**[Start of transcript]**

**Interviewer:**  Okay, we are recording. I will be asking you questions about your child’s transition to adulthood in relation to his sensory sensitivities and some sensory interests. And, we’ll be doing something a semi-structured interview, which means I have my planned questions here but will also be adapting the questions to follow our conversation, to make it actually fit to what for what we’re talking about. Do you have any questions before I begin?

**Interviewee:**  No, I’m good.

**Interviewer:**  Okay, awesome. And, if there are any questions that you don’t want to answer, that make you uncomfortable, that’s perfectly fine, we want to make this a positive experience.

**Interviewee:**  Okay.

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

**Interviewee:**  Okay, so you mean like things that he’s sensitive about? Like, what bothers him and stuff?

**Interviewer:**  Yeah, like either things that bother him or things he really likes or both.

**Interviewee:**  Okay, so umm, I know, I think right now, he tends to go through phases, you know like he changes from…like for a long when he was younger he would like walk sideways everywhere he went and only use like one hand, like if I made him go with me to like the store or something, he would push the cart just using like one hand and he would do things like that. And, so through the years he’s kind of transitioned to different things. The latest one he does now is he doesn’t want anyone behind him, like looking at him behind, so sometimes he’ll turn…like if he’s putting the dishes away, he’ll turn completely around if someone else is in the kitchen and face and then do things behind him and things like that. If he has to be out, he’ll pull his shirt down real low, so I guess it’s his way. I’m trying to figure it out. I always feel like if I can figure out what’s causing it, then maybe I can try to help him deal with it better. And, so I think that’s his way of trying to cover himself from behind so no one can see him. Right now, he has his computer desk, in the other room but his chair sits in the corner so no one can come behind him and no one can see his computer, no one can see any of the stuff he’s doing and so part of that is just being behind him. It’s a very odd thing. It’s frustrating but that’s what he does. Let’s see, as far as…he still will walk sideways, a lot of that is just to, I think it’s mostly just to avoid anyone getting behind him. **[0:3:00]** He will not wear like shorts, he only wears long pants and he only likes to wear like track pants, he won’t wear jeans. And, when he was working for a short period of time, he would wear dress pants, he didn’t want to but he would. He went through a long phase where he would constantly wear his bath robe and I think again that’s a way to keep people from seeing him and to work with that we compromised because I’m like, *“You can’t go to work wearing a bath robe.”* He would wear a suit jacket, even though it was way over what was necessary, he wore a dress jacket. I actually got him a couple that were a little over sized, so it could help cover him.

**Interviewer:**  Yeah, no, that’s a great compromise.

**Interviewee:**  Yeah, so I try to find things like that, to try to work with him and help him fit it or at least be out there. I can’t think…

**Interviewer:**  I think on the form you mentioned he doesn’t like being touched?

**Interviewee:**  Oh, yeah, yeah, yeah. I cut his hair, I don’t take him anywhere to get his hair cut and he lets me do that. It was a while before he would get really comfortable but I can’t just come up and touch his hair but if he knows, *“Okay, we’re going to cut your hair now,”* then he’s okay with it. But, I couldn’t just like come up and give him a hug or something or even like touch him on the shoulder. I think if you said, *“I want to touch you here”* as long as he knows you’re coming then he’s fine with it. I don’t think he likes anyone touching him. I don’t think he even let’s his siblings touch him. I mean, he’ll let you if you have to but yeah, there’s no like, walking up and giving him a hug.

**Interviewer:**  Yeah. On the form you also indicated having a limited pallet and dislike of loud noises.

**Interviewee:**  Yeah, so he doesn’t like use any condiments. He won’t use ketchup, mustard on French fries, on his hamburgers on nothing. When he eats a hamburger it’s like he eats bread and a hamburger.

**Interviewer:**  And that’s it?

**Interviewee:**  That’s it. I make him eat, well I don’t make him, when we had dinner, whatever we have, he has to eat at least a bite or two of everything and it seems like over the years he has gotten better at eating things. I won’t even put like coleslaw or something like that **[0:06:00]** on his plate but I’ll give him the cabbage and he’ll eat the cabbage. Or, he won’t eat a salad with salad dressing, of course none of my kids eat salad, it’s so weird but anyway.

**Interviewer:**  My boyfriend doesn’t either.

**Interviewee:**  I guess it’s healthier, it’s the best way to eat it. He’ll take the spinach and just eat spinach; you know what I mean. He’ll eat what I want him to eat but he especially doesn’t like…he complains all the time about things being sour. He doesn’t like tomato sauce cause he says it sour and I’ve questioned whether or not he’s…they have super tasters or something? He just seems to be super sensitive to tastes. He doesn’t really want too much flavour. He’ll eat barbeque chicken pizza though; he will eat that but I have to be really light on the barbeque sauce. I’m trying to think, a lot of times now he’s been doing this thing where he has his glass of water when he eats and then he’ll…especially if it’s something he doesn’t like, he’ll put the food in his mouth and then he takes a big wad of…big drink of water and the chews it up and swallows it all at once.

**Interviewer:**  Like deaden the flavour.

**Interviewee:**  Yes, I don’t know. I mean there are certain things he’ll always eat. He’ll always eat peanut butter, he’ll always eat yogurt, those were the things I think saved him from starving to death when he was young, peanut butter and yogurt and he likes cereal. He use to drink milk all the time but he doesn’t like milk anymore, so he just drinks water mostly.

**Interviewer:**  So, you said that he’s better at eating now, was he much more limited previously?

**Interviewee:**  I think he would just…I think it’s just over the years or just complaining a lot about it. I think I would just…like I told you, I would make him eat at least one bite of everything and now he just does it. Before, it would be like, *“Just try it, just try it”* Now, I think he’s just gotten to where he just shoves down and moves on.

**Interviewer:**  What does he do after he has those couple bites if he doesn’t like it? Will he get something else that he likes or will he not eat?

**Interviewee:**  Oh no, he’ll eat other stuff. He’ll eat more of whatever else. If I do…what did I make the other night? I can’t remember what I made. I use to have…when I use to make spaghetti separate from the sauce, now I just too it all in the instant pot but before the instant pot I’d make spaghetti and then I’d have sauce and then he would just want to take a big pile of noodles and so I would be okay with that as long as he ate also a little bit of sauce, even if it was on the side. He would just gobble it down and **[0:09:00]** then enjoy his big pile of noodles.

**Interviewer:**  Gotcha. Thank you. And then also on the form you said he doesn’t like loud noises sometimes, could you talk about that?

**Interviewee:**  Yeah, I mean I don’t know. I think all of my kids, I think everyone in my family is very sensitive to sounds, like chewing noises, slurping noises, things like seems to both…well it bothers me, it bothers everybody, we all seem to be a little sensitive to sounds and stuff like that. Yeah but that’s gotten better, I just think most because he knows now where they’re coming from. I think when he was younger and maybe a fire truck went by or the smoke alarm went off or something like that, he didn’t know what was going on, so it kind of scared him. I think now, he knows where most of that comes from, so he’s better with that.

**Interviewer:**  Can I ask a follow up question? We’re talking about touch and cloths, is that okay?

**Interviewee:**  Yeah.

**Interviewer:**  You said that he doesn’t like shorts and only prefers pants that are like track suit material?

**Interviewee:**  Yeah.

**Interviewer:**  Does he have a textural or clothing type preference for other types of cloths? Like for shirts maybe?

**Interviewee:**  Yeah, he wears t-shirts and he prefers then to not have anything on them, just be plain, no writing or anything. It’s just gotten over the years where he has whatever stacked in there. He doesn’t leave the house; he doesn’t really go out much so it doesn’t really matter. He wants them long, he wants everything long, like his t-shirts long, he doesn’t want one that actually fits him right, he wants it to be long.Yeah, I’m trying to remember, he came out of…we started home schooling him when he was a freshmen, I’m trying to remember, I think he wore track pants to school, the first part of his freshmen year and in middle school. He use to wear…I’d just make him wear jeans, when they’re younger…put them on, you know what I mean? Then they get older and they’re like, *“No,”* dressing themselves. I’m trying to remember. I could probably ask his brother when he stopped, when he switched completely. I don’t really remember exactly when.

**Interviewer:**  Do you know, about the jeans, does he not like the tightness of it or the texture? They can be kind of scratchy sometimes.

**Interviewee:**  That’s a good question. I think he like the feel of them because I asked him the other day, he has a couple pairs that he likes the best and they seemed to be the slickest. There are two types, there’s basically the ones that are like polyester type and then there’s the other kind that are like windbreaker material **[0:12:00]** and he likes the polyester ones better, I don’t know if because it’s they’re soft, I’m not sure exactly. I think it might be because they’re soft.

**Interviewer:**  And the shirts that he wears, are they cotton shirts?

**Interviewee:**  Cotton t-shirts, yeah.

**Interviewer:**  And what if he has to go outside? Is he okay with jackets that might be less soft or something?

**Interviewee:**  He prefers…he mows the grass and he’ll go outside and it will be 90 something and he’ll wear his coat, his winter coat and his fleece pants. I think it’s cause he just wants to hide and be covered up and so that’s usually an argument between us because I really don’t want him to have heat stroke, we’re way off the road, nobody can see him and then he just makes me promise that I won’t look out the window and watch him mow the grass, I guess he can go straight with the lawn mower because pushing the lawn mower backwards with one hand is not really very safe.

**Interviewer:**  That would be hard. How does he manage these sensitives or how do you help him manage these sensitives?

**Interviewee:**  Well, I let him have his computer desk the way he wants, so no one can look behind him. Like I said, with the coat we did that. When he was actually doing his internship, we did the coat thing, the suit jacket. I made a stress ball out of flour and I just busted it. His dad one time took him to the dentist and he was 15 or 16 and I wasn’t home, I was somewhere and so his dad had to take him and he let him wear his bath robe, I don’t do that. He’s not two, he can’t wear his bath robe. We compromise with…I try to find lighter weight things to wear in the summer, they can be long sleeve but let’s find a jacket that’s long enough that you feel comfortable with but that won’t cause you to have heat stroke, things like that. That’s what we do, outside too, if he’s going to mow, I try to find jackets that are lighter so that he can…

**Interviewer:**  Kind of like safer substitutes in a way?

**Interviewee:**  Yeah and then he’ll ask me sometimes to leave. He’s gotten better at knowing he doesn’t want anyone else. If he’s putting dishes away, I’ll say, *“Can you please turn around and face so you don’t break anything?”* And he’ll be like, *“Can you leave?”* So, I’ll leave the kitchen so he can put the dishes away with no one looking over behind him. Those kinds of things. **[0:15:00]**

**Interviewer:**  What about for sounds and for touch, how does he manage those sensitivities as well?

**Interviewee:**  He has headphones that he can put on if he needs to tune out of everybody. He also is … basically is either in his room or he’s in the computer room. He…it’s kind of more isolated anyway, so it’s a little bit quieter in there, I guess. He can come ask if somethings bothering him but usually, he’s just gotten use to us I think over the years.

**Interviewer:**  Gotcha. What about for touch? You talked about kind of like preparing him for moments where you need touch him, do you do anything else to help him with that?

**Interviewee:**  I go slow, I’ll tell him what I’m going to. Sometimes it will take me a few tries to…like with is haircut, he just knows, I can just go right at him and he’s fine with that. He, he grows a beard, he’s like has this big orange beard which is so funny because he’s kind of slight, he only weighs like a 108 pounds and short but then he has this big, giant beard, looks like a pirate, like read beard or something. I’ll be like, *“Can we get that off your face?”* and so the only way he’ll shave…this is so gross, he’ll be really mad at me if he heard me telling you, is that he has a beard bag, so he has a plastic bag, this was our compromise, what can I do to get that beard off your face? And the only way I could get the beard off his face was if we save it. So, he has big Ziplock bags, he has a Ziplock bag that says beard and then he has one says moustache because apparently, they’re two different things and so when we shave it, we have to catch it and put it in the bag. I’m like whatever, if it gets it off your face.

**Interviewer:**  It’s a compromise, you’re both happy.

**Interviewee:**  It’s fine, I just say, *“Keep it in your room, I don’t want to see the bag”* He does have a tendency to hoard things.

**Interviewer:**  And then with taste, your talked about asking him to try lots of things, how else does manage? How else have you helped him manage his sensitivity to taste?

**Interviewee:**  I’m trying to think. That’s basically it. I usually just cook one meal deal usually, the rest of it they’re 20 something, he’s 25, so he certainly should be able to find something for breakfast. So, he’ll make **[0:18:00]**is own lunch and then then I usually make dinner and then so he has to eat whatever he has or if I really know he’s going to hate it, I’ll make something. If I’m going to do fried rice or something, I’ll just have some plain rice for him. There are a couple times, like I said with the noodles thing that I’ll do that because I mean it’s not fair that has to always eat our stuff. He makes his own and I just make sure that he’s trying to think about being healthy, like, *“If you eat peanut butter can you eat yogurt or can you eat some fruit with it?”* and he’ll do that kind of thing.

**Interviewer:**  That’s great. Has he received any services or interventions to help him with his sensory sensitivities?

**Interviewee:**  No, no, not really. We had a first evaluation cause he…before we knew what was going on, second grade he got to where he was like…wouldn’t speak at school, soon as he walked into the school doors, he just was completely non-verbal and then he would come home and he would be fine. We almost pulled him out of the school and put him…because I think to me, it was like he associated the school with whatever the issue was, it was the school that was causing it. Basically, what we figured out or at least what I think figured out, was that they didn’t know really what was going on and they kept trying to help him and the more they tried to not mother him but help him, the worse it got. So, they would say things to him like, *“Okay, Ian, would you like to go music class?”* And he’d be like*, “No, I don’t want to go to music class,”* because he didn’t like all the changes, moving from here, to here, to here and in second grade it was crazy, they were changing like every 15 minutes, they were moving, doing something else, either going to gym or going to art or moving from tables to go into this. Because I did a checklist to try to help, to encourage him to participate, I make up a checklist and then if he did enough checks the teacher would check it and I couldn’t fit all the things they did in the day on one sheet of paper. I have them, so I kept them and I showed them to the teacher, I said, *“Look at this,”* and I have simplified this, this is a lot of stuff for any child to be switching every day and then you’ve got a child who he’s fine once he gets into something but transitioning from one thing to another was really difficult and would take…it just took him a little while to catch up and by the time he caught up **[0:21:00]** they were moving on to something else and it just got to the point where he just had such a hard time. I completely forgot what your question was.

**Interviewer:**  No, that’s okay. I kind of forget what my question was too, so I can go onto my next one. That was really interesting, thank you.

**Interviewee:**  I still have those checklists though. It didn’t make any difference.

**Interviewer:**  I had asked if he had received services and you said not really.

**Interviewee:**  So, we took him in, he got his diagnosis I guess, it was a while ago, they were like Asperger tendency or something like, which was enough apparently to get him and IEP, which was fine. What they recommended was socialization. I’m like*, “Okay, well that makes sense because that was his biggest issue.”* He was fine academically, he was fine with other things, it was just his social, he just didn’t know how to talk to people. I had suggested that they do like a lunch buddy group or something, a few of the kids could come and then he could just practice, *“Yeah, yeah, yeah,”* that didn’t happen. Basically, what they ended up doing was putting him in speech class and so he would go to speech therapy with the other students, even though he didn’t need speech therapy and the other students would go, *“What are you doing here? Why are you in speech therapy?”* They literally would say that because he would come home and say, *“they asked me again mom”* It helped sometimes with the other students I guess, I guess in that way it helped him a little bit. I don’t know. I guess I could have put him in a bunch of stuff. I think at the time, everything that I was reading was things…you go back and forth with, I should have done this, I should have done that and if I’d have done this would it have been better? I know the school was absolutely zero help, zero. No, he didn’t have anything.

**Interviewer:**  It’s okay. I’m sure you did your best with what information you had at the time and that’s all you can do, right?

**Interviewee:**  Yeah, yeah, I guess, I don’t know. Again, I go back and forth with, should have I kept him in the school system instead of pulling him out? Should I have done this, done that? I don’t know. You just do what you can do, I guess.

**Interviewer:** Absolutely. I the beginning of our conversation you talked about how he goes through phases with sensory sensitivities, so how have they changed over time? How have his sensory sensitivities changed?

**Interviewee:**  So, I guess maybe not so much his sensitivities **[0:24:00]** cause those seem now that I’m thinking about, those seem to be with the clothing, with sounds, with touch basically, like always. What changes is his quirks or the way he reacts when he gets stressed, I think, that’s kind of the things that changed. I think for a while, I’m trying to remember because it’s been so long, I don’t write all this stuff down, you think you’ll remember it. I think he was doing some weird clicky things, like with his eyebrows and stuff for a while and then he did something with hands and it was just really repetitive and I don’t if the repetitive stuff was comforting to him. When I took him in to see a paediatric neurologist because he was doing the side walking which I thought it was very odd, even more odd than just some of his other stuff but it just seemed like…it just was really weird, the whole walking sideways and only using one hand and so, I thought, *“Maybe there is something neurological, maybe a physical thing going on too in addition that’s causing him wanting to do…?”* Anyway, that out to be not, I guess. It was just weird the way the neurologist looked at him when he was walking, it was just the weirdest, I don’t know, I was really offended. I thought, *“You’re a neurologist, you never seen any child do something weird?”* that’s kind of how felt about it. She was like, *“That’s really odd.”*

**Interviewer:**  Even if she hadn’t, you would think she would know how to react better.

**Interviewee:**  You would think. I’ve gotten that a lot through Ian’s life, *“We’ve never had anyone like Ian before. We’ve never seen anybody like this before.”* First kindergarten teacher said that to me. Apparently, the neurologist, the paediatric neurologist said that too me, a lot of teachers have said that too me throughout his years, which is… I don’t know, I was glad that I had training in social work so I didn’t take it personally and overact and think. I would just think, *“Aren’t you a professional? Should you be…even it’s true, should you really be saying these things to a parent, to make them…?”* I don’t know.

**Interviewer:**  I’m sorry that happened.

**Interviewee:**  I’m use to it. It still happens actually, so there you, what do you do?

**Interviewer:**  I’m sorry to hear that, it must be really hard?

**Interviewee:**  It can be.

**Interviewer:**  What about his sensitivity to food, has that remained the same as well?

**Interviewee:**  He’s always been really picky. **[0:27:00]** I’m trying to think, I don’t think it’s really changed much, he’s always liked plain food, no nothing, just plain. That’s pretty much stayed the same.

**Interviewer:**  You talked about he’s more willing to try all the foods you want him to though, do you think that change is related to any independence that he’s gained over time or any other changes that you’ve noticed?

**Interviewee:**  I think it seems to…what we think with Ian is that now that he’s gotten older, I think he realizes that it’s more important that he try because I think when he was young…so my parenting style was more of a take away a privilege, instead of punishing I would say*, “Oh, well Ian, you’ve lost your computer time or you can’t do this or whatever or you can’t have that toy or whatever it was.”* And what Ian would do, is if you tried to use that on him, he would just say, *“The hell with it, I don’t want that anyway.”* Well now what do I do? If he knew you were going to power struggle with him, he would just give up, *“I don’t want nothing to do with this.”* I learned pretty early that you had to come at it with a different way. *“Ian, if you want to fit in with other people, you have to try to do this or that.”* He was like, *“I don’t care.”* You have to remember, Ian is a twin, so he has a built-in friend sitting right next to him every day. Also, my friend’s son is their age and she was here all the time, so he was here all the time. It’s not like he had to go out of his way to try to find other people, he had a couple built in. I think that kind of made things easier for him in that way, that he didn’t’ have to do that. So, my point is, until Ian wants to do it, until Ian thinks it’s important, it ain’t happening. You can’t make it do it. I’ve never been able to make him do anything. People say, *“Just make him,”* have you not met him, he’s just not going to do it. If doesn’t want to do it, he’s not going to do it. And so, I think when he did is internship, he did an internship with Department of Defence over the summer right before he graduated, the year before he graduated and it was completely, terribly unsuccessful and for a lot of reasons, that’s a whole interview process right there. But, since there **[0:30:00]** I think he’s had a lot of time to think about and we’ve talked a lot about what happened and what things he could do to be more successful and I think he cares now. I think he sees his brother going to work every day and he sees my friend; my friend’s son is a police officer and he sees him going to work and he’s not still and his sister now is in college. I think he realizes that now maybe he has to try a little harder and so I think he seems to have made more progress but it’s only because he’s decided that maybe this is important, not because you care. You couldn’t influence him, you just couldn’t. We had a couple incidents where I took his computer away, now if you mess with his computer, he gets very upset, so it was the only thing I could do cause nothing else mattered so I took his computer away for something, I can’t remember what it was. He had to take out the garbage or something really simple and he’s like, *“I’ll take out the garbage when you give me my computer back.” “No, take out the garbage and then you can have your computer.”* My husband was like, you two drive me crazy because you’re both stubborn. He went up to his room and he would not come out of his room for like a day and a half. He just was not going to budge, he was not taking that garbage out, he just wasn’t going to do it. Finally, I just said, *“He’s going to starve to death,”* so finally I said, *“Fine, you can have your computer back,”* and he went right to the garbage and took it out. That’s the…so, when Ian wants to do something Ian’s motivated to do something but if he doesn’t, you can’t make him do it.

**Interviewer:**  Do you think the drives that you’re talking about, like his desire to try things now, do you think that’s related to independence that he’s gained over time or perhaps seeing that his brother and his friend have gained more independence?

**Interviewee:**  I think both, I think both. I think seeing that, *“Oh, I guess I am getting older, other people are getting older.”* I think it’s part of it. We’ve talked many times about dad and I aren’t going to be here forever, so what are you going to do? We have to get you ready to be able to take care of yourself and that means learning how to go to the store and interaction. He’s got his permit but getting your driver’s license and finding a job and being able to be successful there. I mean he’s got his degree, he graduated from college so he’s smart, he just **[0:33:00]** so yeah, I guess in that sense I think it’s probably been both.

**Interviewer:**  For sure, awesome. Thank you. And then when he is faced with scenarios where is exposed to sensitivities that doesn’t like, perhaps clothing that is not of his liking, loud noises, touch that is unexpected, does that cause or increase anxiety for him?

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

**Interviewer:**  What does that look like for him?

**Interviewee:**  Let’s say I make him go to the store with me or something, shoulders go up like this, he’ll hunch over, he’ll pull his shirt down, he looks like super paranoid, he’s eyes will dart back and forth, he’ll try to walk up against walls. Yeah, it can be really…he’s extremely anxious.

**Interviewer:**  How does he manage that or how do you help him manage that anxiety?

**Interviewee:**  That’s a good question. It’s hard because sometimes it’s just like, *“It’s not even worth, if he has to go through all that, it’s not even worth dealing with it.”* Part of it is I just try to encourage him, *“Okay, I’m going on this errand will you drive the car? Will you go?”* Trying to get him out, trying to take him to places where he is more comfortable, over at his friend’s house or places he’s been before. He went on vacation with us to Maine, I drove up to Maine.

**Interviewer:**  That’s a big drive.

**Interviewee:**  Yeah, it was a long drive. I drove up by myself, the kids just sat and read their books. Anyways, he didn’t want to go but doesn’t cost anymore to have him sitting in the car, he can sit at home or he can sit in the car, so I was like*, “Just come with us, I promise I won’t make you do anything you don’t want to do, that’s our deal. I’ll ask you to do all the things we’re going to do but if you don’t want to do them, I’m not going to make you do them, you can stay in the house.”* That was our deal. We went up there and my sister was there too and I would hear her in the other room, “*Oh, come on, Ian, come on.”* I said, *“No, that’s not the deal. The deal is we would ask him to go.”* And she’s like, *“You should make him go.”* I’m like, *“No, that’s not the deal. I’m not going to go back on my word. I made a deal with him and I’m not going to pressure him and I’m not going to make him feel bad.”* I finally got him to go…we were going to go look at some light houses and I said*, “Would you please just come? You don’t have to get out of the car, you don’t have to get out of the car, at least come in the car with us.”* He came in the car with us and then I’m like, *“Do you want to come out of the car?” “No.”* **[0:36:00]** I’m like, *“If you change your mind, we’re going to be right there, you can see us.”* There’s my sister again*, “Come out, come out, come out.”* I’m like, *“You really have to leave us alone because he’ll never do this with me again. He’ll remember this forever and he’ll never trust me again.”* He was fine with it, he didn’t care, he never came out of the car but you know, he did go, he went with us.

**Interviewer:**  Yeah, that’s good.

**Interviewee:**  You know, what are you going to do?

**Interviewer:**  Absolutely. And have these sensory situations always caused anxiety for him?

**Interviewee:**  I think yes but I think when you’re younger, I think you can cover it better. When you’re 10 or eight or six, it’s not unusual to be really shy and quiet and sit in the corner. When you’re 20 it’s kind of weird. I think as he got older, it seemed that his quirks and ticks and weird things that he would do would stand out more because he was bigger, you know what I mean and older. It’s a little weird now. I think he’s always had the anxieties and stuff it’s just they show themselves more now, I think.

**Interviewer:**  Absolutely. Then, thinking to future, what are your goals or hopes for your son in regards to the sensory sensitivities and sensory interests?

**Interviewee:**  Well, I’m hoping at some point he’ll get to the place where he’ll be able to actually go and do a job, be a programmer or whatever somewhere, in an office with other people and be able to set it up where he can feel comfort but yet still be able to do a job like everyone else. I mean there are days when I think, *“He can do this.”* My friend will come over be like, *“I can’t do my computer whatever,”* and I’ll have Ian help her because I want him to practice. He’s very calm, very patience and he’s an excellent teacher because there is no question that is stupid for him and he’ll take all the time you need and he’s really good at it. I think, *“He’s going to be great.”* And then there is other days where*, “Dude, I’ve asked you 100 times, can you just write this email, it’s only two sentences?”* And it will take him three days to write an email with two sentences and you’re like, *“He’s never gone to.”* I don’t know. That’s my hope is that he’ll be able to…I guess if he wanted to live independently he could live independently, if that’s what he wanted to do, that he would be able to have a job that he could get to and get home from, **[0:39:00]** he would able to pay his bills and live independently and be happy. I told him, *“You got to get a job to make enough money, have good internet and a nice compute because games is what’s it’s all about and you need a job for that.”*

**Interviewer:**  Absolutely. Now shifting gears slightly. As Ian has grown up and aged a bit, how has your and his community reacted to his sensory sensitivities?

**Interviewee:**  I remember…. well, like I said, I think when he was younger people would just go, *“Oh, look, he’s just a cute, little, shy kid.”* And I think as he’s gotten older it’s not as tolerable when you have a child who’s doing that. And, I think when looking for services and stuff, there’s hardly anything for young adults. If you’re under 18 there is all these things and all these programs and all this stuff, which is great because they weren’t there, I think a few years ago when Ian was under 18, so that’s a good sign. For young adults, I know there is a ton of kids like Ian around here that would be employees if they could find someone who would be supportive of them in the workplace but there just isn’t that, they’re just not there. Sorry, I don’t know why this is making me tear up.

**Interviewer:**  No, it’s okay. Are you already?

**Interviewee:**  Yeah, I’m fine. I’m fine.

**Interviewer:**  Do you want to take a bit of a break; we can also resume at another time if you’d like?

**Interviewee:**  Nah, I’m already, go ahead. I think that’s the most frustrating, there’s just not support in the community yet for that, you know?

**Interviewer:** Absolutely. I think a lot of parents share this frustration and like deep upset about the lack of services. I’ve done a bunch of these interviews so far and that’s been a really strong theme. You’re definitely along in that feeling and it’s a shame that feeling has to exist.

**Interviewee:**  I mean I think if he was more…not as smart as he is it in some ways might be easier, I don’t know, maybe not.

**Interviewer:**  Absolutely.

**Interviewee:**  I’m sure there’s a lot of people like me, I’m sure. Just got to find those people in the workforce that will be willing to, you know, go out of their way a little but to help them.

**Interviewer:** Absolutely. You’ve said this a couple times but would you say that when he was younger his community was more accepting of him? **[0:42:00]**

**Interviewee:** Absolutely, yeah.

**Interviewer:**  Were there specific aspects of the community that were more or still are more accepting of him? You’ve talked about school briefly being not helpful, what about family or friends? You’ve talked about his workplace.

**Interviewee:** Definitely, I mean I can’t say the workplace was a good place and now it’s not because he hasn’t been there. Family, my family lives in Illinois, which is quite a way’s away so we don’t really see each other often. The few times that we have, they’d always seem to be so shocked, it’s fine, you know what I mean? But because they hadn’t seen him in a while and so I’ll get some grief about that. I got grief about home-schooling, I got grief about him not being in programs, if there were programs, I didn’t even know about them that he could be in, you know what I mean? What do you want me to put him in? So, there is some of that. I don’t really know how my family would respond to them. I don’t really, we don’t really take him around that much. I don’t know.

**Interviewer:**  Yeah, absolutely. Thank you. I just have one more question in this section than we’re going to switch topics, so we’re almost done with this one. What are your hopes or worries how his community will react in the future?

**Interviewee:**  Well, I’m hoping at some, we’re been trying to get him into some sort of work program, where we he would have support at least in the beginning of his…until he got till where he could be comfortable in the job or they could be comfortable around him. Just little things like knowing you can’t just walk up to Ian and say, *“Do this, this and this,”* and walk away, you know what I mean? It’s not going to work with him but if you write it down and hand it to him, he’ll be fine kind of thing or that you might have to…he might be a little slower on some things but very methodical, like there aren’t a lot of people that will sit and look through code. Ian sat a calculus test, it was like eight and a half, nine hours, did not take a break cause you can’t, you can’t leave it’s in the testing centre at the college, couldn’t leave, sat in there, I went there going, *“Where is he?”* they had literally closed the testing centre, his teacher took him out of the testing centre and took him to this classroom, testing centre was black and there’s no Ian…like eight, nine hours, this is crazy. It was one problem and he knew the answer wasn’t right, even though he kept getting the same answer **[0:45:00]** he just kept doing it over and over and over and he worked on one answer for two and half, three hours, plus he went back over the other ones but he finally got the answer that he knew was right. There aren’t a lot of people that will do that. In some ways that can be very not useful, when it takes you two days to write an email with two lines in it and other times, you need people that are willing to do that kind of work.

**Interviewer:** Absolutely.

**Interviewee:**  But until… I mean we just did…he got into the WRP program, which is the workforce recruitment program, where they’re supposed to take people that are recent graduates and help them find jobs and I was all excited and of course nothing ever…by the time Federal Government…I mean Alec was working, trying to get him someone take him back because his internship was unsuccessful, so I think he has a big black mark on record there but he found a group that would take him and all of that and by the time Federal Government got around to saying okay, it was we only recruit in the spring and it was already two weeks after that. That didn’t come out. Then there was another one Dars, he was part of Dars, that’s not working out. It just seems like we keep getting these…maybe these opportunities and then nothing ever seems to pan out on the other side of which starts to get really frustrating. Right now, we’re looking at the WIOA, which is the…through Goodwill but what Ian needs, he needs someone…he needs a company that’s willing to do a little extra work with him, to help him get acclimated. He needs a consoler or a support system person who can come in there and kind of…I think if he would have had that with his internship it would have been successful because they could have found that that wasn’t the right group for him, he needed to be somewhere else and they could have found out what was going on with him, instead of him just going in everyday and feeling lost and confused and not sure what to do. At that point, Ian didn’t want to disclose, he’s learned that that’s important, that he needs to do that. That’s a learning lesson. But, until he has those two things, I don’t…unless he accidently got into a job how also has a child who has Asperger’s, who understands you have to be very specific, you have to be very literal, you have to be very patient, you have to be very directive, unless he gets that, I just don’t see how it can happen. **[0:48:00]** I think he would be fine once he got there, he can’t through a job interview, he just can’t. He thinks he does well, he just…his mannerisms, he’s so nervous, you can imagine, he’s like this, they’re just like….and he comes across as someone who’s not very smart, I mean he graduated with honours, he can do the work, you know what I mean? He’s just not going to go have cake with you for your birthday.

**Interviewer:**  That’s okay.

**Interviewee:**  He’ll eat the cake but he’s not going to go and stand in that group of people that are singing, there’s no way, it ain’t happening. So, yeah, anyways. If he gets into the right position and sorry, I talked to long.

**Interviewer:**  You’re good. You answered my question, you’re good.

**Interviewee:**  You know, that’s what’s getting most frustrating, it’s cause it seems like a simple…he did get accepted into Dars but they have three levels of… they have moderately disabled, significantly disabled and severely disabled and Ian got labelled the middle, significantly but right now, they only have enough funds to work with the most disabled, so he’s on a waitlist.

**Interviewer:**  That’s such a bummer because you’re so close.

**Interviewee:**  I know, it keeps happening. I try not to get my hopes up that this is going to be the thing that’s going to help him get in the door but anyway.

**Interviewer:**  I’ll keep my fingers crossed for you.

**Interviewee:**  Yeah, so it’s frustrating, it’s frustrating.

**Interviewer:**  It sounds like it. We’re going to move on to our next chunk of questions if that’s okay?

**Interviewee:**  Sorry.

**Interviewer:**  No, no, don’t apologize. We’ll go back to this area too, so no need to apologize, please don’t. In terms of the transition to adulthood, where do you see Ian?

**Interviewee:**  Right now? Where do I see him as…he definitely…if I could compare him to my other kids, I see him at about 14, you know what I mean? That’s the way I look at him, 14, 15, can do somethings but most things, he’s just not ready mature wise and in some ways, I don’t know, he’s interesting that way. Some ways he’s very independent and in other ways no, not at all but that’s kind of where I see him, if that answers your question?

**Interviewer:**  Yeah. Could you give some examples of **[0:51:00]** ways in which he is independent but ways in which is also not independent? I have some prompts if it helps?

**Interviewee:**  Okay.

**Interviewer:**  You talked about cooking; can he also shop for himself for food?

**Interviewee:**  He never has, I guess I probably should be doing that. Make him do that with me. I get worried though, with the virus, he’s kind of slight and small and I worry about him being out.

**Interviewer:**  For sure.

**Interviewee:**  He’s very happy with the virus, that no one’s leaving the house. Let’s see. He can use the microwave now, he went for years without using the microwave and wouldn’t tell me why he wouldn’t use it and I finally found out it was cause one time he had to make food and he said, *“I started fire,”* and I’m like, *“That was in the toaster over, not the microwave,”* and as soon as I told him that, he went right back to using the microwave.

**Interviewer:**  Okay.

**Interviewee:**  But it took me like three years to get him to tell my why he wouldn’t use the microwave, three years, *“Tell me why so I can figure it out,”* and usually, if you can figure it out what it is that’s behind all this, I can’t figure out the side walking thing, I haven’t figured that one out yet. So, he can’t make breakfast and lunch, which isn’t really making, it’s kind of like putting it together. He does his own laundry.

**Interviewer:**  That’s great.

**Interviewee:**  Takes a while in between but he does his own laundry. Let’s see, he can, we’ll his got his permit, so he is driving, kind of. He mows the grass, I mean he does chores, he’s pretty much the only one that empties the dishwasher and loads it back up, so he’ll do chores and things like that. He takes out the garbage. Our thing right now that we’re struggling with is every Wednesday the garbage has to go down and it’s like, *“Dude, just put a reminder on your phone, it will go off and remind you,”* and so that’s just trying to get him to use tools to make his life better and I’ve even talked to him about…since there isn’t an app that we can find that he likes, I said, *“Why don’t you write an app, you’re home?”* He’s writing a couple games, his own games, he’s making up a game that he’s writing and doing the code for it. One of the things that Ian does is he doesn’t like to use other people’s stuff, so he does a lot of things from scratch instead 0:54:00] saving the time. I don’t understand it because I’m not a programmer but that’s why my husband and other son say that he does, he wastes a lot of time doing things that have already been done. So, I guess in that way he’s independent, I guess.

**Interviewer:**  What about personal hygiene, is he good with that? Does he need reminders?

**Interviewee:**  Well, yeah. See, I think that’s one of those things where he doesn’t care, cause I’ll say, *“Dude, you smell, go get a shower,”* and he’ll be like, *“I can’t smell it.”* Doesn’t matter, I’m telling you, as someone who can smell you smell, go get a shower. And so, that was another thing with trying to use the tool to remind. I think Ian would probably ever bathe again but I don’t know and he’d probably wear the same clothes everyday if you don’t just, *“Dude, you’re killing me here,”* every once and a while he’ll go, *“Oh, do you think I should shave, I’m feeling kind of itchy?”* I’m like, *“Dude, you’re 25, shave if you want to shave. Go get your bag.”* We’re trying to work on that but I mean he brushes his teeth twice a day and he flosses. He’s better at washing his hair when he does get up there but I do have to remind him most of the time. I’ve tried to get him to use his app to remind him to go take a shower, even though he doesn’t think he smells.

**Interviewer:**  Gotcha. Does express interest about wanting to live on this own one day?

**Interviewee:**  No. My sister and I were talking one time because her husband works, he also works in computer science, he’s more of a network guy and he’s in Illinois and he had talked…this was another time where I got my hopes up, he was talking to them about bringing Ian in as an intern, even an unpaid, I said, *“I don’t care, he didn’t have to get paid, he just needs to work somewhere and get experience and get comfortable,”* and so his company was up for it and everything ended up not panning out but when I told him, I said*, “You would have to like Illinois because that’s where they’re at,”* and he said, *“I want to live in my own house.”* I don’t think he really wants too, to live anywhere else, I think he wants to be here with us. I don’t think he wants to be anywhere else.

**Interviewer:**  What about money management skills, how is he with that?

**Interviewee:**  None of my kids like to spend money, I guess that’s a good problem to have.

**Interviewer:**  I’d say so.

**Interviewee:**  He has like all his birthday money he’s ever had. He will buy…they do buy games on Steam, like he’ll buy computer games. **[0:57:00]** But it’s usually $1, $2, but he’ll give me the money, *“Here, I bought this in Steam,”* he’ll use my PayPal and he’ll give me money. I guess in that…I don’t know. I guess in that sense he prefers to buy his own stuff, we say, *“We can get you a new computer,”* and he’s like, *“Oh, I’ll buy it,”* because he did make money when he was working at his internship, so he has…plus he has all the money for his birthday’s and Christmas’s and everything. The worst would be that he would never spend it, you know what I mean? That he works and have millions in the bank.

**Interviewer:**  Yeah and not use them for things he needs to.

**Interviewee:**  Right, exactly.

**Interviewer:**  Like, he is able to pay bills if he were to have bills? Like would he know the concept of that?

**Interviewee:**  Oh yeah. He knows when he buys something on PayPal, he has to pay me and he does right away, he comes and pays me. I think he would…the trick would be to try to get him to do auto pay or something, that would be better for him, it’s better for me, I don’t forget that was either. Just knowing that okay, this is something that it’s not your strength, so how can we make it so you can be successful? Auto pay, there you go. He doesn’t have any bills or anything other than that little bit of stuff and that’s been always.

**Interviewer:**  What about friends? You talked about the built-in friends of the family friend and his brother and his other sibling, does he have friends outside of that? Does he manage a social life of sorts?

**Interviewee:**  No. I don’t know if he…I think for a while that he had some people that he played online with but they were people he knew before, that he knew from school and I don’t know if he was doing it because of him or with his brother who was doing it and so he was doing it as well. I think there are but if you ask him, pretty sure, who are your friends, he talks about Davide like they’re still hanging out all the time, you know what I mean? We see David on maybe holidays. David is a really nice kid, he’s just really…he’s always just found Ian really interesting and different and plus he always looked out for him and stood up from him and stuff so he didn’t get picked on. He always took care of him.

**Interviewer:**  That’s nice.

**Interviewee:**  I don’t know if Ian ever knew that.

**Interviewer:**  Is this your friends’ son or a different kid?

**Interviewee:**  Yeah, the same one. Now, that’s been…I made Ian do Boy Scouts **[1:00:00]** but again, I think in a way it was harder in some ways because Alec was there too, you know what I mean, so. Now, he mostly hangs out with his sister a lot, they play games, since she’s home now and his brother too.

**Interviewer:**  Gotcha. You talked about his job a lot; does he want a job? I know he doesn’t have one right now.

**Interviewee:**  I think if he could pick, no. I think Ian’s perfectly happy sitting in there playing his games all day long. He would be perfectly happy with that and not have a problem with and I don’t think he would every feel like…I guess in some ways that’s a blessing that he isn’t…I’ve seen other shows about adults with Asperger’s and how they struggle so much to make connections and really want to have friends and can’t seem to figure it out and it causes them a lot of pain. Ian doesn’t care, you know what I mean? In some ways, I guess that’s a blessing because he doesn’t have that. Unless he wants to.

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

**Interviewee:**  I think so. I think…again, he would have to want to. His brother’s been talking about moving to West Coast or somewhere and that might be what it takes to and his sister, she’s going to Korea. When they’re gone, it might be what is that kind of push for him to go out but I don’t know.

**Interviewer:**  You talked a lot about his drive as being what motivates him. Do you think there are other things that could help him move into adulthood?

**Interviewee:** Like?

**Interviewer:**  Like maybe services or interventions that you wish he had access to?

**Interviewee:**  I go back and forth with that. I mean I’ve talked to him about that. Again, maybe I just let him get away with it in some ways. My whole experience with him his whole like has been like, if he doesn’t want to do it, it ain’t going to help. So, when you ask him*, “Would you want to go talk to somebody?” “No,”* he doesn’t want to do it. I guess I could push him but, yeah, I don’t know, maybe. He has been…I have had him go to the college to talk to them at the career services, probably do that more when the world gets back, **[1:03:00]** we kind of stopped doing that. He was at the disability inn and he did have a mentor, she called him every now and then and they talked and that was all that every came of that but he talked to her. He’s been to some job fairs and he probably…when I think about it, we probably ought to do more…he’s pretty quiet so sometimes you forget, *“He hasn’t done that I a while, probably should make him do something,”* he’s not going to do it on his own, you know what I mean? I have to go, *“Hey Ian, have you looked for any job fairs or did you call at Mayor Walsh to look at your resume again?”* he should probably do more of that interview practicing. He has been doing a lot of…in computer science, when you go on job interviews, I’m trying to remember what the name of it is, something code, lead code is what I think it’s called and so what it is, is a bunch of small programming challenges and so a lot of times on job interviews with computer science they’ll say, *“Here, solve this, do this code,”* and so he does that, he does that all the time.

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

**Interviewee:** Actually, talked to him about whether…because he was thinking about doing cyber security or something like that, so I had him sign up for an online master’s level class, he was so stressed about that, so we dropped that. I think he would have been fine but it was the first class he would have taken that his brother wasn’t taking because his brother is computer science as well, so they were through college together, they did the same classes, a couple that were different but mostly the same. That was really stressful so I just said, *“Drop it, it’s not worth it doing that.”* Again, I should write down your questions.

**Interviewer:**  I can send you this interview if it would be helpful, it’s all in writing already.

**Interviewee:**  Sorry, I do talk a lot.

**Interviewer:**  No, please don’t apologize. This is the beauty of an interview, I get to learn from whatever you want to say, so they more the merrier, please don’t apologize.

**Interviewee:**  Yeah, so that’s what we’re looking at. I probably can try to find. For a while we were going to, there was a group in Fredericksburg for adults with Autism and my husband, who is actually finally realizing that he thinks he might be on the spectrum as well, I kind of knew that a long time ago **[1:06:00]** he’s just now kind of putting it together, he took him because I said, *“You take him,”* but the people…and that’s fine, it’s great for what it was but they dentist come in and talking about the proper way to brush teeth, Dan’s like*, “It’s not really what Ian’s needs,”* that’s for people who are much more lower functioning then were Ian is . Unfortunately, that didn’t really pan out. We did try that a few times. He was working at a…he was teaching computer skills at a group home for mentally disabled people and one of the kids had Downs Syndrome and I don’t even know what the other, some women’s in a wheelchair, there is different levels of functioning but he would go once a week and help them individually one on one on their computers, my husband went too until he felt comfortable. But he did a really good job with that but unfortunately COVID came and then we had to stop doing that. I thought that would help him because it probably be the first time Ian’s been a room with people who he would actually feel like he was higher functioning, you know what I mean? So, that was a good thing we were trying to do and I thought that was therapy in a way.

**Interviewer:**  Yeah, for sure. It sounds like experience is what is helpful for him in that sense, like it was a great experience for him.

**Interviewee:**  Yeah.

**Interviewer:**  We’re going to shift gears again if that’s okay? So, not putting these two things together, sensory sensitivities and this transition to adulthood, how do they intersect for Ian?

**Interviewee:**  I think in order…it’s weird because you’re like*, “Shouldn’t he just be able to be who he is?”* but in order to be accepted in society there’s a certain way that people expect you to behave and is normal kind of thing, with him and his sensitivities, especially to people being behind him and having to walk into a room with a bunch of people you don’t know and all that stuff, that until he can get more practice with that I guess or find ways to deal with that, I don’t know…I mean it’s going to be really hard for him to be out in the world, just being a…you know what I mean?

**Interviewer:**  Yeah.

**Interviewee:**  Unless people know, you know what I mean? It’s just him because he does look very odd, very odd when does, it’s just very odd **[1:09:00].** I think his other thing is I think he has this weird, to me it’s weird, twisted view of his diagnosis, his Asperger’s, he sees it as an unfair advantage. So, at junior college and at school they knew ‘cause he had an EP and then he had a 504 and then he had nothing and big mistake for go for EP to 504, don’t ever encourage anybody to do that cause they completely just drop the ball completely, 100 percent, he didn’t have a consoler anymore. He never wanted to tell anybody, so he had a problem with one teacher who gave him a C in history because she took his lack of not participating and his how he looks like he’s sleeping sometimes when he’s closing his eyes so he can concentrate as not participating and so even though there was a score where he participated, she dropped him to a C in the class because she said he wasn’t participating or whatever, even though that wasn’t part of …it really mad me made. We worked with his consoler, that’s really not fair, his advisor, it’s really not fair because if she would have stopped him at any moment and asked him what she was talking about, he would have been able to tell her everything she was saying but she just read his body language and misinterpreted it and then punished it. He missed a B by like 0.003 percent or something like. Anyways, I’m still bitter about that. But yea, it was really unfair, I thought because she misinterpreted it. Use to have another teacher there that he went into for communication class of all things, introduction to communication and she told him at the end of class that he would be much better in an online class and I thought, that teacher, first of all that’s fine because she’s an idiot because she missed an opportunity to teach her other students how to communicate and how there are people who communicate differently and how we could use this as a learning experience for all of us, so I’m like, *“She’s not the teacher for you,”* so we switched. But…so he had his disclosure letter in **[1:12:00]** and he had accommodations when he went to college, when he went UMW he didn’t want nothing to do with it. His accommodations at junior college were extra time on tests, I think that was it, I think that was his only accommodation that he would accept, but he didn’t want any of them at UMW, so he didn’t have anything. Now, his teachers of course could pretty much tell there was something a little different but he didn’t have…he everything like everybody else did. And so, he thinks that telling people gives him…it’s hard to understand, I’ve tried so many times to understand and explain it, I think he thinks it gives him an advantage, *“So I get extra time, that’s not fair to you that I get extra time.”* We talked about if you’re golfing with someone else and you know, they’re a much better golfer than you and you’re competing that it’s not fair that you just do it from scratch because you want to make elite level. I’m thinking that as soon as he can agree with that, realize that, maybe in some ways it’s not fair, that I’m not equal. Some ways his Asperger’s makes him a much stronger candidate but in other ways it doesn’t and so we’ve talked about that. I think until he can accept that and learn how to talk about the autism and what it means, then I think he’s going to have a hard time fitting in.

**Interviewer:**  Do you think his sensitivities to sound or touch or taste impact his transition to adulthood?

**Interviewee:**  I think so because yeah, it triggers his… the way he moves, the way he stands, the way he walks, the way he talks and all those things and so when he gets anxious because of everything around him, I think definitely it impacts it.

**Interviewer:**  And do you see his sensitivities as an obstacle, a vehicle or a bit of both or neither towards his independence?

**Interviewee:**  I definitely see it as an obstacle. I think he just…he needs to learn how to overcome them I guess, I don’t know. It some ways it makes me mad because it’s like, he just is who he is, why is that wrong? But, yeah. Yeah, I think it’s definitely an obstacle, yeah.

**Interviewer:**  What do you anticipate as being challenging for him **[1:15:00]** as he does gain more independence in regards to his sensitivities?

**Interviewee:**  I think with him, I think it’s just getting confidence, I don’t think right now he…like if you talk to him, *“How are you with programming?”* He says he’s slow, he reads slow, I can’t think as fast as other people, so that means he’s not as good as other people, so I don’t think he thinks that can do a good job. I think even though his brother has told him, who works with other people, *“I’d rather have 100 of you than any of those people that I have on my team that are dragging everybody down, at least I know that I’d have to work a little more up front but in the end, I’d have something quality at the end.”* So, I think…I don’t know if he buys it yet, you know what I mean? I don’t think he’s believing that yet. Right now, I just think he sees other people thinking and moving and everything is much faster than what’s going on in his brain and I think that makes him feel inadequate and not as smart as other people in that sense.

**Interviewer:**  Absolutely.

**Interviewee:**  But it’s really interesting because we’ll be sitting at dinner and Dan, cause all three of them are computer and Dan will bring up something, my husband and then Alec will start talking about it, something they did in school or something and Ian will be sitting there and he’ll go, *“No, Alex, that’s not right,”* and then he’ll correct him and it’s just so interesting to me. It’s like Jesus, how do you remember that? But he’s able to do that but still that doesn’t bring him any confidence, you know what I mean?

**Interviewer:**  Like realizing he actually is skilled in this area.

**Interviewee:**  When Alec first started, he would call Ian at home and say, *“Ian, how do we do this?”* and then Ian would help, you know what I mean? And so, it’s just interesting to me.

**Interviewer:** Absolutely.

**Interviewee:**  Can someone let the dog out please? Sorry. Can someone let the dog out please? Thank you.

**Interviewer:**  We can pause if you need to do it?

**Interviewee:**  No, she’s ringing the doorbell. We have a bell on the door and she rings it when she wants to go out.

**Interviewer:**  That’s really clever.

**Interviewee:**  Accept some days she just rings and rings and rings. Thank you. Thank you, Ian.

**Interviewer:**  We’re almost done. What do you think will help in this regard, in this intersection of sensory sensitivities in his transition to adulthood?

**Interviewee:**  What do I think what now?

**Interviewer:**  Would help him?

**Interviewee:**  I think exposure. **[1:18:00]** I think exposure, exposure, exposure and that’s on me, I feel like I’ve probably dropped the ball on that because life gets busy and you’re like, *“Just got to store, I don’t time to get him to push the cart right.”* You know what I mean? Part of that’s on me, a lot of that’s one me. So, I just think repetition, exposure, some way to get confidence and having support there and maybe I’m missing the agency that’s out there that’s there for him that I can’t find. Part of the problem is, we don’t qualify financially for outside services, we have too much and then other times it’s he’s not disabled enough or he’s out of school too long or he’s not still in school.

**Interviewer:**  That perfect fit for him.

**Interviewee:**  Yeah, it’s really hard to find it. I read stat the other day of how many…the percentage of people, the adults with Asperger’s that have a college degree that are unemployed, it’s very small percentage, I don’t even remember off the top but I know that it wasn’t very many and that made me depressed. It’s like how many have college degrees, one woman was like, *“My son has two masters degrees and can’t find a job.”* Holy crap, I don’t know how he could ever get through an interview if it wasn’t set up with…someone who has a disability that we want to bring in, we’re hiring people with autism, here you go, here’s one. Just regular walk in the door. When I kicked him out of the car when he went to the job fair, I was just like, *“Oh my god, I can’t believe I’m sending him in there in his own.”* He was fine with it but I can’t imagine it went well. He was fine, he’s like, *“Works fine.”*

**Interviewer:**  That’s good at least though. Do you think there are particular services or interventions that could help him in this intersection?

**Interviewee:**  Yeah, absolutely. I think if he had a job coach. I think if he had… because we went to the Virginia Department of whatever it was, something, that’s where the Dars was, rehabilitation, anyway. **[1:21:00]** they were supposed to help you search for jobs and get your skills. Well, he has the skills, he just needs to have someone, have companies that are willing to take people with a disability and then have somebody transition him through the interview process and then give him some support while he’s first starting out. It wouldn’t be a permanent thing, it would just be, you know, however long it took for him to feel comfortable where he was and them to feel comfortable, figuring out how can we make you be successful.

**Interviewer:**  Yeah, for sure. Do you think there are gaps in the available services and interventions?

**Interviewee:**  100 percent yes, big gaps.

**Interviewer:**  What do you wish existed? Is it this job coach position that you’re describing or what else do you think needs to be out there?

**Interviewee:**  I think in addition to that they could have possibly services that…I think they might have apartments, I think they have apartments here in town, where people who are higher functioning, they live independently but they have monitoring and I think that’s here, we’ve never really looked into it too much, I thought I heard that it was here, but if there is, there’s probably not enough. I can probably guarantee you there is probably not enough.

**Interviewer:**  Yeah, it feels like that’s always the case unfortunately.

**Interviewee:**  But that would be… I just think a lot of people like Ian just get overlooked and forgotten about, I think. Like I said, he’s not disabled enough but disabled enough.

**Interviewer:**  Yeah, I understand what you’re saying. And then, kind using a bigger picture approach or thought process, how has Ian’s sensitivities affected your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:**  Well, I think I said this before. I go back and forth, almost sometimes on a daily basis, of whether or not I think he could be completely independent and have a job and be fine and other days where I’m like, he needs to go on disability, you know what I mean? We’ve never pursued that cause I don’t really want that for him but you know, there is no way this kid could survive on his own, I mean he’d starve to death. I mean, I don’t know, it depends because I think he has better days than others, you know what I mean? **[1:24:00]** Again, my friend is terribly technology challenged, she’s just awful, she’s terrible and she had to do this yearbook thing and it was this whole thing online and she was just like, she called me crying and I’m like, *“Come over,”* and instead of me trying to help her, I’m not much better, I can get through, I just, *“Ian,”* but the end of the couple hours she knew what she was doing, I mean she really did, she’s like, *“I can’t believe I know how to do this.”* I’m like, there’s some stuff their kid, you know what I mean, look what do you did. Yeah, it’s just trying to find a…I think we’ll always have to supplement him because I know that he’ll ever be in a job where he can be…if he’s going to do something like, he’s not going to be making much money. I don’t know. Anyway, yeah. I think there is a place for him, definitely a place for him. I can’t see him getting married and having kids and all that stuff. I guess it’s possible if someone found him maybe but he definitely isn’t looking for it, at all, at all.

**Interviewer:**  That’s okay too though. Moving on to our last chunk of questions, it’s short, so we’re almost there.

**Interviewee:**  I can make it long, just wait.

**Interviewer:**  That’s perfectly fine too. As a mom, as a caregiver and as a parent with ASD and also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:**  So, I don’t know that I necessarily care whether or not he has his own apartment and that kind of stuff, you know what I mean? I want him…for me, he needs to know how to pay bills, whether or not he does it or not, is not really important it’s just at some point when he has to, he knows how to do that. That he knows how to shop, that he knows how to clean, that he knows how to do his laundry. That he knows how to get from point A to point B and hopefully have a job and find some way to make him happy and make sure that he’s happy and all, not just do those things but make sure, at least for him, whatever that is for him, that that makes him happy.

**Interviewer:**  Absolutely.

**Interviewee:**  It’s come home after work and playing video games all day than that’s fine if that’s what he wants to do, as long as he is healthy and doing the things that he needs to do, whether its living with us until he can’t do that anymore or he get’s his own place at some point **[1:27:00]** or whatever, it’s whatever…I don’t necessarily see that it’s wrong if he lives with us. I mean there are some people that feel like they have to be out there. If he wanted to, I’d like him to be able to, if that’s what he wanted to, that he has the choice to do it or not do it.

**Interviewer:**  Absolutely. Has this perspective changed for you over time?

**Interviewee:**  I think, I think it just changes, again I think it just changes on a daily basis or even sometimes on an hourly basis. What I think can accomplish but there was a time where I wasn’t even sure if he would be able to get through college and he did. Now, he also had his brother to say, *“Dude, that paper is due,”* to remind him. He did have some classes on his own but he did have some support that other people wouldn’t have had, for better or worse, I don’t know if that made it worse or made it better. He’s got some accomplishments that he’s done, there were times where I didn’t think he’d be able to do that and then he did that. There are times I think there is no way he could ever get his license but I’m sure there are worse drivers out there. It’s just that he’s over cautious, just very careful and very slow and very cautious. That can be dangerous too. So, I don’t know. I guess it’s, I don’t know, I don’t know how to answer that cause there are some times where I thought*, “Oh yeah, he’ll get better as he gets older,”* and he’s gotten worse in some ways and some ways he’s gotten better. But mostly, it’s on a daily thing sometimes, where it changes, more than…six months ago I would have said, *“It’s not like that with him.”*

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

**Interviewee:**  What do I see happening? I hope he can get a job; I don’t know why that’s so important to me but I guess that means independent because how else…I guess he could go on disability but I don’t even know if he’d qualify? I don’t know that he’s disabled enough to be on disability, isn’t it hard for people, like hard functioning autistic’s to?

**Interviewer:**  Is it possible or?

**Interviewee:**  Yeah, I think it’s difficult, isn’t it? I think they change…

**Interviewer:**  I don’t actually know. That’ a good question.

**Interviewee:**  I see a lot more research and I see a lot more understanding and I think I’m seeing more programs and stuff **[1:30:00]** and then more companies that are coming around to see there’s a resource here, I guess, so in that ways, I guess I get more positive about it. I don’t know.

**Interviewer:**  Yeah, that’s okay.

**Interviewee:**  Tell him to write a good app and sell it for a million bucks and he’ll be fine.

**Interviewer:**  Yeah, he’ll be set up for life, you don’t need a job after that and you still have the security. I have one final question for you. How have Ian’s sensory sensitivities impacted this perspective that you just articulated?

**Interviewee:**  Well, I think if he could hide it better, we wouldn’t be having this conversation, you know what I mean? If he could fake it better, which a lot people can do, if he could fake it enough to get through an interview, he’d be fine but he just can’t. He just doesn’t know how or he just can’t physically do it, you know what I mean? It’s like somebody with terrets, can’t help themselves at this point. Yeah, so I think it severely impacts him, actually. When it doesn’t work out for him, I think that hurts his confidence, which just makes it all worse.

**Interviewer:** Absolutely. That’s all I have on my end; would you like to add anything? You can.

**Interviewee:** I probably added enough. I can about this forever. Yeah, no, I just hope that all of it…I’m excited, we’re looking at doing another spark or something, DNA. I guess it’s legit because they’re connected with Stanford and Yale.

**Interviewer:**  We use it, that’s how we do a lot of recruitment, it’s very legit, you’re in good hands.

**Interviewee:**  Good, so I saw that and that made me excited. He’s been working on filling out the applications, it’s day three now. I try not to get too frustrated, it’s like, *“Dude, literally just do it,”* that takes a while sometimes. We’re going to be doing that. It’s just interesting to see the more research. I think if I would have known, if I would have known this…when we moved to Virginia when Ian was six and he was always just kind of real quiet and saw the world a little differently than other people, I always give the example of the end of preschool they did. they had to do a picture of gingerbread man and so, **[1:33:00]** went to school to see their artwork and they also did humpty dumpty, little picture of humpty dumpty, this is when he was four or five and there is this big wall of all these smiley, smiley gingerbread men and then there is one with a big frown. I’m like, *“Ian, which one is yours?”* He’s like*, “That one with the frown,” “Why is it a frown?”* He’s like, *“Well, the wolf eats him.”* Well, you’re right. Then there is all these humpty dumpty’s and then there is this smashed humpty dumpty, he’s like, *“Well, they couldn’t put him back together mom.”* And so this always been Ian. I kept telling him, you get on the right team, you’re probably not a very good independent worker but as a team, you see things differently than other people do. Look at that, 100 people would do the humpty dumpty smiling sitting on the wall and there’s yours, everyone’s thinking the same way, you need people like you to think differently, otherwise you can’t invent things or think of another way to do something that hasn’t been working.

**Interviewer:**  Absolutely.

**Interviewee:**  I think, again, I should write down your question.

**Interviewer:**  I could send them to you, would you like?

**Interviewee:**  I forgot where I start with thing when I go off. For me, I think just as he’s gotten older, it’s just – what was your question, do you remember?

**Interviewer:**  I said I was done; did you want to add anything but you’re doing great.

**Interviewee:**  Anyway. Yeah, anyways, I think just trying to find where he can fit, I think is the goal, hopefully at some point and use that different way of thinking.

**Interviewer:**  Absolutely. Well, thank you so much for sharing your time and your insight. I really do appreciate all you had to say, please don’t feel bad about how much talked, it’s really helpful, honest to god.

**Interviewee:**  Oh my gosh, it’s three o’clock., okay.

**Interviewer:**  It is kind of late, that’s okay though. Thank you for time and your insight and your vulnerability too, I know these can be hard questions so I appreciate you answering them all.

**Interviewee:**  I kept it together pretty good.

**Interviewer:**  You did great but I appreciate it because I know it can be hard. Do you know anyone else who might want to participate in this study by any chance?

**Interviewee:**  You know, I do have someone who also has…he’s older than Ian, he’s a couple years older than Ian, so that would be too old than right?

**Interviewer:**  Yeah, our cut off is 26 so Ian just makes it.

**Interviewee:**  I’ll ask my teacher friend, knows tons of…and also I have another friend who works with Autistic, she works in the…she’s a para **[1:36:00]** works in the classroom with Autistic…if I would have known about Ian, I would have probably moved to North Carolina or somewhere like that instead of here because they have so many more services, that was the point, sorry.

**Interviewer:**  Gotcha.

**Interviewee:**  I knew there was a reason I was rambling on about that. I will ask both of those if they know of anyone and are you looking for higher functioning or just anyone?

**Interviewer:**  Any functioning. We’re looking for folks who are 16 and just under 26 with Autism and some sensory sensitivities, past or present.

**Interviewee:** Would it be much more autistic?

**Interviewer:**  Yep, they can be non-verbal, minimally verbal, they can intellectual disability, they cannot have an intellectual disability, functioning isn’t part of criteria.

**Interviewee:**  Okay, so where do you want me, would they contact you at the email?

**Interviewer:**  Yeah, the email is totally fine. I can also send you something, would that be helpful?

**Interviewee:**  Yeah, send me something, then I can forward it to them and they can forward. I know Sherry would know because she works…that’s what she works with, she’d have to think…how old did you say?

**Interviewer:**  Just under 26, 25 and 11 months.

**Interviewee:**  What’s the youngest though?

**Interviewer:**  16, sorry.

**Interviewee:**  Alright. She works in the grade school. Have you ever thought of reaching out to some of the high schools?

**Interviewer:**  I have not, that’s a great idea, I’m going to write that down.

**Interviewee:**  Cause every single high school is going to have an Autistic program.

**Interviewer:**  Yeah, that’s an excellent point.

**Interviewee:**  There’s a lot at that age.

**Interviewer:**  Yeah for sure. We have a big participant registry is what we call it and so we’ve reached out to those people and then from there, everyone has found other people it’s really spread pretty wide, it’s been pretty great.

**Interviewee:**  Yeah.

**Interviewer:**  Again, thank you so much. Do you want me to send you a copy of the questions for you think about? I don’t mind, I can if it’s helpful for you?

**Interviewee:**  You can if you want, it doesn’t matter. I just forget what I was answering, the original question, when I would go off on my tangent, what was I answering? I don’t even pay attention to myself.

**Interviewer:**  That’s okay.

**Interviewee:**  I’ve went on too long, I’ve stopped listening to myself.

**Interviewer:**  That’s okay. So, if you could finish off the questionnaires that would be super helpful.

**Interviewee:**  Oh yes, I’m sorry about that, I thought I was done with that.

**Interviewer:**  No worries, people have done it before, not a problem. As soon as I get those back from you, I will send you a thank you gift card as compensation for your time and effort and sharing everything with us, we appreciate it.

**Interviewee:**  Yeah, great, it’s been interesting.

**Interviewer:**  Thank you so much. If you need anything from me in the future, have any questions, please feel free to reach out, happy to help in whatever way I can.

**Interviewee:**  Okay, awesome.

**Interviewer:**  Awesome. Thank you so much, I look forward to hearing from you.

**Interviewee:**  Alright great. It was nice to meet you.

**Interviewer:**  Nice to meet you too, have a nice rest of your week.

**Interviewee:**  You too. Bye.

**Interviewer:**  Bye.

**[End of transcript]**