous people. He even went on air three, four times and he got to go back his third year. I mean, he's just the luckiest kid. So whatever he puts his attention to, I think he'll be fine, it's just, he'll be fine.

**Interviewer:** Sounds like that, sounds like you're prepared him very well. That sounds like your need to do the best you can has also really benefited your son.

**Interviewee:** Yeah. He can do anything he wants. It's just, whoever has to deal with him’s just got to have a little patience to figure out multiple ways to get him to understand things sometimes, like I remember in fourth grade he didn't get fractions. And he's really good with math, which is weird. But all the other math he gets, like he was even taking pre-calculus. I was like,*“oh!”* Whatever. Anyway, but fractions he didn't get, so I had to go get the plastic little pieces of fractions, so he can sit them on top so he can see the difference. Because he said when they're drawn on paper, they’re all the same. So that, sometimes that's what it takes, it's figuring out a different way to get him to understand something. I just don't know if everybody is going to take the time to figure, oh, this person needs this versus this way to work.

**Interviewer:** Got you.

**Interviewee:** So. But as long as I'm around and his sister’s around, we’ll probably figure it out for him. Help him or help him communicate to his boss or whoever he's working for, you know, that he may need a little more time. Matter of fact, that was one of the things I made mandatory when he took on the summer job since then, *“you don't have to talk to your boss the first week, but by that second week, you need to talk to your boss one on one about your diagnosis, and anything else you think you need to tell him.”* Now like the summer job I didn't worry about so much, because they got paid if they showed up. Well, he took on one more job, oh the Halloween store. Now that one he had to go get by himself, it was all part of the ABA thing. We wanted to see what…put him through the whole paces. He had to apply for the job, get the job, interview for the job and so forth. Oh my gosh, they were the most patient people in the world.

**Interviewer:** That’s so great.

**Interviewee:** He showed up on the wrong day. He wouldn’t write his schedule down right. It took him three weeks to fill out the application, it was just **[chuckles]**…but they were patient with him, and when it was all over they were like, *“he was the best employee,”* and as I said, he's the luckiest kid in the world, *“we would love him to work for us again next Halloween.”* He was **[1:09:08 inaudible].** And he worked across the street from across our apartment, I mean he literally had to walk out the door to go to work, and it's like you can't even do that on time! But it was an eye-opening experience for him too because he got to see the things we were talking about that he needs to work on, so.

**Interviewer:** Got you. It sounds like a great experience.

**Interviewee:** I think he'll be fine, we’re going to have some hiccups, but I think he'll work through it.

**Interviewer:** Sounds like he will. So my last like official question.

**Interviewee:** Okay.

**Interviewer:** Did or how did his sensory sensitivities impact your current perspective?

**Interviewee:** My current perspective?

**Interviewer:** Yeah. So you, yeah go ahead.

**Interviewee:** Like for his future?

**Interviewer:** Yeah, because like in a question of like, what does transitioning to adulthood mean to you as a mom of a kid with ASD and sensory sensitivities? Like…and you said success, that's what it means to you, and it’s been a positive change.

**Interviewee:** I would say definitely that the world is a little more open now, than it was 20 years ago. So I think there's a little more, tolerance, acceptance.

**Interviewer:** Yeah.

**Interviewee:** And a little more knowledge about it, because when they first brought out ASD to me when he was in third grade, I didn't know much about it. I’d never heard it before and I worked in occupational therapy, physical therapy and speech for about 10 years before that. I never heard autism brought up before. So it was brand new to me.

**Interviewer:** Yeah.

**Interviewee:** So of course, me being me, I researched everything and anything on it and, I still do that to this day. I'm always looking to see if there's new therapies out there, there’s new information, I join new groups. Right now he's filling out scholarships for college for autistic, or people with disability things. Of course, he missed a lot of deadlines for some others, but we've got a year. But we’re getting him in the process. He just could not find the time during school, he was just overwhelmed with all the things he had to do and I think the biggest thing for him was when they told him it was the last day of school, he just released this big sigh of relief like, *“oh thank you Lord, it’s over,”* and I'm like, *“dude were you that overwhelmed?”* He said, *“mom, it just felt like a big weight was sitting on my chest, and I was having a hard time breathing because it was just so much stuff to get done.”* Because he had a hiccup right after they closed the schools, he slept for three weeks straight. I can actually tell you that, he wouldn't come out his room, he barely was eating. All he wanted to do was sleep, sleep, sleep, sleep. All we can do is just make sure he is safe. And then about the third week he kind of…the therapist started calling more often. ABA was able to get started again because it had stopped because they had to get all the proof for the, what is this?

**Interviewer:** Telehealth?

**Interviewee:** Yeah, and that took a minute.

**Interviewer:** Oh, yeah. Yes it does.

**Interviewee:** It was, yeah. It was rough, because those three weeks, even that next month after those three weeks was rough. Trying to get him out of bed to do his homework, meet before his classes, all of that. I'm hoping this is also training wheels for anything that comes his way. He should be able to handle it too, because I mean everybody had to adjust. We still wear our masks every time we go out, people look at us like we’re weird, but I'm like, *“I'm sorry, his chances are really high, so we can't get the chance of catching it because we're old”* **[chuckles]**. You know, he’s immune compromised. So yes, we have to wear a mask everywhere. I don't make him wear gloves, but we hand sanitize, you know, throughout the whole event while we're out and about, so. I think this also has been a good eye-opening thing too, because one of the things we have problems with him before was invading other people's space. Teaching him not to you know, be too… *“this has taught him…”* we don't have to worry about that.

**Interviewer:** That's good. That's a great silver lining **[laughing]**.

**Interviewee:** We don’t have worry it. I was like, *“oh my gosh, we had to have a pandemic to solve that problem.”*

**Interviewer:** Now we can just work on the volume, because he does do that too. He has it *really* loud sometimes, and it’s just **[1:13:51 crosstalk].**

**Interviewer:** Is that because of the headphones, because he can't hear?

**Interviewee:** It is part of it, but I don't know, he's just really loud, to the point that it’s annoying sometimes. So I've tried…I'm trying to teach him, start out as a whisper and if someone says, *“I can't hear you,”* then that’s a hint to come up a little bit. Start out as a whisper **[whispering],** that’s going to take a little bit long.

**Interviewer:** Yeah.

**Interviewee:** Did I answer your question?

**Interviewer:** Yeah, you did great. Yeah. So those are for my official questions. Do you want to add anything else? Any other thoughts that you have?

**Interviewee:** I would just wish there were more programs for teenagers, for independence living, like putting them somewhere where they're away from their parents because we are a crutch, and I don't care…we could, we can stay all day long that we're not being crutches, but we are a crutch. They know we are a crutch, and they use it **[chuckles]**. They need more programs for social skills for the teenagers. I mean, Stephan is better than some, I know that because he can walk into a room and 90% of people won't know he's ASD until maybe after the third or fourth time they meet him. So he's able to keep it under control the first couple times he meets someone, but they need those and then they need, like I said, some type of mentoring program where they can mentor with someone who's ASD, maybe even in their field or close to their field that they could talk about life challenges.

Because I know the one that's coming up that's going to be the biggest frame. He's had girlfriends in the past, but he says he's lonely, so there needs to be some type of social thing to help them navigate that because, they get…they tend to get in trouble with dates, for one, they don't disclose their diagnosis or they disclose it too soon or they don't know what's appropriate at the time and place at the position, where they are in that relationship. Like if it's brand-new, you don't talk about your sexual preferences **[chuckles],** those types of thing right off the bat. That's later, that's even if you get to that point. It's like, you know, don't bring up your ASD on your first date. When should you? Later, like if you make it to your fifth and sixth date you may want to mention it. Probably she’s already figured it out you’re a little different, but you want to make sure that, you know, going forward that you didn't hide it, because if she finds out later, it can cause problems and probably ruin your relationship because it's something you didn't disclose.

**Interviewer:** Yeah.

**Interviewee:** So, it's just like if somebody has bipolar or something, I'm sorry, that's something you need to tell someone, so that they'll know if you’re freaking out and having an episode.

**Interviewer:** I’m bipolar and therefore you may want to relocate until I calm down, my sister's bipolar that's why I can say that. She doesn't communicate real well with her situation either, but definitely those things. They need those things in place for them to be independent and successful.

**Interviewer:** Absolutely.

**Interviewee:** I won't say that they need to be in their own space per se, but they just built one in Rockville. He's on the waiting list, but I don't know if that's a good idea either. I think they need to be in apartment buildings with other people so that they can learn to deal with other people. If they're around their own kind or people with disabilities, they to tend to not learn how to deal with normal people, so to speak, you know. And I think they need they need a mixture of both.

**Interviewer:** Mixing of both learning experiences are valuable.

**Interviewee:** Yeah. Yeah, maybe it's in the beginning they can be in the special place, but then they need to move gravitate from that once they master some things, to a physical facility that allows mixed housing.

**Interviewer:** **[1:17:54]** For sure. That's a great thought. Is there anything else that you'd like to add about this topic maybe in relation to sensitivities or not?

**Interviewee:** No, we all have quirks, like I didn't realize that I twirl my hair a lot until it was brought up to me and I was like, *“I do?”* They said, *“you do it a lot.”* I was like, oh. So we all have quirks. I'm a former nail-biter, during the COVID, I started my biting my nails again. So it’s just something that as long as he figures out how to work around it, like I said, when to do it, when is it appropriate to put his headphones on, and when to disclose his diagnosis to people, and who needs to know. Like for instance, I've told his co-workers don't need to know, your boss needs to know. And then if, you know, there's an incident or a problem that you may need to tell the person so that they are not offended. But until that point, you don't have to tell them. That would probably my two. Just, you know.

**Interviewer:** Oh, that’s perfect, thank you. Yeah, so that's like it for my official questions. Thank you so much for your time and for your thoughts and working through your headache also.

**Interviewee:** Oh, no problem. My headache is lifting up.

**Interviewer:** Great! I hope I helped. But no, we so appreciate the time and your insight and just allowing us to learn from you, it's so valuable and we so appreciate.

**Interviewee:** No problem.

**Interviewer:** Yeah do know anyone else who might want to participate by any chance?

**Interviewee:** Oh, I wish I did.

**Interviewer:** If you don't, that's okay.

**Interviewee:** Yeah, if I think of anyone, I’ll send you their contact **[1:19:25]**

**Interviewer:** Yeah, I’d love that. We’d love to learn from more people.

**Interviewee:** Someone asked me why do I participate in these things, I said, *“well, one they don't have many blacks participate because one, we don't look out for these things.”* But I used to work at this school when I went to college, and one of their little departments was for research and I worked there as the receptionist in between classes of course, but that was one of the things the head research person told me. She said, *“if you can talk more black people into participating.”* I said, *“why?”* She's like, *“they won't participate, unless we, you know, go out there and actively seeking, but most people don't want to participate and in order for us to have more services for you guys, we need you to participate.”* So that's why I seek out these things sometimes.

**Interviewer:** Well, we appreciate it so much. We appreciate learning from you, we appreciate your participation, thank you.

**Interviewee:** Thank you.

**Interviewer:** Yeah, of course, my pleasure. So, this is it from me. I have placed an order for the gift card as a thank you for you. As soon as the order comes in, I will send it to you. It's an electronic gift card.

**Interviewee:** Okay.

**Interviewer:** So expect that coming, hopefully soon. I just talked to the person who supposed to order them and he said he's checking on it. So it'll be in your inbox soon.

**Interviewee:** Okay, thank you.

**Interviewer:** Yeah, and if you have any questions for me and you need anything else from me in the future, please, please reach out.

**Interviewee:** All right, thank you so much. And you are in Boston right?

**Interviewer:** Yeah, I work with Helen.

**Interviewee:** Okay.

**Interviewer:** Yeah.

**Interviewee:** All righty

**Interviewer:** Have a lovely day. Bye!

**Interviewee:** You too, bye.

**[End of Transcript]**