**[START OF TRANSCRIPT]**

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

**Interviewee:** Nope. I think we’re good.

**Interviewer:** Okay. And if there are any questions that you don’t want to answer for whatever reason, that is perfectly fine. *“I don’t know”* is a perfectly fine answer too. And if things pop up from earlier, feel free to bring them up as they come to mind.

**Interviewee:** Okay.

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

**Interviewee:** So, he’s had them since birth basically and I guess what I saw across the board as a child is a very young baby of one, we started figuring out some fabric sensitivities pretty early on, kind of coming into toddlerhood. That’s when we started really seeing more especially the noise and group kind of things where he would get very quickly overwhelmed in any kind of a group setting, like a family get together or preschool. His teacher at preschool called him the little CEO, she said he would stand up with his hands over his ears and yell *“everybody be quiet, everybody be quiet.”* If we tried to go to a restaurant, as a toddler all the way through his childhood, he would get kind of crazy acting and crawl on the chairs and things like that. It turned out he also had pharyngeal dysphagia which is a swallow disorder where food sticks in your esophagus rather than washing it down and it’s right at the top of your windpipe. So we noticed him choking even on milk, rice, cereal, things like that. And when we would try to go to a restaurant, we stopped doing it because he would inadvertently have a choking episode every time. And we had paramedics come running over one time, the whole restaurant would go quiet. I was very versed in Heimlich back then. We realized that that overstimulation was somehow kind of aggravating that as well. And just moving on up through the school years, definitely started seeing more aggravation by fluorescent lights. Everything just kind of continued to get worse. The distractions with other kids moving near him. I’ll just say that it continued more and more through high school to be an issue and after we had a lot of problems in one public school system, we moved him to a private school system where on the one hand, it was quieter I guess you could say, but the whole environment was a little less unstructured, so the kids were studying [in a] back-to-back public-school environment. They were sharing quads of desks and things. From a sensory perspective, that turned out to be a train wreck. We thought that was going to be a good school because it was on a farm, they had all this outdoor time and stuff and one of the teachers there really talked the talk about sensory perception and they did let him use fidgets and things like that. But it completely just killed his ability to concentrate on anything and he started kicking the kids under the table, stuff like that, ‘cause they were in motion, they were kids, and then he was in motion too obviously and we started to see some of the sort of repetitive behaviors I think at that point with him when he kind of tossed things in his hands. So, we had a really bad episode actually in high school where he went after a kid one day, which aggression was never an issue with him, but it has been an issue with him. And he had just come back from a camping trip the day before, he was overtired and after this episode, he went totally silent, the school just assumed it was his fault. And we didn’t find out until two days later, after he had kind of decompressed in a dark room for two days, this kid had been doing things the whole semester. When the teacher would turn his head, this kid would poke him in the back with a pencil or shake a water bottle underneath his ear, things that would really aggravate anybody. Crumple paper near him where he couldn’t see it, but he could hear it and so that…I just remember calling a psychologist before I knew what had happened and she was like *“something happened; something triggered him from a sensory perspective because this is so out of his scope of behavior.”* We did send him to school in Connecticut for the remainder of high school to a school, Franklin Academy which is for high functioning kids on the spectrum. In a lot of ways, that was a night and day from what we had been… I just saw his whole-body agitation drop. I really realized how much he was on guard the whole time. Not only socially, but with all the physical stimuli and stuff as well. When I saw him very visibly relaxed, he became very used to that environment, so he did still struggle a lot with initiative, motivation and stuff like that. They did not have fluorescent lights, they kept things quiet, they did a lot of things to help him. So kind of where we are now that I’ve seen all these years is that all that stimuli exhausts him. He’s always complaining of being tired. He’s always exhausted. And he never opens his curtains, his room’s always dark, he prefers darkness to light, and he prefers quiet. He gets agitated if other people are playing music that’s not music he specifically likes and will leave the room immediately and stuff. In the car and stuff, we will always have earbuds on. If we’re out in public, he always has his earbuds so because I’m working with a caseworker here, they have found him an ideal job. He was working as a bookkeeper’s assistant in this older woman’s house, she was 73 and she let him work in a dark room with a dog and his feed and total quiet and that had been a very good situation for us up until the pandemic hit and then he had to come back home and try to work from home. It just all fell apart. He could not concentrate here. Coupled with this but not really affecting him from a work perspective, he’s definitely got food texture sensitivities. [They] are a big thing and interestingly, smell is always kind of a big thing. He used some zinc nasal spray some years ago and swears he’s had very little smell since then.

**Interviewer:** Like for a cold?

**Interviewee:** Yeah. And I think that that happened to a lot of people. I don’t know if there was an actual lawsuit but there was talk about that and I think it nearly came off the market. So he’ll tell you he can’t smell very well but he has discovered that scented candles are very relaxing so he’s burning them all the time. I’m like *“well, clearly you can smell the candles”* and clearly, he will be very repulsed by smells and scents. And I haven’t honestly really paid attention enough to notice *“okay, what’s the pattern?”* Is it certain smells that he’s picking up and not others or what? I don’t feel like his taste is affected, the way like if you lost your sense of smell completely that it would be. So that may just be like his perception of smell is down. We were very much in agreement when we did the questionnaire last night, I had him do the answers, but I was very much like guessing what he was going to say, very much followed that pattern when he was talking about *“oh, I can’t smell.”* Anyhow, just now, going forward from a work perspective, we’re hoping he can get back into bookkeeping or something. He clearly needs something quiet, where he can have dark, where he can have little commotion. It’s exhausting being around people so we’re steering him towards bookkeeping, accounting. Who knows how that’s going to work out? I’m trying to think if there’s been any…We did years of occupational therapy, many, many years of that. I guess that’s another one, he uses a weighted blanket many, many years now and so much of his therapy was around compression kind of stuff. He will wear a heavy winter coat in the middle of a hot summer. If I were to take him out of the door right now, he would put on his heavy ski jacket. He likes not the heat but the compression of it. So all childhood, he wore ski jacket after ski jacket and he will wear pants when he went to work but he has worn probably like seven years now the same pairs of grey and black nylon Under Armour men’s sports pants. I bought him like 10 or 15 pairs of them and that’s all he wears at home, that or the shorts version of that. Only wears black and grey and so that is something I think from again a work perspective, places where he has to go, he has to put on other clothes, nothing like t-shirts, buttons and all that stuff are things that just kind of exhaust him more so that will keep you going.

**Interviewer:** That was wonderful. You answered so many of my questions. Thank you. I’ve got a couple of follow up questions if that’s okay?

**Interviewee:** Sure.

**Interviewer:** So, in the beginning, you talked about fabric preferences. Could you talk a little bit about what fabrics he likes?

**Interviewee:** Yeah. We’ve actually seen some reversals on that. So when he was very little, he fell in love with these polar fleece pajamas. He called them the star pajamas and he would wear those pajamas all day long if he could. I had to buy these sleep pajamas so he’s all closed in. I had to buy those in multiple sizes to grow from one pair to the next and now he cannot stand polar fleece. His preference now is, kind of interesting cause I hadn’t thought about this, cotton t-shirts but nylon pants. **[00:11:22]** Can’t stand nylon shirts. Doesn’t like cotton pants. And shoes have always been a huge issue for him. Not only has he struggled from a motor skill perspective but the feel of the shoes. When he had to wear shoes to school, we always had to get the seamless socks. They bothered him less. He didn’t like the feel of tennis shoes, so I always got him the slip-on shoes. He discovered crocs in maybe seventh grade and that is all he has worn since. And we had trouble at Franklin because it was in Connecticut and he was going to wear crocs when it was zero degrees outside. He was fine with that, but the school was not. And on top of that, up until literally a few weeks ago, he’s worn the same pair of crocs for probably six years, even though the bottoms were all worn in and everything because of how they felt. So, and now, the ski jacket, he only wears cotton t-shirts, but he’ll only wear the nylon jackets against his skin. No polar fleece. No wool. No anything like that. And, obviously, we have sheets, that kind of stuff as well. But he perplexes people; people will obviously come when it’s 102 degrees here and he’s wearing his ski jacket outdoors. So, anyhow, that’s probably the main one I can think of.

**Interviewer:** No, thank you, that was wonderful. And you talked about food textures. What does that look like for him?

**Interviewee:** He’ll tell you it kicks in his gag reflex. My husband has a lot of food texture issues as well and I had one as a child, so I understand where he’s coming from because if you put cold beans in my mouth, I start to gag. That has kind of flip-flopped a little bit over the years, but right now, he will not touch bell peppers, he will not touch tomatoes, for years he will not eat onions, he does eat onions now, and for years he didn’t like olives, he’ll eat olives now. And some of it may be taste, but when I ask him, he’ll specifically tell you, *“no, it’s the texture”* and he does also I would say, I don’t know how much of this is texture related but he does not eat a lot of fruits and vegetables and I just know that when I’m cooking, if there’s a bell pepper or if there’s a tomato, sometimes he can pick it out but he won’t eat it and there’s other things that he will, but that gives you an example of that.

**Interviewer:** That’s wonderful. Thank you. And then you were talking about sounds a lot and you used examples like crowds in schools and things like that. What about more mechanical noises like will sirens, trucks, things like that, alarms, do those bother him?

**Interviewee:** Yes. Yes. And he prefers, and I understand this too cause I’m very agitated by sounds also. He wants stone cold silence unless it’s music that he’s listening to that he likes. And we really saw that come to culmination, we lived in Ireland years ago and we lived in a very nice area, but it was at an intersection right near Queen’s College and you could hear cars and trucks and stuff going by even with the windows closed. And he was just in a constant state of agitation from that. We had all kinds of issues with him over there. Just across the board, any kind of sounds and I know in elementary school, he complained and complained about the humming sound that the fish tank in the room next door made and so very hypersensitive to some things sometimes. He was very soothed by the sound of running faucets and my aunt would call him a water baby because he’d scream at the top of his lungs until you turn the faucet on and then he stopped. So, now, that’s not an appealing sound to him but it was for years. Just again, with music and stuff, he immediately gets agitated. If you go to a get together or anything where there’s background music and it’s not his music, it becomes really difficult for him very quickly.

**Interviewer:** Yeah. Thank you. And you’ve alluded to this throughout what we’ve talked about so far today, but how have his sensory sensitivities changed over time?

**Interviewee:** I’m just checking. Just had a bunch of texts come in. Just making sure it’s not a work emergency.

**Interviewer:** No, if you have to stop for whatever reason, don’t worry about it.

**Interviewee:** I think we’re good. So, like I said, with the fabrics, it’s just been interesting how we had that morph from the only winning polar fleece to not touching polar fleece and I’m trying to think. Remind me again, ‘cause I got distracted by that, are we talking about across the board with the sensitivities?

**Interviewer:** Yeah. In general, do you think they’ve increased, decreased, stayed the same?

**Interviewee:** I would say more or less, they’ve probably stayed the same in a bouncing kind of way. Some things kind of probably bother him more and some things bother him less but they’re all still very much a part of his life. Aside from those biggies, like I said with the fabric change. I’m trying to think if I can think of any other examples, but, yeah, otherwise, the fabrics have stayed the same for a very large amount of time. I’m just trying to think through anything else that jumps out. So I would just say it all probably comes out in the wash.

**Interviewer:** Yeah. Totally.

**Interviewee:** I’ll tell you one more. I’ll tell you one more. It’s a biggie. Grooming is very difficult for him and he does not like the way that shower water feels. Occasionally, he’ll take a bath, mostly if he doesn’t feel well. But it’s very hard to get him, he will shower if he knows he’s going out somewhere, but if he’s not, I mean he will go a month without a shower. Same thing with toothbrushing. I brush his teeth for him for years. He’ll go long, long periods without brushing his teeth so that has been a big issue. He’ll use a hair comb occasionally, but he doesn’t like brushes and combs. He doesn’t like being touched at all. We had huge issues…the girl that cuts his hair started washing his hair herself because the girl that was paid to do it, Chance didn’t like the way he touched her head. And so that’s another one, from a grooming perspective has been very challenging for us.

**Interviewer:** I’m sure. And for the teeth brushing, is it a feeling thing as well as a sensory thing?

**Interviewee:** As far as I can tell. There’s no reason to not brush them otherwise. Like I said, I brushed them all the years he was a child. I think he would be brushing them if it were not for a texture issue.

**Interviewer:** Absolutely. Thank you. And thinking about change over time. For the things that have changed a little bit, I know the net is zero but for things that have changed, do you think that’s related to any independence that he’s gained over time?

**Interviewee:** No.

**Interviewer:** No?

**Interviewee:** Uh-uh.

**Interviewer:** Okay. And you again alluded to this in our conversation so far, but when your son is in a sensory experience that is aversive to him, does that cause or increase anxiety for him?

**Interviewee:** Absolutely. Yeah. Sometimes he’ll just get up and leave. Even like a family thing, even when he’s around cousins he likes and stuff, he will just get up and leave. Whenever we travel, always there will be a day when he is just like, and it doesn’t matter how badly he wants to do or say something, there will always be a day when he’s like *“just leave me here.”* He will have the lights out, total dark, silence, just have a decompression day and the first time he did that was maybe in middle school or late elementary school. We’d gone down to see some cousins who he loves, and we had gone down to do some Mardi Gras stuff with them and all of a sudden, we were getting ready to go, he was like *“I can’t, I can’t, I just need to be alone.”* And I was like *“okay, I feel weird leaving this young kid.*” He wasn’t that young, he was probably eleven or something, but I was like *“well okay,”* and sure enough, we came back, and he was in a much better mood and much calmer and everything. And really ever since then, just anywhere he ever travels, there’s always a day of darkness. *“Just leave me alone. I don’t want to be around…”* And then he’s always good after that.

**Interviewer:** And has this changed over time how he’s managed this anxiety or how sensory things have caused anxiety?

**Interviewee:** Well, I think he’s learned, because of all these years of therapy and also probably just some maturation, he’s gotten better at maybe recognizing a lot of times when the agitation is building up and he needs to step away from it. And so, we had all kinds of, not really meltdowns, he would shut down as a kid, he would go silent. We saw this even at Franklin. He would just not talk to anybody. Shut himself off, more so than acting out. And he just has kind of crossed that threshold over the years. He is recognizing *“I’m hitting capacity”* and whatever’s causing it, whether it’s texture, sound or light or whatever and to me, that’s a good thing that he’s starting to recognize so he can step away before he does cross a line or anything.

**Interviewer:** Yeah. Absolutely. You’ve given me such wonderful segues. Thank you. So again, you’ve talked about this in not so many words, but how does your son cope with, manage or handle his sensory sensitivities?

**Interviewee:** Well, obviously, with the foods, he’s just going to over wade stuff. Same thing with the clothing. I mean he will dress up in a tuxedo or something like that if he has to, but again, it just adds to his agitation levels. But I think he recognizes it’s for a limited amount of time so but even going to work, he’d still wear his ski jacket. **[00:22:44]** And then, I would say all the time, when he’s not out and about, which is most of the time, his room is always dark, I can’t imagine walking in with the lights all on or anything. He doesn’t like sunlight. That’s another: it’s very hard to get him to go outdoors and do stuff. He wants to be in the house all the time. Again, earbuds when he goes out. He’s always got them. Even if we’re riding in the car quietly, he’s got his earbuds in. And he’ll, if I turn around, he’ll immediately pull them off to listen but, so, he uses those a lot. We tried all kinds of headphones, big headphones, earplugs and all that. He could not tolerate any of that. **[Phone goes]** Just a second.

**Interviewer:** No worries.

**Interviewee:** Let me send her one quick text.

**Interviewer:** Take your time. Not a problem.

**Interviewee:** Almost done.

**Interviewer:** No, take your time. Not a problem at all.

**Interviewee:** There we go. Okay. So that would really be it from…he cannot stand people touching him, so he keeps his distance from people. He does isolate himself, either because of sound, lights or noise exposure. Again, with travel and stuff like that, he’ll put himself in his room. I think I’ve kind of probably touched on most of the things he does to manage. I’m trying to think if there’s anything else. He has his fidgets and stuff like that. I guess that’s another. He has a little Rubik’s Cube so when he is agitated, and he’s out in public or something, he’ll have, it’s a small one, he’ll have it in his hand just rotating it. When he’s at home, he tosses a water bottle all the time, almost juggles it in his hand. So those are probably the two big [things]. Nothing else is really jumping out at me.

**Interviewer:** That was wonderful. Thank you. And you touched on this briefly when you mentioned OT, but has he received specific services or interventions for his sensory sensitivities?

**Interviewee:** Oh yeah! Yeah. So, like I said, many years of occupational therapy, starting really in first grade. Hold on one second.

**Interviewer:** You’re good. We can stop if you need to.

**Interviewee:** No, I just need to respond to this.

**Interviewer:** Sure.

**Interviewee:** I run apartment properties. There’s always stuff going on.

**Interviewer:** Sure.

**Interviewee:** Okay. Now where were we?

**Interviewer:** You’re good. I was asking about services or interventions?

**Interviewee:** Yeah. Yeah. Yeah. So, many, many years of occupational therapy. Even before we realized what was going on, I figured it out. Even as a baby, we figured out he liked very, very firm compression. He wanted to be swaddled tightly. He slept great in the stroller and the doctor told me you can’t do that because he had all the padding and cushioning around him. When we finally moved him to a crib, he did not sleep for a year. He was up every two hours. And now I know, I didn’t know at the time what was going on. It was because the doctor, when we finally got the diagnosis, she was like *“that would be like throwing him in the ocean without a raft and not knowing what’s around him.*” He’s come from this very safe mental place. Even when I was pregnant, if I touched my stomach very quickly, he would kick very hard. And we had the funniest story. My husband put his head down to my stomach one day to see if he could hear him and sure enough my son kicked so hard, my husband jumped back. He was like *“I’m not doing that again.”* We kind of joke about it. Even in the womb, he had this weird sensitivity. I mean he was always the minute you touched within seconds *“Baam!”* And so, very quickly as a baby, we figured out. I had no idea what autism looked like back then or Asperger’s or anything, but we figured out something was up. And so, we did a lot of years of OT. We did tons of therapies across the board and some of those crossed into OT as well. He did physical therapy. He did swallow therapy. As a kid, one of the things I did constantly to calm him down was this game called huggy mommy monster where the kids would run around the room and I was the monster and I grabbed him and would squeeze him in my arms as hard as I could and make them come up with a password, based on his agitation level. I would hold him, *“no, that’s not it, that’s not it.”* And that was a very calming thing. Again, I figured it out. I didn’t realize what was going on at the time. But he continued therapies really one to another up through to middle school I would say. Outside of pure OT, we did camps that were specific to kids with disabilities and issues. So he did outdoor therapy camps and things like that where it was getting them climbing trees and that was a huge shift that we did see. As a child from babyhood, the outdoors was very calming to him and because I realized he did so much of it outdoors, we spent tons and tons of time outdoors. The second he came home from school, we were out walking, bike riding, scootering, all that. Now, he cannot stand to go outdoors unless we are on a trip and we are hiking, and it is the light, he will complain it’s too hot. We’re actually going up to Connecticut in just a few weeks because we’re moving him back up there and he’s always [like] *“it’s too hot.”* But even when it’s cold here, he still doesn’t go out. We’ve probably done the bulk of therapies out there. I’m actually trying to remember if we did anything from a smell perspective. Some of it’s a blur. We did so many. It seems like we did do some stuff with smell at one point and then they actually did a lot, when they were doing the swallow therapy, they also were working with food textures as a part of that. And then really at high school, at that point, aside from when he was at Franklin, they did force the kids outdoors and stuff, but he didn’t do any OT or anything there.

**Interviewer:** Did all of those sensory specific therapies, did those you think help him?

**Interviewee:** Honestly, in the end, it’s really hard to say. We tried everything trying to help him. You always hear somebody’s going to say this, maybe it will be different for my child. He’s very high functioning, he’s super high IQ, and those parents especially, you’re like *“okay, if he can overcome these obstacles enough…”* His psychiatrist is like this is the kid who could cure cancer. You do everything you can, and you spend everything you can trying to get them to a place where they can have a life, so we tried all kinds of alternative therapies. Reiki and all kinds of stuff, we tried homeopathies, you name it, we tried it. Honestly, what was so interesting to me, and this is kind of another thing that came up, that was I would say was part of the stress and the sensory, I mean it’s very typical for kids on the spectrum, he had horrific stomach issues from first grade on. Eventually, they diagnosed him with IBS but when he got to Franklin, within a month of being there, he went off all his stomach meds and never complained of stomach problems after that. **[00:31:44]** It was being in an environment around other kids just like him and I wish it would have been great to see it on video. It was so interesting to me. We got there to Franklin to do this trial interview and they had some kids come around and meet him and I literally in seconds saw a different child to what I had seen. His whole guard just dropped. He relaxed. And the changes we saw with him in that environment being around other kids, they were not only autistic, but autistic like him. It was stunning. He dealt with everything better after that and that’s what we’re trying to get him back into. We’ve seen how harmful it is pulling him out of that environment and that’s why we’re going to Chapel Haven in a couple of weeks to see about getting him into an adult situation like that. Everyone at Franklin did more than any therapy we ever tried. We saw massive quantifiable differences, physically I would say some of his sensory stuff calmed down. He got very comfortable talking about the fact that he was on the spectrum. He was clearly happier. We had tried some schools here, but they took in lower functioning kids and he was so intimidated by the fact that *“I don’t want to look like any masks, masks big time like all the high IQ kids do”* and he would curl up in a ball and not talk for two days after we tried some of those schools. Really seeing him at Franklin made me wish so badly that the kids, it would be very interesting to me to see kids that were diagnosed as high functioning autistic be in an environment from elementary on with just kids like them. How different their lives might look and so if I had to do it again, I probably would have pulled back on almost all of those therapies we did and that in the end, I can’t say that they helped, and Franklin was it.

**Interviewer:** That’s wonderful. Thank you for sharing that. And now thinking a little bit more broadly, what goals or hopes do you have for your son in terms of his sensory sensitivities?

**Interviewee:** They’re never going to go away. I think he could be doing some things to maybe make it better, but I don’t think there’s a lot at this point and really what we’re hoping, as an adult, is just he can get in an environment where he’s able to find work options and social interactions and things that just enable him to have a happier, better life. I think he’s happier when he’s working, using his very intelligent brain and so if he can get in an environment, like he had before, he has the ability. He doesn’t have initiative, and he doesn’t think on his own but if you tell him *“do this,”* he will do it in a stunningly rapid and accurate way. I could see him working for an accounting firm if they could get him in a quiet office where he could have the lights out or something. We’re not counting on it ‘cause we’ve been burned so many times when we get our hopes up too much on things but that is our hope is that he can get into a job. I don’t think he’ll ever work full-time because he’s too exhausted by everything but if he could get a good part-time job. In my perfect world, living in an environment like what Chapel Haven offers. They have an adult living where he could be around other people like him and have happiness from that. When he was in that environment, he would go out and play card games and very much enjoy it. That’s what we want for him again and there’s just nothing like that in the south.

**Interviewer:** Absolutely. Thank you for sharing that. We’re going to shift gears a little bit. So as your child has grown up a bit, how has his and your community reacted to his sensory sensitivities and sensory needs?

**Interviewee:** The community?

**Interviewer:** Mm-hmm.

**Interviewee:** I mean clearly in school, they did stuff to try to help him. I know one of the big things they did was have, like when they went down the hallway and stuff in line to lunch, those were times that were hard for him. They had him carry rings of paper just to kind of get some weight. We had tremendous frustrations with the first school system we were in because they demanded that he have occupational therapy. Even though they had an occupational therapy room right next to his classroom, they would not give it to us through the school, even though it was right there. And their justification was he’s too intelligent, he’s doing well on tests and that’s an age when it’s rope learning which is what autistic kids do well. It’s when they get into the more introspective thinking and so they demanded that he have OT twice a week, but they would not give it to him. It was expensive and I pulled him out of school so blessedly, the school system’s we went to after that, he was able to get therapy. Really in terms of when he was younger, the neighborhood we lived in, the parents always thought he was kind of a little bit off the beaten path. I don’t remember them doing anything to accommodate him or anything specific. Community, in terms of family, the family members to an extent, especially my husband’s parents, once he got that diagnosis, got a lot more understanding in some ways. They pretty much thought he was the bad kid up until we got that diagnosis and even some after that. But he doesn’t have enough interaction I guess with people now, he doesn’t have any friends or anything here where he’s interacting where I could say he has any outreach with the community. We did have a very long and frustrating process finally getting to this one agency with the state that helped him get the job. We stumbled on that through back doors, and it was really frustrating that they didn’t even tell us that this agency existed upfront. And so, the whole process of finding work for him, they sent us to the vocational resources thing where they did testing, and then they came back and said *“well, mostly what we provide is working at goodwill or stocking a store and he’s way too smart for that so we can’t help you.”* And they were affiliated with another agency that very much could help us and we only found out about that through a friend of a friend and the minute we found them *“oh yeah, he’s exactly the kind of kid we work with.”* And, so, once we found them, they were tremendously helpful. They assigned a caseworker to him who came up to our house, interviewed Chance to understand what appealed to him and went out and actively sought…the guy came back, and he was like *“you need a job”* because we were thinking like a night clerk at a hotel. He was like *“that’s going to be too stressful for you.”* And he said *“you need a job in accounting or bookkeeping. I’m going to go find you one.*” Sure enough, he found him this job working as a bookkeeper’s assistant. Even after the pandemic, he found him an accounting job where he could go to the office, but Chance was too scared during the pandemic so that’s really the only things I can think of. He’s out in the community so little.

**Interviewer:** No, you did a stellar job answering that question, you got most of my sub questions. Thank you. Would you say that the community was more or less accepting when he was younger?

**Interviewee:** If the community is our neighbors, I would say yes.

**Interviewer:** Yes, less or yes, more.

**Interviewee:** More. And he had a best friend and he played at the houses of several kids and stuff like that. School again was a huge battle in his early years, and we tried moving him to that private school I mentioned and that was an even bigger battle still. So many of the teachers, they had a peripheral understanding of autism. They can talk the talk, but they don’t really understand how to walk the walk when it comes to having those kids in class. And I honestly can’t think of other situations. We did him in some regular camps and things like that where he would sometimes have behavior things come up. And I guess one of the things that come to mind, he did have two friends at high school. And one of them was the one that that incident came up with when he went after him that day. When I told the mom that he’s on the autism spectrum, she was like *“oh, that’s his problem.”* And then it turned out after that conversation, her son had been the instigator of everything and didn’t hear back from her again. Anyhow, it’s hard to answer that question because the community for us has been all the autism support services that he’s received and the families of the few friends that he had. So, I don’t know how else to answer that.

**Interviewer:** No, you did great. There’s no right or wrong answer here. Whatever you answer is going to be great no matter what. So again, thinking a little bit more broadly again towards the future, what hopes or worries do you have in terms of how his community will react to him and his sensory needs in the future?

**Interviewee:** I think in a way we are blessed because as difficult as it’s been for us, I’m sure it was a thousand times more difficult for people even five years ahead of him. And I think there’s so many more kids getting diagnosed. All the focus right now is on early childhood intervention. **[00:42:50]** They really drop you off a ledge after high school in terms of what you can get. And so, my hope for him is that there will be more living opportunities available and services for adults that are not so very difficult to even find. It took us forever. Even after all my tones of internet searching, I found Chapel Haven through a friend of mine whose daughter just was diagnosed. And one of the things they said at Chapel Haven is because there’s a hot pocket area for autism because of all the high tech and stuff, that the community of New Haven in general is more accepting of these corky kids being there and so our big hope is just he can have as much of a normal life as he can and when we’re not around, be in a situation where he’s able to take care of himself and have all the support he needs. I really want him to be around people he can be friends with. Again, I feel like that’s really lacking in his life right now. He has a younger brother; I don’t want him to end up being a burden on his younger brother and that’s probably it. I hope he can be in a situation where he feels as happy as he possibly is able to. **[Dog barks]** And there is my dog.

**Interviewer:** No, no worries. We’re going to shift again. In the quote-unquote transition to adulthood, where do you see your son?

**Interviewee:** Where in that process he is right now?

**Interviewer:** Mm-hmm.

**Interviewee:** I think he’s had some good maturity in the ways that he, I attribute a lot of it to Franklin but in the ways that he views himself and his special corks and needs. He’s much more understanding and accepting of those now. And we talked about I think he’s in a good place with kind of having some self-regulation, *“I need to step away from things.”* In other ways, with maybe spending money and taking care of his basic needs, and some of his social interactions and stuff, he’s probably still more like a 15-year-old or something. Those are areas where he’s going to lag behind. He did have a girlfriend at Franklin, and I didn’t know if that would ever happen. It was very magical to watch how that whole autistic relationship unfolded with them. They dated for several years and I don’t know if he’ll ever date again. She initiated that entire relationship, and it takes a special person to do that. But that is something that I would hope for him as well. I feel like he was definitely happier when he had this person. Sometimes, he felt a little bit overwhelmed, but you know how it is when you break up with somebody. He’s like *“wow, that was a good thing I had.”* He got to go to prom, he got to do things where I was just like *“wow.”* I’d seen him around one other little girl who was on the spectrum when he was younger, and I saw how they were comfortable together and I was kind of like maybe. He’s not the easiest person to be with and it was very cute to see the two of them accept each other’s very big challenges. So that is something I really hope again that he could have, that kind of experience. Just as a cute aside, I had asked him at one point, ‘cause Chase told me *“mom, I cannot read faces.”* He *said “if I put all of my energy into looking at your face, I can tell you if you’re happy or sad, but I can’t hear what you’re saying because I’m having to focus so hard on reading your face.”* So, I was like *“well if that’s the case, how did you and Paige ever end up together?”* And he was like *“oh well, she just came to me, clearly, we liked each other, we needed to date, and I was okay with that.*” But he said he was like *“you think as a neurotypical you have it better, but you don’t ‘cause you misread each other’s signals and you get mad at each other and don’t talk about it.”* This is what he saw with other people in high school, and he said you know, *“we just tell it like it is.”* And I thought that was a really interesting perspective. Once you lock into that relationship, and I think as much as his issues affect his life, if he ever dates, it’s going to have to be somebody on the spectrum. But I just thought that was a really interesting perspective – *“we actually have it better than you folks.”* So that was cool.

**Interviewer:** Yeah. That’s wonderful. I’m glad he had that experience. Thinking a little bit about his stage of independence, could you describe some areas where he has independent versus some areas where he still needs some support?

**Interviewee:** You know we kind of hit on all those again already. He can go to the grocery store, he did not want to drive, and he hates driving but we did several years of DBT and they did actually get him to get a driver’s license, so he was able to drive to his job and that was a huge thing ‘cause I was having to drive him many, many hours a week I was driving him to things. So, I feel like he can feed himself. I think grooming is going to be a huge issue for him. Clothing is kind of an issue. I think he discovered at maybe fourth grade that if he wore t-shirts with funny or corky sayings, people would talk to him. They would stop and laugh at his shirt or something. It would create an interaction and so from that point on, for years, he wore nothing but t-shirts. We had like 30 or 40 and they all had sayings. I’d be at the airport watch people just laughing, *“hey, that’s really funny.”* And so it was interesting that he kind of figured that out and now, he wears some of those but he’s morphed into t-shirts and he's got like 20 or 30 of them all related to this one cartoon or podcast or something he's interested in that wouldn't make sense to other people and where I'm going with all of this is he spent a whole lot of his money on these t-shirts which I didn't realize he was doing. But he won't buy other clothes for himself. He will not buy shoes or socks or pants or jackets or anything. I don't know how he's going to cross that line. I can't even get him to tell me *“would you wear these pants”* so that's going to be a problem and he's very good with bookkeeping and money understanding wise but he's very poor with money management in you give him money and he will send it and that's going to be a big struggle for him that we worry about. We did recently have some doubts with drinking that we’re concerned about. He went into a dual diagnosis rehab that turned out to be a train reck because they didn’t really understand autism. We had to speak very quickly on drinking and autism and it’s a very different thing than a typical alcoholic. We came to realize that even AA and things are not necessarily very good things for people on the spectrum. Right now, he stopped cold turkey and has been fine. But that has been a concern when he’s away from us that that could be an issue again. But I could also argue he had the maturity to stop. He’s held off that. And I don’t know how much this is a maturity thing because I think it’s going to stick with him for the rest of his life, but his hands down biggest challenge, which has always been his biggest challenge and will continue to be, is he has zero initiative. He will know all these things he should do but he is not able to, even with the things he knows he will enjoy, he cannot seem to watch. And that keeps him from a lot of things and causes a lot of problems. Again, I don’t know if I would call it a maturity thing, but I’ve seen no change on that at all. He doesn’t tend to think of things to do unless he’s told to do them, and I don’t know that that’s ever going to change. Socially, I would say, he comes across to people as extremely mature socially. He’s very articulate. One of the things he has got extremely good at, even though he hates it and it’s distracting, is he makes incredible eye contact and that’s part of the reason I think it’s very difficult for people to figure out he’s on the spectrum. You will feel like you’re having a normal conversation in terms of eye contact with him, and he will make facial expressions back and he gets sarcasm very easily so he will laugh and joke. He will talk at length about things that drive people nuts. He does have all that kind of stuff going for him. But what I repeatedly hear, and have heard from adults for all these years, is he’s so polite, he’s so respectful, he’s so pleasant to talk to so he comes across as very mature in that way and that’s going to help him. And I’m trying to think maturity wise. We’ve probably covered most of what I could think of.

**Interviewer:** Yeah. No. That was wonderful. Thank you. **[00:53:33]** Does he ever express interest in wanting to live on his own or be a little bit more independent in that capacity?

**Interviewee:** Yeah. I mean I think he…I don’t know that he wants to be away from us, but we’ve all recognized that this is not a good situation for him right now. If he had his brothers, he would probably live in like a dorm. He likes small spaces, but he likes having a space to himself and what Chapel Haven has, he will start out in an independent room, but then a year, he’ll move into an apartment with somebody where they will share an apartment space. And I think he very much would like to live on his own someday. That is a desire that he’s expressed that’s come up in therapy sessions and things like that. We love him but we all recognize this is not a good situation for him. For any of us. Especially for him. He, from my perspective, needs to live in like a shared living environment, like at Chapel Haven or at least have a roommate or he would just lock himself in a room and never come out is my suspicion. So, yeah, I do see that happening. If he were just to go out on his own, I don’t know how he would manage with keeping up with taxes and all that kind of stuff.

**Interviewer:** Yeah. Absolutely. And how is he with helping with the household chores and things like that?

**Interviewee:** Horrible.

**Interviewer:** Oh, horrible? Okay.

**Interviewee:** That is a lot of sensory stuff. He hates the sound of the vacuum cleaner. He cannot stand to hold sponges, or he’s grossed out by other people’s dirty dishes. He doesn’t like the feel of water on his hands, like for cleaning sinks and stuff. And so, I’ve gotten like *“well, here’s the sponge on a stick”* or whatever. But aside from maybe occasionally unloading the dishwasher or taking out the trash, his sensory issues get in the way of pretty much everything else.

**Interviewer:** Yeah, absolutely, that makes sense. And you talked about feeding himself briefly. Can he prepare simple meals and cook a little bit?

**Interviewee:** Yes, he does. That was the thing they focused on at Franklin and he can cook stir fry and he’s a big lover of Asian food, so he is capable for sure of doing that.

**Interviewer:** That's wonderful. You mentioned some friends briefly. You talked about his previous girlfriend. Does he manage a social life to some extent?

**Interviewee:** To some extent. Here, he has no friends and no one he goes out with. He had one friend from Franklin who was at UT **[00:56:16 inaudible]** which is a two-hour drive from here and they met up a couple of times before the pandemic and they did talk some. He stayed in touch with several friends from Franklin in a gaming environment. If I asked him, *“oh, what’s going on in his life? I don’t know.”* They game together and he has started with one of his cousins and a couple friends of his doing a Friday night dungeons and dragons thing and he’s got a couple of other online groups he hangs out with. But no physical contact which is another reason we want him back in Connecticut. It’s all just online. Aside from this one kid, Joe. They did get together a few times. And I think that’s something he needs. I don’t know how much he recognizes that he needs it, but we see a noticeable improvement when he has in-person contact with people in terms of personality and stuff.

**Interviewer:** Yeah. Thank you. And then do you think he will be able to achieve more independence in the future?

**Interviewee:** We hope so. Again, that big kicker right now is with the initiative and that he just can’t generate *“I should go do this, I should take care of that.”* He will do what he is told but it won’t dawn on him to think beyond that point. And I don’t know because of that, it’s too early in the game. He ran up his credit card, but he did pay the monthly payment, so we’ve seen some tip of the iceberg stuff that yeah, he can do some basic things. But it’s very hard to get a clear picture right now. If I were to throw him in an apartment or something without the support, what that would look like.

**Interviewer:** Yeah. Thank you for sharing that. Is there anything that you think would help him move into adulthood a little bit more?

**Interviewee:** Being back in this environment.

**Interviewer:** So, in Franklin you mean?

**Interviewee:** Just any environment anywhere where he can live with other people on the spectrum and one of the things, I would do Franklin all over again, but it cost more than our house. It’s like $80,000 a year and it’s not something that you can maintain. That was the one thing that hit me was so many of the families there were not wealthy families. It was people who were at the end of their ropes like we were, and over and over for parents when we got there I heard *“you are not going to recognize your child a month from now. They’re going to be so changed by this place.”* And I because I actually rang all these families, you know,maybewe should start something like that here, but I’m overwhelmed enough as it is. I mean I wish you could see it. How powerful the difference it made to have him in that environment in terms of what he was capable of doing. They would push him in ways that the regular school system could not socially. And I just really have come to the conclusion that it’s a better life for him if he can be…and I think it’s because he was able to drop his guard and not feel worn out by the people he’s hanging out with. I don’t see him functioning well in any environment outside of that. And my hope for everybody with autism is that these communities become more and more affordable. That is one thing which Chapel Haven, from a cost perspective, they’ve got some grants and stuff like that that make it a much more affordable situation than some of the other programs we’ve found out there.

**Interviewer:** Yeah. That makes sense. Thank you for sharing that. So now putting these two things more explicitly together, his sensory sensitivities and his transition to adulthood, how do those things intersect for your son?

**Interviewee:** Well, clearly, from a job perspective, that’s huge. It’s going to limit how many hours a week he can work. There are jobs he would probably be very good at that are just off the table because of sensory issues and I think there’s certainly jobs out there that would work for him, going to be more challenging to find. Again, I think from the other things, if we found enough adaptations and he knows he has to be asked to wear certain clothes for certain things, he’ll do that. He can get around all the food stuff by just avoiding what he doesn’t like. It’s going to close some doors for him as an adult. But I think there’s enough go-arounds that in the right sort of circumstances, he can find something that works for him. We can find something that works for him. And then, I think even a lot of people that aren’t on the spectrum get exhausted being around other people. I’m exhausted if we have company for several days. Those are things I think people can be, to an extent, more understanding of. It may be not such a big deal for him as an adult. And it has been really helpful to us, I’m looking away cause I’m thinking so much. But it’s been helpful to us just seeing with the work environment that he has been in. This was a great exercise for us because he did get plopped into an ideal work environment for him, working for this sweet little lady in this quiet room with dark and dog and all that. Without that perspective, we had no idea, like can he work five hours a week? Is he capable of full-time? And I would say at this point, he is not capable of a full-time job. He’s worn out by 20 hours a week in the best of circumstances. At least we know that now. And, so, I don’t see that changing. And that is probably the biggest thing where the sensory would affect him. It’s going to limit how many hours he’s capable of working. I keep telling him if you do pursue the mathematical career thing, you’re going to make a lot more as a CPA and as a bookkeeper you may want to think about a situation where you just buckle down and do taxes, taxes, taxes for several months, make a whole ton of money, don’t work for the rest of the year. Or some such version of that where I’m trying to encourage him if you can only work 20 hours, make as much money as you can in that 20 hours. That’s probably the biggest barrier he’s going to be up against is just that he can put himself in those environments and wear those clothes but there’s a top limit.

**Interviewer:** Thank you. That was wonderful. And would you say his sensory sensitivities are an obstacle, a vehicle, neither or a bit of both towards his independence? **[01:03:38]**

**Interviewee:** A bit of both. I think he’s found coping mechanisms for a lot of it. But it is going to be an obstacle in terms of how many hours a week he can work. What maybe to an extent what his social life is going to look like.

**Interviewer:** Yeah. Absolutely. And then relatedly, what do you anticipate as being challenging for your son as he does gain more independence in relation to his sensory sensitivities?

**Interviewee:** I don’t know the answer to that question right now. Just because he and we have figured out a lot of stuff that I can tell you, he doesn’t like fabrics, but a lot of people have this thing, have variations, milder variations of that. And because we have seen so many adapting mechanisms. If he can be in an environment that’s like a Franklin or a Chapel Haven, then he can work 20 hours a week and he can make enough to support himself and have some physical social life, I think he’s going to be in a good place as an adult.

**Interviewer:** Yeah. Sounds like it. Is there anything that you think would help your son at this intersection?

**Interviewee:** I mean clearly again, being back in an environment…what I was pondering, when you said that, is there any way, but I don’t think there is, this whole initiative thing, is there anything that we have missed that can help him with that? And clearly, we would have done it if there was. That would be hands down the thing that would help him the most but that may just not be part of his brain hardwiring. It looks to be a losing battle right now. Again, just getting back in that environment where he’s around people like him. Lots of levels is probably the best thing that’s going too…I may tell you something, he may tell you differently a year from now.

**Interviewer:** That’s okay. Things change. Beyond this environment you’ve talked about so many times, is there a particular therapy or intervention that you think could be helpful?

**Interviewee:** So, one thing I’ve read a lot about on the alcohol side of things is how helpful CBT is and we had not done as much in that realm. He did several years of DBT and whether he lands at Chapel Haven which looks very likely or does not, CBT when we get past the pandemic, is something that I do want to pursue with him. From everything I’ve read, that’s one of the best things to deal with, from an alcohol perspective over AA and rehab programs and all of that. And I’d be curious from the DBT, I would say the biggest thing he got out of that was him driving, and if we can see some small wins with that, that is something I would want to pursue. Otherwise, at this juncture, I feel like we have exhausted everything we could find. I could go on at length about all the interventions and therapies. It’s a long list.

**Interviewer:** I believe that. And do you feel like there are gaps in the available services and interventions for folks like your son?

**Interviewee:** Oh yeah. They all kind of have their limitations and I think this is true in any situation, but especially someone on the autism spectrum, it’s finding the right person who, there were therapy people that I really liked, it’s just he didn’t click with. It’s actually funny like the first psychologist who diagnosed him when he was a child, he never went back to her after the diagnosis, but I’ve stayed in touch with her all these years. She checks in on me. I have called her at midnight before. But he didn’t click with her. She read him like a book. And I was mesmerized watching how she pulled answers out of him that I didn’t think possible. So clearly, there’s just that whole element of it. And then we’ve bumped into a number of people over the years, psychologists and stuff that very quickly, you start seeing they really don’t grasp what autism feels like. They have the title, not the experience and that was very frustratingly true in this program we just did, this dual diagnosis program with the alcohol that they were like *“oh, yeah, we get some people on the spectrum and stuff”* and very clearly, we were like *“this is a horrible environment for him.”* So, there are definitely gaps there.

**Interviewer:** Thank you, no, that’s wonderful. Thank you for sharing that. And then broadly again, how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Well, clearly, we now have that understanding again of what he is capable of working. That’s hands down the biggest thing. How many hours. One of the things that we had read even when he was very young and got the diagnosis is you have got to start thinking now about where your kid’s going to land as an adult because you’re going to have to push them towards that. They’re not likely to find it on their own. Is your child good with numbers or are they better with…and that was the fascinating thing at Franklin was to see the different things that all these kids gravitated towards. One of them became a pilot. It was just like all over the board. You’re like *“wow.”* So, from a very young age, I’ve always kind of had that in mind, you know, where’s he going to land. He’s always been on the math, science side. He did try some engineering in college, not his thing. He's not interested in computers and so I do feel like this whole accounting, bookkeeping is going to right now be his sweet spot. He does have a lot of interest in science, so I can see him maybe working for a science or technology company in that capacity. Otherwise, I would say that I can’t think of anything now cause it’s something we’ve been focused on for so long. And again, clearly what we have seen in this last year, prior to the pandemic, is he is capable of some level of work in the right environment. And that’s going to drive everything going forward.

**Interviewer:** Absolutely. Thank you. We’re going to move onto our last chunk of questions. It’s the shortest ones so we’re almost done. Thank you. So finally, as a caregiver, as a parent, as a mom of someone with autism but also these sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** Hands down, and you probably will hear this answer from every parent, our biggest fear is what happens when we’re not here anymore. And that’s going to be the crossover line for me. And I’m going to categorize him as an adult, when he’s in any situation that he can sustain for the rest of his life, with living and work. And in terms of maturity and other areas, those will come with time and as much as he’s not as far along in some ways… I feel like he’s an adult to me right now, just the way he talks and the way he behaves. The fact that he’s got this understanding of what pushes his buttons. It’s not perfect by any means. He still has his moments. But we’ve come a very long way. Can we get him into a situation where we’re out of the equation so we’re comfortable if something happened tomorrow or ten years from now or whatever? I don’t want him to end up on the street. And he has no, no, what’s the word I’m looking for that most kids don’t have, not initiative but he won’t stand up for himself. Advocation. And so that’s my big fear like if things did go wrong for him, he’s not likely to reach out to anybody and that’s where we could see him ending up on the street or something. And so that is our big focus right now. That’s the crossover line when I can say *“okay, he can clearly make enough money”* and we will get him qualified for a disability at some point. But just to sustain a life without us.

**Interviewer:** Mm-hmm. Yeah. Thank you for sharing that. I appreciate it. Has this perspective changed over time for you?

**Interviewee**: No. It’s been our goal for many, many years now.

**Interviewer:** Yeah, no, that’s wonderful. And what do you see happening in your son’s future?

**Interviewee:** One thing that I’ve learned is that I don’t because so many times when we’ve pinned hopes or thought things were going to work out a certain way, it’s come back to bite. **[01:13:45]** And so, after so many of those kinds of experiences, it’s just day-to-day. While Franklin was perfect and he would go back there now, he was ready to leave there by the time he left. I think he understands though *“okay, maybe those things bothering me weren’t so bad after all.”* So, my husband and I have a very clear understanding that something can work out and then it can suddenly not work out anymore. And so that very much tampers it. We have hopes but not expectations.

**Interviewer:** Do you see him having a part-time job, even if you’re trying to keep your expectations loose?

**Interviewee:** Yeah. I mean I think we’ve seen he’s capable of that and the one thing we’ve seen with him is…part of the social challenge, when you’re locked in a room and you’re playing games with people all day is you really don’t have anything to talk about with other people. *“Gee, what’s going on in your life? Well, sitting and computer gaming all day.”* It gives him something to talk about and feel important about. And he briefly helped me at a period a few years ago with a situation that had come up with work and I called him to run a lot of numbers with my father-in-law and it kind of, and I heard him talking to his cousins about it. I was like he’s finally got something to talk about. So, I think that’s probably a big piece of his social life is that if he can have work, it gives him something to talk about with somebody. It’s stunning all these kids he games with that he was friends with at school. He has no idea what’s going on. If they’re working. If they’re not. Anything. Sometimes where they’re living.

**Interviewer:** And do you see him moving into a support living environment that you’ve described?

**Interviewee:** Yeah.

**Interviewer:** And do you see him having a family of sorts, whatever that may mean for him?

**Interviewee:** I think he has enough appreciation now of the relationship that he had. It was hard to see that break up. I think he would go back to that girl in a heartbeat. Now that he kind of understands, he said *“I realize now what I didn’t before”* which was another grown up thing. But if he could get back in that situation, I would be thrilled. And it was so interesting and cute as a parent looking in to see how they took care of each other on their bad days. How incredibly supportive that relationship was to both of them. He held her up. She held him up. And it’s hard to find females on the spectrum. Even the year that he went into that school was a very strange year because they had almost a 50/50 split of female/male. And Chapel Haven, on the other hand, I don’t even know if there’s any women there. So the likelihood of him meeting somebody is going to be greater in that place than it is in the community but it’s still going to be challenging. I cannot see him having kids. I would not want him having kids. I even worry about my other son having kids because of how very, very hard it’s been for us all these years. We would not wish that on either of them. So I hope that he does not have children, especially if he does have a wife on the spectrum as well. That’s going to really set the odds in a bad way. But I would love to see him even in just a girlfriend situation or something.

**Interviewer:** Yeah. Absolutely. Thank you. Last final question, so how have your son’s sensory sensitivities impacted this perspective you just described in terms of what it means for him to transition into adulthood?

**Interviewee:** Again, clearly, it’s affecting work. That’s a lot of what adulthood is, is you transition from a student life to a working and self-supportive life. I would say it’s probably going to limit the types of social interactions he has but he’s still very capable in the right environment of having the kind of interactions he needs to have. I don’t think the food textures and things like that are going to be a deal breaker for him. And that kind of need for quiet, I’m kind of working my way through the senses here, that need for quiet is something he can get. He’s still capable of going to a parade or things like that. It’s just knowing he’s going to need those two days of quiet to recover from it. Also from a noise perspective, I could see it affecting… he would have to be in a quiet office and it’s going to affect where he lives to a point cause seeing when we were in Ireland how agitated he was with that street sound and stuff. He doesn’t like the light, but he’ll go ahead into the light if something is pushing him. He will go to work; he will get on that schedule and he will meet up with friends in the daytime and stuff. So I don’t see visually that being an issue. I’m just thinking through kind of adulthood and how this comes into play. So I don’t know that it’s creating unsurmountable barriers. It’s him realizing the adaptations he needs to make to keep him from pushing past his point of what he can cope with. And so, absolutely, it’s going to paint what his future looks like and what he is as an adult. There’s no jigging around that. But it’s not in such a fundamental way that it’s going to change his life in a way that he perceives, in a bad way.

**Interviewer:** That makes sense. Thank you. That’s all I have. Thank you. Would you like to add anything else?

**Interviewee:** No, I think we’ve kind of covered. Nothing’s jumping out. We’ve covered it pretty well.

**Interviewer:** Okay. Thank you so much. I know it went over but it was such a pleasure to learn from you and it was so valuable. Thank you for all your time.

**Interviewee:** It was great talking to you as well. So, are we all done with this study or what?

**Interviewer:** Yeah. We’re great. So the next step is as soon as we’re doing chatting, this audio and video will start to render. It’ll take a few hours. So either later this afternoon or tomorrow morning, I’ll send you a final follow-up email and it will include the gift card as compensation for all of your time and effort.

**Interviewee:** I just feel like the people who pave the road to get to where we are who helped us out have been through hell and the people coming up behind us are going through their own personal hell and anything we can do to help those people coming up and help his age group. I sincerely, sincerely hope that they start putting more focus on adults because it’s really frustrating to us right now how much everything is geared to little children, we’re like as soon as they’re done with the Emory and the Marcus Institute and all of that… When we hit issues like the alcoholism, *“nope, can’t help you,* *we don’t have any resources”* and I’m kind of like *“you know these kids you’re studying, they’re going to be adults someday”* and so that’s kind of one of my goals right now is just how do we help back. And when we hit the alcohol issue, there’s only like two studies out there but they were massively helpful to us when we suddenly hit that barrier. And thank God, those studies had been done. And so, I hope the kind of stuff you’re doing makes life easier for some parents coming up and some kids coming up.

**Interviewer:** Thank you. Well, we couldn’t do it without you. And I do actually know somebody doing an alcohol study with older individuals. It is on people’s radar and I do think that people are realizing that little kids are not little forever. From my perspective, I think it’s shifting towards that direction so hopefully it keeps on going that way.

**Interviewee:** Yeah. Absolutely.

**Interviewer:** Hopefully, your son gets the support he needs as well.

**Interviewee:** Yeah. Yeah, so okay, well, thank you so much.

**Interviewer:** Of course. My pleasure. Do you have any final questions for me, anything I could do to clarify?

**Interviewee:** I think we’re good. It’s been a very big pleasure talking to you and thank you.

**Interviewer:** Likewise. My pleasure. If you need me, please reach out. You know where to find me.

**Interviewee:** Okay. Will do. Take care, Rachel, thank you so much.

**Interviewer:** Bye.

**Interviewee:** Bye.

**[END OF TRANSCRIPT]**