**[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 sensitivities and sensory interests.

**Interviewee:** OK.

**Interviewer:** And we’ll be doing something called a ‘semi structured interview,’ which means I have my planned questions here on my script, but I’ll be adapting our conversation and the questions to fit what we’re talking about and to actually make it make sense for us.

**Interviewee:** OK.

**Interviewer:** Do you have any questions?

**Interviewee:** None.

**Interviewer:** OK, cool. If there are any questions that you don’t want to answer, that make you uncomfortable, you don’t have to. And also, if you think of something later on, that you didn’t mention earlier, feel free to jump in. This is going to be, like, a very fluid conversation. So don’t worry about that.

**Interviewee:** OK.

**Interviewer:** Awesome. Ready?

**Interviewee:** Yes.

**Interviewer:** OK, cool. So could you please start off by telling me about your child’s sensory sensitivities and sensory interests.

**Interviewee:** I don’t really know much about his … because **[01:00]** he was, I would say, recently diagnosed when he was 14. He’s 22 now, so a lot of the stuff I had to learn on my own, but I do know, he doesn’t like bright lights. He, he sits in the dark in his room. He reads in the dark. So I think he has an issue with bright lights. I do know he has issues with clothing. He doesn’t like the way certain clothing feels: the textures, how it lays on him. And I think the tag is an issue, but I think that’s just standard for kids across the board. But I do know that he’ll wear his clothes backwards so the tag doesn’t rub up against him, versus just ripping the tag off. He just wears his clothes backwards.

**Interviewer:** OK.

**Interviewee:** Then he also doesn’t realize that he’s wearing his clothes backwards sometimes, until somebody points it out. That could be because he’s getting dressed in the dark. Who knows? Let’s see … what else? I’m trying to think of anything that would stand out to me, which I really ... other than those ... those are the main ones that stand out.

**Interviewer:** So, for the light sensitivity, does … You talked about, like, being in the dark in his home, in his room: what about outside do … like, does, like, sunlight bother him?

**Interviewee:** He doesn’t go outside.

**Interviewer:** OK.

**Interviewee:** He stays … he’s mostly in the house. Only time he goes outside is if he needs to go to the store to buy something, or if he’s going to work. But he doesn’t go outside at all. As a kid, I never really heard him complain about the sunlight. He, he would go outside, but it wasn’t often.

**Interviewer:** OK. When he does, like, have to go outside, will he wear sunglasses or anything like that?

**Interviewee:** No, he doesn’t have any.

**Interviewer:** Got you. And then for clothes, do you, like … are there certain clothes that he dislikes more than others, like scratchy things … maybe your extra tight things?

**Interviewee:** His clothes has to be loose. He wears baggy jeans. He doesn’t like tight clothing. Let’s see. All his clothing ... I’m trying to think because most of his clothing does not have buttons on them. And I think that’s because he, he would have issues when he was younger with buttoning up. So I just made sure I didn’t get any clothes with buttons. But yeah, most of his shirts is just cotton T-shirts and they’re, and they’re big and loose. So he doesn’t like anything form fitting or tight. Or the **[inaudible at 03:45]** size. So all his clothes are technically baggy.

**Interviewer:** Got you. What about, like, when it’s cold out? Is he OK wearing, like, a jacket—because those can be a little bit more restrictive?

**Interviewee:** His jackets are big and bulky, too. So …

**Interviewer:** Got it.

**Interviewee:** So, **[04:00]** but I think when it’s, when it’s … depending on the temperature, I do know that it’ll be a slight chill and he’ll wear a full-on winter coat, as if it’s freezing cold outside and then he seems to be fine with that. Even though I tell him, “*Hey, you can just wear a windbreaker or a jacket*,” no, he, he gets the full-on big winter coat.

**Interviewer:** Is he cold easily? Or …

**Interviewee:** He says he’s not. But I don’t think he’s the type to complain. So I don’t … so I wouldn’t even know, if he was too cold, if he, if he would tell me or not.

**Interviewer:** Got you. Is he, is he sensitive to, like, any particular sounds at all, like, volume?

**Interviewee:** I’m trying to think … because he doesn’t listen to loud music and he’s never complained about anything too loud. So I don’t know. He’s gone to movies. I would say in, in a crowd format, when there’s a lot of people, he doesn’t like that. So I don’t know if it’s a crowd thing or if it could be noise. But I do know he does not like being in large crowds.

**Interviewer:** Do things like sirens or, like, alarms bother him, like, more than the average person?

**Interviewee:** Not sure because he’s never had an alarm.

**Interviewer:** Even at school? **[crosstalk at 05:32]**

**Interviewee:** Huh?

**Interviewer:** Like, even at school, he never had like, an alarm, like, a ...?

**Interviewee:** Even at school, he never had an alarm because I was the one that would wake them up.

**Interviewer:** OK.

**Interviewee:** I was hitting **[inaudible at 5:41]** the alarm.

**Interviewer:** Fair, fair.

**Interviewee:** He’s never had an alarm. And then I do know, because I complain about it a lot with him … his phone … he always has his ringer on silent. So when I attempt to call him, he says, “*Oh, I didn’t get your call*. *I didn’t know you called.*” I was like, “*Well, did your phone ring?*” And he says, “*No, I have it on silent*.” So maybe he does not like the sound of the ringing of a telephone. So I do know, it’s all on silent.

**Interviewer:** Got you. And then what about smells? Is he sensitive to particular smells?

**Interviewee:** No, he’s never complained about … I don’t even think he can smell because there’s beene times that I tell him that he smells and he’s doesn’t … he, he tells me he doesn’t notice. So yeah, he’s never complained about any particular smells.

**Interviewer:** Does he … is he not able to smell in other contexts besides his own hygiene, like, if you’re cooking or someone else is cooking?

**Interviewee:** I don’t know. He’s, he’s a quiet person. He doesn’t talk a lot.

**Interviewer:** Yeah.

**Interviewee:** He doesn’t express himself. So honestly, I wouldn’t know if he had **[07:00]** any issues with the cooking. Most people, if I’m cooking something, they’ll come downstairs and say “*Hey, what’re you cooking? I smell something*.” He doesn’t.

**Interviewer:** OK.

**Interviewee:** He doesn’t even come down and say anything. But then he’ll come later, after everybody ate and says “*What’s for dinner?*” So I don’t know if he can smell or not to be honest.

**Interviewer:** No, fair, absolutely fair. And then, what about taste, like, does he have a particular, like, limited palate in any way … is ...?

**Interviewee:** Very limited. He only eats spaghetti and hamburgers and ribs. That’s it. He won’t eat vegetables. He won’t eat fruit. But mainly, I would say, 98% of his diet consists of spaghetti.

**Interviewer:** Is it, like, plain noodles or, like, noodles and tomato sauce?

**Interviewee:** Noodles and tomato sauce.

**Interviewer:** Do you know if it’s, like, a flavor thing, like, a familiarity thing?

**Interviewee:** Honestly, I don’t know. I was assuming it was just because it was easy to make and cook. But I don’t, I don’t know if it … I’ve never really asked him why spaghetti is his, his …

**Interviewer:** Yeah.

**Interviewee:** … is his chosen food.

**Interviewer:** Fair. So how have these things changed over time for him? Or have they not changed over time?

**Interviewee:** I’m trying to think … because everything is different because how he was … from when he was a child to now. Things have changed. Just that because I didn’t know he was autistic at the time. They just said it was just ADHD. So I probably didn’t pay attention to a lot of things that I should have. Just assuming that I trust the doctors to say he was just attention deficit.

**Interviewer:** Yeah.

**Interviewee:** But, I would say, I would say they’ve changed over the years. He’s become more reclusive, I can tell you that. As a kid, he was more active. I think just because he was forced to be more active, you know, going to school and, you know, having to go to daycare or something like that. He was forced into that. But now that he’s, he’s an adult … but, as a teenage, he started just not wanting to be involved with other people and around other people, so I think … to the point where he just stays in his room most of the time.

**Interviewer:** Yeah. Did his, like, sensitivity to, like, lights or his preference for, like, loose clothes … did that change as he aged as well?

**Interviewee:** I would say yes, because now he gets to pick and choose what he wants to wear, versus me going out and buying stuff for him as a kid. Because when he was a kid, I did not buy baggy clothes for **[10:00]** him, he had clothes that fit, and so … But he did complain that he didn’t like some of the clothes that I bought, or some of the stuff didn’t feel right against his skin. He wasn’t particularly descriptive on why they weren’t, he just said he just didn’t like it or it just didn’t feel right. So then I would just get something a little bit more simple and cotton seems to be the best choice versus anything else. I guess because it’s breathable, I don’t know. But he just likes cotton and I get that **[kink? at 10:36]** anything else. So other than that … and then, as far as sensitivity to light, that has completely changed because now he’s in almost complete darkness in his room, other than the natural sunlight that comes in during the day. But most of time, he’s in darkness, reads in the dark and I’ve told him plenty of times, “*Get a light*.” His eyesight is pretty bad. So … so, I don’t think he likes light and I think that’s changed over the years. And then, as a child, he always was particular or picky about the food. But he would, he would eat the food that we make—because spaghetti is not my favorite, so I definitely was not making spaghetti. But his dad would make spaghetti. I wouldn’t make spaghetti. But now that seems like that’s the only thing he ever eats.

**Interviewer:** Got you.

**Interviewee:** So **[inaudible at 11:37]** I do say he was very picky, because he doesn’t like mashed potatoes and he’s very vocal about that. But he can’t explain why he don’t like mashed potatoes. Definitely don’t like vegetables. He won’t eat fruit. So …

**Interviewer:** And was that always the case, like, he always wouldn’t eat fruits or veg?

**Interviewee:** Well, we would force him, we would say, “*You have to eat your food. We make it, it’s on your plate, you got to eat it*.” It would take him a long time. But he would eventually eat it and then be, you know, dismissed from the table. But, other than that, he’s always complained about eating those items.

**Interviewer:** Got you.

**Interviewee: [inaudible at 12:18]** he’s older, he gets to pick and choose where he wants to eat. So he does not eat vegetables, even though I tell him he needs vegetables.

**Interviewer:** Got you.

**Interviewee:** So, he has the option … instead of doing vegetables, he’s now bought vitamins, vitamins instead of vegetables.

**Interviewer:** At least he’s getting his vitamins, you know? That works to a degree, right?

**Interviewee:** It does, but I would prefer him to eat vegetables. But …

**Interviewer:** You said his sensitive, sensitivity to light has changed. When he was a kid, was he not always in the dark or just not allowed to always be in the dark?

**Interviewee:** Not allowed **[13:00]** to be in the dark. Because, for me, I like light.

**Interviewer:** Yeah.

**Interviewee:** So, in their room, the room was light colors … because his room right now is a dark red. Then he always keeps his blinds closed and, growing up, blinds had to be open, it was every morning, “*Open your blinds*” type of thing. That’s what I would do: go around the house every morning and open up blinds. So they had no choice.

**Interviewer:** Do you think if he had a choice when he was younger, he would have chose to close the blinds and make his room a bit darker, as it is now?

**Interviewee:** Yes. Because when he got the option when he got older and got his own room, he never opened the blinds. So when he became a teenager, like around 12, 13, that’s when I stopped just going in the room and changing stuff. His room was kind of dark.

**Interviewer:** Got you. Yeah, that makes sense. Do you think any of these changes you just articulated are related to any independence that he’s gained over time?

**Interviewee:** I would say yes, being that I am less involved in his daily activities, so he gets to be more independent. Yes, I would say a lot of things have changed from versus when I was more active in his daily life.

**Interviewer:** Do you think he likes that he’s able to make these choices for himself now?

**Interviewee:** Yes.

**Interviewer:** Got you. OK. Next question. So how does he manage or handle his sensitivities in his daily life?

**Interviewee:** I would say, anything that he doesn’t like, he avoids. And he sticks to what he likes.

**Interviewer:** Are there any contexts in which he will force himself to not avoid these things?

**Interviewee:** When he has no choice, I would say more in a public and social environment, when he has limited options, then he will just go with the flow.

**Interviewer:** OK. That makes sense. And has he ever received particular, like, therapies or interventions to help him with his sensitivities?

**Interviewee:** No.

**Interviewer:** Got you. And if he is in a situation where he’s not able to avoid, say, the bright lights or, like, he isn’t able to have loose clothes or he has to eat things other than, like, spaghetti, does that cause or increase anxiety for him?

**Interviewee:** No, I don’t think so. I think he just manages it and understands that, you know, sometimes you have to do things that are out of your comfort level, for the time being, so I don’t think … he’s never complained or expressed discomfort if he’s out in public. **[16:00]** So I think he’s just more of “*I’ll follow the crowd while I’m here, but then*,” you know, “*when I’m alone, then I can do whatever I want*.”

**Interviewer:** Got you. And has that always been the case? Has it ever caused anxiety for him when he was younger?

**Interviewee:** I don’t think so. Yeah, he’s, he’s, he’s not a child who’s vocal in his discomfort. Like, he’ll tell you if he feels comfortable with you, but I don’t think he’s ever expressed himself in that manner of saying whether he, he likes something or not unless, well, if it was the food, he’d definitely tell you and as far as clothes he’d definitely tell you, but as far as, like, lights and stuff, he’s never mentioned anything like that to me. And when we’re out in public, he’s never said anything that, you know, he didn’t like or was uncomfortable with.

**Interviewer:** So you just, like ... he’ll, he’ll, like, tell you if he doesn’t like the food or the clothes. Is that only in a home setting or is it also, like, in a more public social setting?

**Interviewee:** I would say that’s more in a home setting. And then on top of that, with the home setting, I have to ask him a specific question to get an answer. If I don’t specifically ask him, he won’t tell me.

**Interviewer:** So he’ll just, like, kind of sit in his discomfort if you don’t ask him?

**Interviewee:** Yeah, yeah.

**Interviewer:** Has that always been the case?

**Interviewee:** I would say yes. If you don’t specifically ask him a question, he won’t just come out and tell you.

**Interviewer:** Got you. And so, what are your, like, hopes or goals for your son in terms of his sensitivities, like, moving forward in the future?

**Interviewee:** Hopefully, he eats more different variety of things. I’m kind of pushing for that. But I would prefer him to be more vocal on things because, if he wants to be independent, as he’s trying to be, and live on his own, if I can’t be around, he needs to be able to vocalize his discomfort to other people, which he has an issue with doing. So, hopefully, he’s figured out some way on how to do that.

**Interviewer:** Yeah. Have you been trying to … how have you been trying to help him learn how to vocalize more?

**Interviewee:** I do, I do I always tell him, “*You have to tell me things.* *You tell people if you don’t like something, you just can’t sit there*.” Especially at his job … he comes home and complains to me. And I’m like, “*Well did you tell your manager? Did you tell*,” you know, “*the supervisor what was going on?*” And then he’s like, “*Well, they won’t understand me*.” And I’m like, “*You have to tell them, you can’t just sit there and not tell them*.” But I end up, most of the time, just going down and having a discussion with the manager, supervisor on his behalf.

**Interviewer:** Got you. So, actually, it’s a good segue to my next chunk of questions. So **[19:00]**, as your son has grown up and aged, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** As far as the community goes, I think most people don’t know autism that well. So he’s had difficulties as far as community-based things, especially in school and dealing with other people, so I’d say that is a major issue at this point is surrounding people because, as far as family wise, since we know a little bit about autism, we can tailor a lot to him. But outside of that, it’s a little different.

**Interviewer:** Yeah. Can you give some examples about school, how they don’t seem to understand him very well?

**Interviewee:** Well, he has a speech issue, so pronouncing words and certain letters are very difficult, so a lot of people claim they don’t understand him. And so they … they call him names and all kinds of stuff, pick on him, bully him, you know …

**Interviewer:** I’m sorry.

**Interviewee:** … because of his speech. Now, he’s used to it now. But he, he had a, he had a lot of issues with that. And then … what other issues we had? Oh, people says he’s weird because he’ll stare off in space sometimes, or he’ll have conversations where it’s … he doesn’t pick up on the cues of other people and he doesn’t realize if they’re done having a conversation with him. Or if they ask him a question, he goes off … completely off topic, and they’re trying to get him back on, he doesn’t catch the cues for that. So I think a lot of that affects his social activities out in the community.

**Interviewer:** You mentioned how a lot of, like, his sensitivities are … you’ve talked about them and tried to make, to make the environment the way he likes it at home. So it doesn’t really seem like it affects him in a community setting—is that, is that accurate?

**Interviewee:** I would say … I would guess … I guess so.

**Interviewer:** Yeah. Do you, like … does his school understand his ... or did his school understand his preference for, like, dark lights or, like, things like that?

**Interviewee:** I don’t think they really cared because he’s only one student out of thousands.

**Interviewer:** Yeah.

**Interviewee:** But I don’t, I don’t think he’s ever maybe had discussion with that, because in classrooms, they have the lights set at a certain level anyways.

**Interviewer:** Yeah.

**Interviewee:** Unless they’re doing something where the lights have to be dimmed. But I don’t think they would take his sensitivities in ... I don’t even think they asked him and matter of fact they never had a questionnaire that asked any of that in any discussion that we have with **[22:00]** IEPs or any of his teachers, none of those sensitivity questions ever came up.

**Interviewer:** Really? Sorry. And it’s so important for them to know that.

**Interviewee:** Yeah, I mean, I guess we … from most autistic parents that I’ve talked to, most of them take their kids out of public school and put them in private institutions. I couldn’t afford it, it was way too expensive.

**Interviewer:** Yeah.

**Interviewee:** So he stayed in a public school and we just had to deal with what … the limitations that the public school offered.

**Interviewer:** Yeah, that makes sense. Was the community more or less accepting of him and his sensitivities when he was younger?

**Interviewee:** I would say less.

**Interviewer:** Yeah.

**Interviewee:** Yeah, less, I think because more of … they didn’t understand and they didn’t … But at the time, when he was under the age of 14, we didn’t know he was, he was autistic. So, a lot … I think, with the misdiagnosis for most of his life, they treated him based on attention deficit versus autistic. So I think they may have not considered that a lot of things that he may have felt discomfort about … they probably didn’t understand that, hey, this is part of being on the spectrum versus, you know, he’s just being hyper and, you know, unfocused or something like that and we just need to calm him down or something. So I think it may be the fact that there was a misdiagnosis. And, you know, nobody fully understand the condition that he was dealing with.

**Interviewer:** Absolutely. So you talked about, like, school and briefly talked about his work. Like, which parts of the community have been, like, more or less accepting of him and, like, his, his diagnosis and his sensory sensitivities?

**Interviewee:** The older he got, I would say, **[24:00]** the less issues he had. Younger, like … elementary and middle school kids are very cruel. So he dealt with a lot of that bullying … got to high school, not as much because he’d tend to stick with his own. He didn’t, he didn’t have any friends. So he pretty much went to school, came home, didn’t maintain any relationships with anybody from the high school. Getting into the workforce has been challenging. I think, as adults … he’s had more issues with adults than he had with teenagers.

**Interviewer:** In what way?

**Interviewee:** He works at McDonald’s as a, as a cashier. So he has described people yelling at him; he’s been physically assaulted at work. Yeah.

**Interviewer:** Woah.

**Interviewee:** Yeah.

**Interviewer:** Like, by employees or by customers?

**Interviewee:** Customers, customers. They’ve called him stupid and dumb. He’s moving too slow. Even though he has an autism … little placard on his thing, they don’t … I don’t know if they understand that he is saying he is autistic or they just … they don’t care. But he’s had incidences where he said there are customers who would get in his face. A couple of them spit on him, they snatched his glasses off and threw them, trying to smash them. Yeah. So he’s experienced that from adults.

**Interviewer:** That’s awful. I’m so sorry. **[crosstalk at 25:40]** That is shocking.

**Interviewee:** That is shocking. **[crosstalk at 25:43]** I could understand it from kids, maybe, but adults … and that’s one of the major issues we have at his job. So …

**Interviewer:** Yeah. I’m so sorry to hear that. That’s awful.

**Interviewee:** It is. But I’ve heard that a lot from people who have … who are disabled adults, that they experience, you know, discrimination out there in the world, and I think it’s … people don’t take in consideration, you know, disabled adults and their issues and their limitations.

**Interviewer:** Absolutely. Earlier, you mentioned that you’ll go in to his work on his behalf and talk to his managers. Are his managers understanding of, like, him as an individual?

**Interviewee:** No. And I think that’s more of a cultural barrier issue versus any medical issues. His managers are … they’re naturalized US citizens, but they’re from cultures that don’t really consider disabilities. So … and I don’t even know if they have a full grasp of autism …

**Interviewer:** Got you.

**Interviewee:** … in their community, so I think it’s more of a cultural issue versus a disability issue.

**Interviewer: [27:00]** No, that makes sense. Thank you for sharing all that. Thinking to the future, what are your hopes or worries for your son in relation to how his community will react to him, in particular to his sensory sensitivities?

**Interviewee:** I don’t have too much faith in the community. I just wish maybe … therefore just needs to be more education out there on the topic and probably bring autism to the forefront. I feel that only people who know someone who’s autistic understands the issues that they face. But people who have no clue, who’ve maybe only heard of the term, but never known someone who’s dealing with it … So, I don’t have too much faith in the community. I’m scared for my son, actually.

**Interviewer:** That’s right.

**Interviewee:** I don’t want him to be as independent as he wants to be, living on his own type of stuff. I would prefer him to be close to home. And I always tell him, if he has issues at work—it’s probably not a good thing, but I always tell him, if he has issues out there to call me first and, of course, I’ll be there take … to care of anything. So I think he relies a lot on me in that aspect. And maybe that’s not trying to, you know, make him as independent as he wants to be. But I just don’t have faith in the community. And I just think it’s because of the lack of knowledge about, you know, his issues and his disability.

**Interviewer:** Yeah, absolutely. You want to protect him.

**Interviewee:** Yeah.

**Interviewer:** Yeah. Thank you. Moving on to our next chunk of questions: in this, like, transition to adulthood, where do you see your son?

**Interviewee:** In regards to what? Why, is there a level?

**Interviewer:** Like, in terms of what ... his independent skills, what does he do on his own? What does he need assistance for? In his ability to become independent, how far do you think he’s come? How far do you think he needs to go?

**Interviewee:** Let’s see. I mean he, he’s, he’s fairly independent of me. He can dress himself. He bathes himself. Only with some prompting, it’s like, I’ve got to remind him because he won’t …

**Interviewer:** Yeah.

**Interviewee:** … every day. But if he’s hungry, he’ll go find … he’ll go fix himself something to eat. He knows how to cook. I taught him how to manage his own money. So, since he gets paid, he understands the value of not overspending, based on his income. He has a credit card, so he manages that. He got excellent credit.

**Interviewer:** That’s great.

**Interviewee:** So he, he spends money on his credit **[30:00]** card and then, soon as he gets paid, he pays off his credit card completely. Every paycheck goes straight to his credit card. So in a sense, he can live on his own, independent and he’s an adult in every way. It’s just, I think more of … the vocalization is the biggest issue. But as far as cooking, cleaning and taking care of himself, I mean, he is pretty good on that, aside for a couple of prompts to remind him that he needs to, you know, clean and he needs to bathe more often. Other than that … he washes his own clothes. He’ll go to the store if he needs anything. Other than that, I mean, only thing is he, he doesn’t drive, so he’s limited in the area he can travel in. So usually I’m picking up and dropping him off places and, if not, he has, he does have the ability to use Uber, which he has in the past. So he’ll do that. He maintains a schedule. So I would say he’s, he’s on par with being an adult, just a couple of small things …

**Interviewer:** Yeah, totally.

**Interviewee:** The prompts that he needs to remind him to do things, you know, more frequently than he normally does.

**Interviewer:** Yeah. You mentioned that in school he doesn’t … he didn’t have friends. Now that he’s out of his school, does he have …?

**Interviewee:** None.

**Interviewer:** No, no friends?

**Interviewee:** Actually, and that’s … actually he did vocalize to me a couple of weeks ago …

**Interviewer:** Good.

**Interviewee:** … that he said he felt a little depressed that he doesn’t have friends.

**Interviewer:** Oh.

**Interviewee:** I know he’s tried in the past to make friends, but I think he eventually gave up when he realized that that wasn’t going to happen. So, as of right now, he doesn’t have any friends. Well, he considers some people on the internet his friends, but I don’t consider them his friends because you never meet them. They just, you know, play games and they talk trash to each other, that’s it. **[inaudible at 32:09]** He’s never met them. He’s never hung out with them. So … But yeah, he has mentioned that he does get a little lonely sometimes, because he doesn’t get to do social activities like normal people do.

**Interviewer:** Yeah. You talked about him managing his own money and paying off his credit card: does he manage his other bills, like, maybe, like, a phone bill or something?

**Interviewee:** He doesn’t have a phone bill. I pay that because it’s on my plan. So the only bill he has is his credit card. And he, he has an app, he goes in, he pays it without me prompting him to pay it. So other than that, I mean, that’s the only bill that he has.

**Interviewer:** That’s an important bill to pay off. So that’s good.

**Interviewee:** Yeah.

**Interviewer:** And you talked about that he wants to be independent. Does he, like … what does that look **[33:00]** like for him when he says that?

**Interviewee:** He definitely told me he wants his own apartment. So that is his goal, to eventually one day get his own apartment, but I don’t think he … I don’t think he visualized beyond, you know, what that would look like. He just said, “*I want to get my own apartment, have my own place*,” but I don’t think he figured out that, you know … what does that entail, like, extra bills you have to pay—because I did tell him. I was like, “*You know, if you get that then you have to pay rent. And then there’s, you know, utilities, you got to pay*,” I said, “*Then, on top of that, you got to get furniture in that, you know, apartment, and then you got to make sure that, you know, if it’s on a bus line, you can get to work or if it’s not, you know, how far away it’s going to take*,”type of thing. So, I don’t think he took in consideration all the other aspects of, you know, being in an apartment by yourself, but he did say that he wants to live on his own.

**Interviewer:** Got you. So you mentioned he doesn’t drive but he does do Uber. Does he do, like, the bus and other public transport?

**Interviewee:** No, because in our area, we don’t have bus or any public … **[inaudible at 34:07]**

**Interviewer: [inaudible at 34:07]** what that would mean ...

**Interviewee:** So Uber is the only option he has.

**Interviewer:** Got you. What do you think, will … Sorry, can I rephrase that?

**Interviewee:** OK.

**Interviewer:** Do you think he’ll be able to achieve more independence in the future?

**Interviewee:** Yes, I definitely do think he can and will. It’s going to take a lot of work. And I’m actually currently looking at programs for independent living skills for people with autism and programs and groups to put him in, so he can get that. But I do think, you know, in the future, he can, you know, live on his own.

**Interviewer:** That’s great. What do you think will help him move into adulthood specifically?

**Interviewee:** Guidance, I think, and maybe mentorship. So I do know that I think those are the most important to help him to understand how to, you know, live on his own, and what it takes. He’s been in a, in a program that taught him a little bit about it, but he really hasn’t been … had a chance to implement any of those things. So I think he has the knowledge a little bit and that’s probably the reason why he’s wanting to live on his own, because he was in a program that taught him stuff like that. But I, I think a lot of the issue would be the … I think more of a social isolation, which will be a problem. Living on his own, he would really be isolated … to really being by himself. Here at the house, he does have his own room, in a completely different section of the house where hardly nobody goes to. So technically, that’s sort of living independently **[36:00]** it’s just under the roof of your mother. So he maintains a lot of that, but I think being in his own apartment, he’ll probably be more isolated because then he wouldn’t have a desire to actually leave and go anywhere, especially if he doesn’t have any friends. He would have to totally rely on family members, if they wanted to come see him or pick him up or take him somewhere.

**Interviewer:** Yeah. You talked about, like, looking into programs for him. Do you think there are particular, like, services or interventions that could help him, you know, gain this practice, experience, you know, this guidance, this mentorship you just talked about?

**Interviewee:** There are programs. They’re very limited. And the amount of people that needs help … I know it’s difficult to get into and there’s waiting lists. So I would say there’s a slim chance that he’s going to get to benefit from any of these programs. Because there’s not, there’s not a substantial amount of help for adults with autism. Children, there’s a lot because the state is required … But once they become an adult, it’s, it’s a lot more difficult. And those … these programs actually are kind of expensive. So I would say it’s a slim chance, and, more likely, he’s just going to have to learn by trial and error and probably help with family.

**Interviewer:** That makes sense. Now putting these two things together, like, his sensory sensitivities and this transition to adulthood, how do they intersect for your son?

**Interviewee:** I would say, I mean, most of it is part of his daily life. I mean, the issues with the sunlight, being in the darkness, all that is relative to his life and his, and his choices of how he wants to be independent. So, I think **[inaudible at 38:06]** … I don’t think they would intersect. It’s just, it’s a concurrent **[inaudible at 38:09]** because of who he is and what he has dealt with … and he just has to figure out how to, you know, work around it for his independent life. I think it’s, it’s just going to be … not necessarily intersect … it’s just going to have to be something that’s intertwined with what he wants to do.

**Interviewer:** Absolutely. You’ve kind of answered this, but do you view his sensitivities as an obstacle, a vehicle, both or neither, towards his independence?

**Interviewee:** I would say definitely not a vehicle, **[39:00]** but I wouldn’t call it an obstacle either. That’s difficult. Because what would the other option be? Because, like, it’s not really an obstacle to being independent because he’s already sort of independent, self-sufficient. So I don’t think any of these issues hinder him in that aspect. It’s just, I guess he just alters his life to include those things and make it work.

**Interviewer:** Yeah, absolutely. Thank you. And so, what do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities and sensory preferences?

**Interviewee:** Repeat the question.

**Interviewer:** Totally. What do you anticipate as being challenging for him as he gains more independence in regards to his sensory preferences?

**Interviewee:** What will be more challenging? OK, so the challenge would be … That’s a good question. Challenge … I mean, many things are a challenge to him. I guess it will be more how he would try to overcome those challenges. But I think he’s already made it work. I do know, if he goes on his own and goes in darkness, that’s going to, that would be a challenge. But I don’t think he’s going to paint rooms dark to make the apartment dark. He will just keep the blinds closed to avoid the lighting. And then, I don’t know, I honestly don’t know, I think the more he became independent, I think, the more he figures out ways how to deal and integrate it into his daily life. So I don’t know what the challenge will be specifically for him and, you know, and adding more to his independence.

**Interviewer:** I mean, it kind of sounds like he has a handle on them. Like, it seems like he knows how to adapt to this environment to fit his needs.

**Interviewee:** Yeah.

**Interviewer:** Which is great.

**Interviewee:** Yeah, it is.

**Interviewer:** That’s what we’re all trying to do, right?

**Interviewee:** Yeah.

**Interviewer:** Do you think there are, like … what do you think will help him in this intersection, or, I guess, in this concurrent system of his sensory sensitivities and his transition to adulthood?

**Interviewee:** I don’t know. I, I can’t say what … I’m not him and I don’t, I don’t have his, his issues. So I don’t, I don’t know what the answer would be for that. That I guess would be more of something **[42:00]** for him to answer. For me, I can only speculate. But honestly wouldn’t know.

**Interviewer:** Yeah, sure. You may not know this, either. But do you think there are particular interventions or services that you think might help him from your perspective, looking at him as your child?

**Interviewee:** As I said in the other question, it’s very limited. And then there’s waiting lists, because there’s so many other disabled children … disabled adults that need services that are probably worse off than my son. I think him being … having a parent such as me able to care for him, have the ability to care for him and have a home for him, I think they wouldn’t see him as someone who would truly need the services. So I, I would say he, he would have very limited or a slim chance of getting any of those services, given the environment that he’s currently in, versus someone else. And, on top of that, these organizations tend to … it’s not specific to autism, they cover other disabilities within the spectrum and also other intellectual disabilities that may not be on the spectrum. So I think once you do that, you open up more people in the population … where he’s probably better off, you know, continuing to live under my roof, versus someone else whose parents … or they themselves may not even have parents or family that can and willing to teach them and help them. So I don’t think … I think there’s a slim chance of any organizations out there that would benefit my son. The programs, they sound nice on their website, but the more and more I read into the eligibility, the admission process, I think he has a slim chance that he would get accepted into those programs.

**Interviewer:** Well, that makes sense. You basically gave me the answer to my next question. But I have to ... **[inaudible crosstalk at 44:12]**. So thank you. You did great. Do you think there are gaps in the available services, in services and intervention?

**Interviewee:** Definitely.

**Interviewer:** Yeah.

**Interviewee:** Definitely. One of the issues I complain about and it doesn’t look like it’s ever going to get any better.

**Interviewer:** Besides just having more of them to meet the needs of everyone, do you think the types of programs are lacking, like, do you wish a different type of service existed?

**Interviewee:** I can’t think of any other types because the ones that they have seems to be what most people on the spectrum are needing. So I can’t think of anything additional that they may have missed. I think they got it covered. It’s just **[45:00]**, the lack of support for the community, the lack of funding and the amount of people that have these disabilities that need help, makes it difficult for a lot of people in the population to benefit from. But I think the organizations that are there, they have a good grasp of what is needed within the community. It’s just that, with the limited funding and the limited areas they cover makes it even worse for those who are suffering from the disability.

**Interviewer:** Yeah, that makes total sense. Are these, are these programs, like, not close to where you live or not accessible for you?

**Interviewee:** They … there’s some a county over, but within my particular county, there’s only two organizations that I know of. But all of my county is considered mostly rural, so lack of funding is a major issue. And then the county next to mine is more of a suburban-urban area and they have more organizations that help, but they are also underfunded, and way too many people are needing their help. So that, I would say Montgomery County has at least 10 organizations, but Montgomery County is big, versus Frederick County has only two, and it covers the suburban part of Frederick and then also the rural part of Frederick. But we’re considered a rural county, so our funding is very, very limited. And then the DC area period doesn’t really have much options, either. I mean, there’s so many people here with intellectual disabilities. And don’t think … because they don’t specifically cater to just the autism spectrum, they consider everything else under the intellectual disabilities category. So then you have thousands of other people that’s just not autistic that’s also benefiting, which most times need the benefits more than autistic and, being that my son is a high-functioning autistic, it’s … basically they’re saying “*He’s slightly autistic, but not really*.” And therefore he can function on his own without the services, versus someone else who might have a severe form of the spectrum disorder that may … who can’t function without extra help. And my son can. I’ve made sure he could function without the extra help, just that I would like for him to have extra help, you know, other than just me.

**Interviewer:** Yeah.

**Interviewee:** But yes, so I, I … for this county, there’s not many options here.

**Interviewer:** Yeah. That must be frustrating.

**Interviewee:** It is, **[48:00]** it is. And it’s no different than for the children … the school systems are not that great for children with autism as well. I mean, even though they give services for it, additional services outside of the school system, it’s very lacking in that regard as well.

**Interviewer:** Got you. So it’s kind of, like, a universal problem.

**Interviewee:** Yes.

**Interviewer:** How has your son’s sensory preferences and sensory sensitivities impacted your goals, hopes and expectations for him in terms of as he’s been navigating adulthood?

**Interviewee:**

His sensitivities are kind of mild so they really haven’t impacted him as much as someone else who, who may be more on the spectrum and suffering from other issues. So I wouldn’t say his sensitivities has technically impacted … I don’t know all his sensitivities. I haven’t even looked at what other sensitivities most people on the spectrum face. I just notice the ones I see, but I don’t think they’re a huge impact on him.

**Interviewer:** Got you. I guess that’s good, though, you know.

**Interviewee:** I guess it is, sort of.

**Interviewer:** And so, for our last chunk of questions: as a caregiver as a parent, as a mom of a child with ASD and some sensory preferences, some sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** Means him living like a typical adult, living on his own, finding love, eventually having a family, having children. I don’t really have too much hope in that. But if Amy Schumer can marry on the spectrum, I’m hoping that’s the same as my son, he’ll find someone who’s, you know, that understands him and that can work with him in that regards. But hopefully … that is what I would like, to see for him, you know, to live … not necessarily … because I know he can’t live as a normal human without the disability issues, but as normal as possible is what … my goal ... and hope that would be for him.

**Interviewer:** Yeah, totally. Has this perspective changed over time?

**Interviewee:** No. I’ve always ... Let me see, thinking about it … Yeah. I mean, no, it hasn’t really changed. Because always I knew that he may live with me for the rest of my life, but I would hope that he could live on his own and that’s what I’m hoping he’s able to do, because I’m not going to always be here.

**Interviewer:** Yeah.

**Interviewee:** So he needs to know how to survive on his own. But, as of right now, I would say my perspective on him has not changed. I, I do believe at some form that he will … Well, he has to be close to me. It can’t be that if I’m living in California, he’s living in DC: that’s never going to be an option for him. It will always have to be “*You have to live within an hour of me*.” At least, that’s about as far as I’m willing to allow him to go. But, you know, technically, I have a feeling that he’s going to be living in my home and until I pass away, yeah, at least living in my home independently. But his goal is to live, you know, independently **[52:00]** of me in his own place. So, but yeah, my, my perspective has not changed.

**Interviewer:** Did you … do you think about, like, that hour demarcation, because, like, you do … you need to go help him sometimes, or you need to pick him up and an hour just, like, logistically as kind of, like, a maximum?

**Interviewee:** Yes. I want to be close enough where, if he needs me, I can be there as quick as possible, versus saying, “*Well, I have to catch a flight. And I can’t be there until tomorrow*,” or, or something like, that, or, something happens, I can’t be there as quick. I want to be, be able to be, like, if he calls or something happens, I’m there, you know, as fast as I can be. And, to me, that’s within an hour.

**Interviewer:** Totally. No, I get that. I lived very far away for a long time. And it was hard, my mom couldn’t come.

**Interviewee:** I’m afraid of that because, like, you never know what might happen. And with him being disabled, I don’t trust the community. I don’t trust people out there. So I’m like, I need to be close by so if anything happens … if he calls me and says “*Mom, you know, somebody did this*” or “*I got robbed*” or something, I want to be able to hop in my car and not hop on the flight. I can hop in my car and be there within an hour.

**Interviewer:** Yeah, no, totally. That makes sense. So you kind of, like, answered this in not so many words, but what do you see happening in his future?

**Interviewee:** More likely right now, living as an adult in my house and that’s about as far as I can go. Because I don’t know if he’s … I don’t see him married only because he doesn’t have social skills. He doesn’t go out. He’s a recluse, so I don’t see how he’s going to find anyone to spark a relationship with and I don’t see him having children. But, then again, I don’t want him to have children, so … because I don’t want to be a grandmother. That is not a goal of mine. I do not want to be a grandmother that ... but yeah, as of right now, I just … I see him living here with me and being an adult in my house.

**Interviewer:** Yeah. Do you see him going back to school? Do you see him continuing to hold jobs like he’s holding now, holding different jobs?

**Interviewee:** I would like him to have a different job. The job he has now, he’s been there for two years. So he … so it’s pretty good. It’s a stable job for him. They haven’t promoted him. I, I feel that he is better than just being a cashier. But I do know, being that he’s disabled, a lot of people don’t want to give him the opportunity to show if he has any leadership skills and they don’t mentor him in those aspects either. But I would like him to be able to be in management of some form versus just, you know, a low-level employee, cashier or a janitor or something like that. I do not want him to be that for the rest of his life. He did express to me what he wanted to do, which is be a game designer. So we did put him in college at one point. So he, he did one year of community college. It was a struggle for him because the public school system did not prepare him for college. I found out that he was on a sixth grade reading level; he was on a ninth grade math level. So he was not prepared to be in college at the time. And the program he was in, which is mostly computers, required a high college level of English and math. So he was in mostly developmental classes, which financial aid does not pay for anymore, which is difficult paying out of your pocket. But when he was in college, he, he struggled because he didn’t have the supports he needed that he used to have in high school. He didn’t have the, the assistant sitting next to him, keeping him organized, keeping him on point. He had to learn how to do it on his own, which is very difficult. Keeping up with deadlines for projects and on a college level was difficult for him. So … But he has expressed that he would like to go back to college. And he would like to get his associates in game design, because he does want to work in the game design field.

**Interviewer:** That’s good. That’s great.

**Interviewee:** Hopefully, we can get that. But again, there are programs for that, but they’re very expensive that they have … they do independent living skills, have them live on campus and have a 24/7 mentor with them, but that’s $60,000 on top of his school tuition, which is … Yeah. Who can afford that?

**Interviewer:** No, that’s brutal.

**Interviewee:** It is and I’m like, that’s not fair …

**Interviewer:** No.

**Interviewee:** … taking advantage of him like that. But, he, he has expressed that he did want to go back to college and eventually complete his degree, but he understands that he needs a lot of developmental education before he can get to that level.

**Interviewer:** Absolutely. So, I have one final question for you:

**Interviewee:** All right.

**Interviewer:** How has your son’s sensory sensitivities and sensory preferences impacted this perspective you have in terms of his transition to adulthood?

**Interviewee:** Repeat that question.

**Interviewer:** How have your son’s sensory preferences **[58:00]** impacted your perspective about what it means for him to become an adult, to transition to adulthood?

**Interviewee:** I don’t think they’ve actually impacted.

**Interviewer:** Yeah.

**Interviewee:** I ... well, I mean, it’s his preferences, I mean, it’s not mine. So I don’t think it has impacted him in transitioning to an adult because he’s, he’s done a lot of things that … he’s self-sufficient, independent already …

**Interviewer:** Yeah.

**Interviewee:** …despite his, you know, sensitivity issues. So, I don’t think it’s impacted him per se because they are mild sensitivities. And I think he’s made it work with, you know, what he wants to do being an adult.

**Interviewer:** That’s great. That’s really good. So that’s all I have on my end. Would you like to add anything else?

**Interviewee:** Well, while we were talking, I thought of another issue. When we took him on his first cruise … I think a lot of his sensitivity showed up then because he has told me he never, ever wants to go on a cruise again. He did complain about … he felt the rocking of the boat.

**Interviewer:** Yeah.

**Interviewee:** He would sleep all day and then he would go out at night. So I think a lot of the, the light sensitivity … being out in the Caribbean and the brightness of the sun affected him. So I do know he would sleep all day. And then, being that it was on a boat and a large ship with the ... and you’re in limited areas and it’s crowded …

**Interviewer:** So crowded.

**Interviewee:** … and he tended to stay in a room more often. He would come up with us when we went to breakfast, lunch or dinner, but, as soon as we finished eating, he’s like, “*OK, I’m gone*,” and leave. And, of course, we never asked him where he’s going or anything like that. But most of the time he did inform us that he ended up going to the room. I think he just didn’t like the loudness, being around that many people. And the fact that it was a different environment that he’s never been involved in ... and the boat, and all the things that … he just, I guess felt more comfortable just being away from everybody and isolating himself.

**Interviewer:** Totally.

**Interviewee:** So I … so that, so that did pop up in my head as we were talking about issues. I was like …

**Interviewer:** Yeah.

**Interviewee:** Forgot about that cruise.

**Interviewer:** Yeah.

**Interviewee:** And he’s expressed that he never wants to do another vacation like that ever again.

**Interviewer:** How old was he when this happened?

**Interviewee:** This was … he was 20.

**Interviewer:** OK. Yeah.

**Interviewee:** Yeah.

**Interviewer:** I mean, cruises are … **[inaudible at 1:00:56]**.

**Interviewee:** Wait. He’s 22 now ... no, it was when he graduated high school, so he was 18 turning 19. Yeah, about 18, 19.

**Interviewer:** I mean, cruises are really overwhelming, though. So I mean, it makes sense that it would kind of amplify everything. Awesome. Anything else? That was really interesting. Thank you.

**Interviewee:** No, I can’t think of ... that one stood out the most.

**Interviewer:** Yeah.

**Interviewee:** Yeah.

**Interviewer:** OK. Well, that’s all I got. Thank you. That was, that was really, really helpful. We appreciate you taking your time, especially during your coursework. So, thank you. So, after this, I will fix that link for you. I’ll resend it to you. And it shouldn’t take too long, hopefully.

**Interviewee:** OK.

**Interviewer:** Do you know anyone else who might want to be part of this study?

**Interviewee:** I don’t know any other persons on the autism spectrum.

**Interviewer:** No worries. That’s OK.

**Interviewee:** I don’t know any other persons on the autism spectrum. Yeah.

**Interviewer:** That is absolutely OK.

**Interviewee: [inaudible at 1:01:58]**

**Interviewer:** No, no, that, that’s great. But again, truly, thank you. We appreciate all of your help and all of your time, especially during the world we’re in right now.

**Interviewee:** Yeah, no problem.

**Interviewer:** Thank you. So as soon as I send you that link and you complete it, I will then send you a gift card as a huge thank you for all of your time and all of your effort.

**Interviewee:** OK, sounds great.

**Interviewer:** Yeah. Do you have any final questions for me? Anything I could help you with?

**Interviewee:** No, none.

**Interviewer:** OK. If anything comes to mind, feel free to reach back out and we’re happy to help you in whatever ways that we can.

**Interviewee:** OK, thanks.

**Interviewer:** Thank you. Good luck on your coursework. All right. Thank you. Bye

**Interviewee:** Bye.

**[End of interview]**