**[START OF TRANSCRIPT]**

**Interviewer:** Alright, 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 I'll be doing something called a semi-structured interview and this means I have my planned questions in my script, but I'll be adapting my questions to follow our conversations to actually fit for what we're talking about.

**Interviewee:** OK.

**Interviewer:** Does that sound…any questions?

**Interviewee:** Nope.

**Interviewer:** OK cool. And if there are any questions you don't want to answer for whatever reason, that's perfectly OK. ‘I don't know’ is an OK answer as well. And if something comes up from earlier later on, feel free to jump in. This doesn't have to be perfectly linear.

**Interviewee:** OK.

**Interviewer:** Alright, could you please start off by telling me about your son's sensory sensitivities?

**Interviewee:** How far back do you want me to go?

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

**Interviewee:** Presently, we notice a lot of things with anything that touches him really, like hand wise. And it can be…it's not necessarily the food he's eating, but it'll be what's left on his hands. So, one of the things he does a lot of is he will continuously wipe them, even though there's nothing there. This crosses over into work because he works with granite, and his previous job he was cutting the granite, so there was always going to be dust on him and that was a huge issue. So, he would constantly stop working to get the granite off of him. So now he kind of is in the same field, he's doing some installation of countertops and islands and backsplashes, and things like that. So, now we're using like the caulking materials, and I've noticed that it's on his work clothes a lot, or like his jackets, things like that. So, I'm sure that it's a matter of he's trying to get it off of…it’s feeling, you know, that feeling of his on his fingers. I don't notice it as much with his face, you know, like if you would have something on your face. But I do know that like – and I don't know if it's a desensitization, but a lot of times when he was growing up, we would have to tell him, like, *“you have snot.”* It's almost like he didn't even recognize it, so even now, as an adult, we try to remind him, like if I know he has a cold, I make him take Kleenex, even though I hope he uses it, but I'm not 100% sure.

**Interviewer:** **[00:02:49]** So, you still have to remind him that he has things on his face even though he's older?

**Interviewee:** Oh, yes! Lack of soap use is huge, so COVID has been very interesting for us, because he *truly* cannot handle that sensation of soap. I don't know what it is, I don't know. I've tried all kinds, liquid, regular bars, things like that, but we know…I mean, I know he's not using the soap 'cause it doesn't go down. Like you know, so that's a clear indication. He used hand sanitizer and he will still use hand sanitizer 'cause I filled that. I don't know if he's dumping it out or what he's doing, but yeah, anything that touches his hands is very…it's got some kind of negative thing for him. Bathing things…**[crosstalk]** go ahead.

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

**Interviewee:** I was just gonna say bathing, things like that, I still have to remind him to go do it. He loves water, he always has loved water. But the products you use, oh, not good. That stuff…

**Interviewer:** And it's like the texture or like the feel of the products?

**Interviewee:** It's gotta be. I mean, I wish I knew. But I mean this was since he was a baby. And when he was little, like I always had to have extra clothes, he could not handle having anything wet, like shirt wet, anything like that. I mean, he was the kid at daycare that I'd come home with multiple outfit changes. Not necessarily pants as much, but the second his chest got wet or anything like that. He wore a bib a lot when he was younger, just because he couldn't handle that sensation.

**Interviewer:** Is that still the case?

**Interviewee:** Yeah, I would say yes. I mean, if he's out doing something and he becomes sweaty, yes. Oh, getting his haircut, immediate, has to come home. The sensation of having that hair on him, he cannot handle, at all. And even for a while – and I don't know if it was the…if it was the actual sensation. Ryan had some surgeries as a baby, and I don't know if it was the…like when the razor actually turned on, if it reminded him of when he had a skull surgery, but we had to do a lot of practice with that. But he can sit for a haircut, he'll go for a haircut. He won't ask to have one, I have to say, *“it's time for your haircut.”* But it is an immediate…like, there is no stopping, he goes immediately to shower or at least rinse off, 'cause I mean, product wise we have everything possible. It takes him forever to run out of something.

**Interviewer:** Got you. So, it kinda sounds like full body, doesn't really like things touching him or like...?

**Interviewee:** Yeah, I mean, interestingly enough, he will overuse deodorant, which I'm happy about. But it's anything that like…I don't know if it's like…I don't know what it is. Well, I guess if it would be hair and body his hands have to touch it, so I don't know if it's a hand sensitivity to those products.

**Interviewer:** **[00:06:12]** Yeah. Has he ever like been bathed by someone else? And has not been bothersome? ‘Cause that would remove the hand part for him.

**Interviewee:** I mean, when he was little, there was no issue ever in a bathtub. I had to be careful with…'cause he didn't like sounds and things like that either. So, we had to kind of do like a desensitization, and I was that mom that didn't like bathroom slime and all that or like the foam that you would…and he…we had to do it and he had to get used to like the noises of that even going into the tub, so I would do it outside the tub while he was in the tub and then transition it. I mean, I remember when he was – God, he couldn't have been maybe a year and a half – and they carved pumpkins at daycare and they made him put his hands in the pumpkin, and he was still crying when I picked him up. And I mean *crying*, it was not a whimper, it was a full blown like, ‘I've lost my mind,’ you know. So yeah, that that kind of stuff has always kind of been with him. He also like…I mean he didn't like tags, but I refused to cut them out of his clothing, so I would just tap it and say you're fine and move him on. I mean, part of it was you gotta get used to your environment I guess, in my head. And I think the last time we talked I told you, Ryan's diagnosis of actual autism just happened in April of this year, so he was already 20. So, there were a lot of these things that we just dealt with.

**Interviewer:** Absolutely. You mentioned sounds, could you talk a little bit about that? Any sensitivities towards sound?

**Interviewee:** Weird sounds, yes. But I mean, I think he likes things louder than not, which is probably not the norm. It's really not the norm. He doesn't mind loud things, like he'll listen to his music and his videos very loud and I have to say, *“oh my gosh, like the whole neighborhood could hear that. You need to turn that down.”* So, I don't know if it's a…I mean there's nothing…I mean, his hearing's been tested multiple times, there's nothing wrong with this hearing, but I don't know if it's that's just how he likes listening to things. But yeah, he's more on the…like noises, things like that didn't bother him, we would go the racetrack and he would fall asleep there.

**Interviewer:** Oh, OK.

**Interviewee:** Yeah, so like, that doesn't bother him.

**Interviewer:** Yes, like not sensitive to noises at all?

**Interviewee:** No, no.

**Interviewer:** Got you. And then what about like taste or smell?

**Interviewee:** Taste wise, he's pretty adventurous. He will try everything. There's really not much he hasn't tried. I mean, we were…I think we were in DC when he tried oysters for the first time, he didn't like ‘em, but he ate it. I mean, God bless him, 'cause I wouldn't even do that so.

**Interviewer:** **[00:0915]** I don't like them either.

**Interviewee:** Ugh! I don't like fish, but like with him, I was different than my older daughter. We just let him try everything, you know, I never hesitated to have him try something. So, I don't think he really has a food sensitivity. He does some weird things with his mouth when he eats. To me, it almost looks like…and maybe that's where the sensation comes in, like he's a lizard almost. It's weird, like I just don't even understand how he does it, but his tongue comes out more and it's like…it's bizarre, it's bizarre. And not like where somebody would be like, ‘what is he doing?’ But if you noticed it, you'd be like, ‘well, that's kind of strange.’

**Interviewer:** Sure, got you.

**Interviewee:** He won't use chapstick, can't put chapstick on him at all. It is the…I call it Kool Aid lip, 'cause that's what I you know, as a kid, I used to have, and that's what we all called it, and he'll do the bottom and I'll try and put chapstick up there, and you could just tell the second that that has touched his face. So, I guess he does have some facial mouth sensitivities, and I know the second I turn around, he wipes it off.

**Interviewer:** Got you. And so he's not bothered by like the pain of a chapped lip or something?

**Interviewee:** Oh no, I don't think that would bother him at all. Ryan does not have – very interesting – he really does not have a sensitivity to pain, if that makes sense?

**Interviewer:** Oh no, that totally makes sense.

**Interviewee:** I think in his 20 years, he's probably told me twice he's had a headache and actually taken medicine. So, I don't know that he feels pain like the rest of us feel pain. I mean, it's now twice. He had his wisdom teeth removed back in… **[to Kelsey]** do you remember when he had his wisdom teeth taken out Kelsey? You were gone, right? **[to Rachel]** October maybe, and he had surgery for it…

**Interviewer:** OK. Like this October?

**Interviewee:** Yes. And he had surgery, so he had to be put out.And I made him take the pain medication, but he never asked for it. Like he never even asked to have the ice re-put on. I just insisted we do it.And he was *swollen*. So, I know that he had…there's no way he didn't have pain. I mean, just normal wisdom teeth coming out is painful. To have surgery, I'm not sure how that didn't bother him. But he doesn't ask for things like that, there would never be a time that he would ask for pain medication.

**Interviewer:** **[00:12:05]** Does this lack of sensitivity for its pain also relate to like a lack of knowing if he's too cold or too hot, like a temperature understanding?

**Interviewee:** Ryan's *always* hot. *Always* hot. Like, my heat's on now and I can guarantee he's in his room and he put his fan on. He runs hot, like he's just hot. And he's been like that since he was little, I cannot…he will not wear a sweatshirt, he will not wear a long sleeve shirt. Now whether that's because of the sensitivity to the material or just that he's…I mean he's always hot. Like we went to a football game, years ago, outside, at Purdue in the late fall, and I literally had to strip him down because I could tell he was going to either throw up or he was going to pass out, and it…

**Interviewer:** ‘Cause it was so hot?

**Interviewee:** Yeah. I mean, you sit close together at a football college football game, but it wasn't overly crazy and I looked at my husband, I'm like, *“he's gonna go down,”* like taking his coat off and taking the sweatshirt off. I mean, he's the only one sitting in the stands in a T-shirt and you know, then he perks back up. So, like I have to watch him for overheating, stuff like that, because he will have a tendency to do that, but he runs…he's warm all the time.

**Interviewer:** Will he know if he's getting dangerously…or not dangerously, but getting too too hot? Will he recognize?

**Interviewee:** Oh no, no. He doesn't recognize any of that. I don't know that he's fully aware of himself like the rest of us are aware of ourselves. He's not. Like he may hurt himself, like he…how did he…he hit his finger or chopped his finger, cut his finger or something at this job, with a razor blade, something that would bother me. And I think it was two days later and he was like, *“oh, I had this accident at work.”* And I was like, *“did you put something on that? How did you handle that?”* I mean, he would pull his teeth out as a kid and just hand them to me and get on the bus.Like, you know, they were ready to come out, I think, who knows! And he would just…and that was on multiple occasions, like we were camping one time and we were driving and he just hands me a tooth. I'm like, *“do you want some water or anything?”* *“No” “OK.”* So, like I said, the pain sensitiv[ity], I don't think he has that.

**Interviewer:** Totally. That definitely sounds like it based on what you said.

**Interviewee:** Yeah, but then the weird sensitivity too is that ‘I can't have anything on my hands.’ I don't know.

**Interviewer:** We all have our things, that's OK, 100% OK. What about smell? Any sensitivity towards smells?

**Interviewee:** I don't think so. I mean, he doesn't really smell anything before he eats it. I mean he will say, like if I'm baking cookies or something like that, he's like, *“oh, that smells good.”* You know, he'll recognize that things smell good, but he's not overly sensitive to that, no.

**Interviewer:** **[00:15:22]** And what about any like visual stimuli? Any sensitiv[ity] to any type of visual stuff?

**Interviewee:** No, he wears glasses and he has some depth perception issues, but he doesn't really seem to have a sensitivity to light or things like that, I mean.

**Interviewer:** Yeah. And so then, how would you say his sensitivities have changed over time, since when he was little to now?

**Interviewee:** Well, everything is tag-less now, so that's a plus. I think the touching of things or having things on him is still there, and I don't think it's…I definitely don't think it's less prominent than it was. I don't know that he would…he will touch things, but it's an immediate that I have to wipe them [off]. And I'm not…he's not necessarily using water or anything, but I mean, he might go through 15 napkins at dinner because he's gotta get that off. I mean, and that's throughout his meal. So, if his meal takes 1/2 hour, he could go through 15 napkins because he's constantly wiping his hands, and it doesn't matter what we eat, he just can't…**[crosstalk]**

**Interviewer:** Oh sorry.

**Interviewee:** No, you're fine.

**Interviewer:** Is that more so than when he was younger or has it always kind of been just like that amount, approximately?

**Interviewee:** I think it's probably more so now than when he was younger, because when he was younger I don't think…I mean, obviously, when he was littler, he would eat with his hands just like everybody else. And then because I think he had the fine and gross motor skill issues, like silverware, stuff like that was harder for him to use in the beginning. But yeah, I think it's probably gotten more pronounced.

**Interviewer:** Got you. And what about this lack of pain perception? Do you think that's the same? Has that changed?

**Interviewee:** I would say that's the same, I don't think he…I mean, he's had four surgeries before he was three, and he had one when he was almost five. And like I said, he's had probably, that I can remember, where he's asked for Tylenol twice in his 20 years. I mean, I've given it to him as a baby if I knew he was sick or that kind of stuff. But as an adult, never, never.

**Interviewer:** **[00:18:08]** Got you. And then this change related to kind of more sensitivity towards things touching his hands, do you think that's related at all to any independence that he's gained overtime?

**Interviewee:** Yeah, I guess you could equate it to the independence as far as like he's been put into different situations, having to, I guess, experience his world more. Because you know, when you're in school and it's just papers and books, that's one thing, and you can avoid things you don't like to touch. He's very…like in high school, he probably took the same lunch for four years, like every day, the same thing. So, those kinds of things, I think he was able to control. But now that he has to be out working and experiencing different things, yeah, I think it's probably intensified in that way then.

**Interviewer:** For sure, that was a wonderful segue, thank you. So how it does he manage or cope with his sensitivities? Or how do you help him manage or cope with them?

**Interviewee:** I'm not very good at it. I probably have the patience of a gnat, 'cause I'm like, *“oh my God, your hands are fine!”* I think in the work world, I know when he worked at the granite place to begin with, which was like his…it was called Green Abilities, but that was a supported work environment. There they would do reminders for him or cues, like, *“Ryan, you're still going to get dirty, 'cause we have 50 more of these to cut. So, you're going to have dust on you.”* Things like that. At this current job, it's more of a confidence issue, so it's…because it's caulking and things like that, I think that's very easily masked, because you can wipe it off because you're caulking, you know. So, the excess shouldn't be there. So, I'm sure he finds ways to mask that. But even when he was bagging and things like that, I'm sure he found ways to go round that stuff.

**Interviewer:** And by mask, do you mean hide that he's wiping his hands so much?

**Interviewee:** *Oh yeah*. Oh yeah, he hides it. Not here at home, but definitely out in the world. 'Cause he likes to – which everybody does. I mean, you just want to fit in, you want to act like there's nothing going on and you're just like everybody else and nobody has issues. So, I think he's learned how to manage that in his environment, if that makes sense?

**Interviewer:** **[00:21:04]** No, it makes 100% sense. And has he ever received specific therapies or interventions for his sensory sensitivities?

**Interviewee:** No. I mean, when he was little, God, we had everything, we had a developmental person, we had OT, PT speech, you name it, we had it. So, if I think about it, looking back, like the things that they all probably did with him, I'm sure there was some of that built in. But like to…again, I think part of it was we were so on top of all of his delays that some of these things we just…we taught him how not to do it, if that makes sense. Like we taught him…I say often to his therapist, *“I hope I didn't cause harm,”* because I didn't want him to…like we would say, *“you can't go to school and do that.”* So, I think we taught him some of the ways of the social norms, you know? So, I don't necessarily think he had like official [therapy], like true ABA or something like that, no. Do I think we did things to desensitize him to his environment? And I'm sure all his therapists that he had through…because he did…like what we have here is called First Step, so that's our early intervention program till they’re three, and then he went right into early intervention preschool. I mean, so Ryan was *never* out of services, from the time he was six months old, he's always had services of some sort in school, social groups, things like that. I mean, even speech she turned into group so that he would learn some social communication and stuff like that so. Formal formal, no. Probably a lot of informal, and now it's a lot of cueing.

**Interviewer [00:23:11]** By you and by folks at work?

**Interviewee:** I think maybe not so much at this new job, because he's only been there two months, so I think they're getting used to it. And again, I think the materials that he uses are different, so I think he can cover it. At his previous job though, I stopped in there to see them and we talked about it and yeah, he was getting – everyday that he was there, he was getting cues to you know, ‘not worry about it, you're still going to be dusty, it's gonna be on you. Before you eat you can take it [off]’ You know, that kind of stuff. And I know his dad and I do it a lot now. Like I'll just have to look at…even if we go out to a restaurant, I'll be like *“Ryan!”* And he'll stop, you know, so.

**Interviewer:** Yeah, absolutely. And when he is in a scenario where you know, say he has something just like on his hands or he has to feel soap or something, does that cause or increase anxiety for him?

**Interviewee:** Oh 100%!

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

**Interviewee:** It's almost like…I would say he gets extremely nervous about it, like if you would look at him you would think like, boy, he seems agitated. But he's not going to yell about it or anything like that, but his movements become very prominent in trying to take off – and seriously, what sometimes I don't even think is there. Like you know, like if it's salt or what, I'm like, oh my gosh, that grain of salt cannot be…you know, but it's a constant **[wiping hands motion]**. And then if I say something to him, his hands will go to his lap and I know he's still doing it. But yeah, it's more of an agitation. I mean, I try to make jokes about it, like when we're…if I want him to wash his face, 'cause he gets up in the morning and I want him to wash his face, I'll like sing. It drives him crazy, but I'm like, *“you gotta have the soap on your face long enough for it to do any good,”* but even that is a struggle. He'll take a washcloth, plain, and wipe his face, like you know, he’ll wet it – I don't even know if it's warm water, he'll wet it and wipe his face, but he will not put soap on that washcloth at all. But that's just…it's his thing. But it makes him more anxious, and you can see it. You can see it on his face, you can see it in his body language, you can just…like somebody that is having an anxious moment, it's him, yeah.

**Interviewer:** Totally. How does he manage that anxiety or that agitation?

**Interviewee:** He…gosh, I would say he escapes most of the time **[laughing]**, like that is his way of managing it, is he escapes. Yeah.

**[00:26:12]** Totally, yeah. And has that anxiety and agitation related to his sensory experiences, has that changed over time or has it also increased or stayed the same?

**Interviewee:** I think as he's gotten older, it's probably increased, because when he's little…boy, you're making me think. But if I really had to say it, you know, when he was little, we just did it. And now I have to truly pay attention that he's doing his self-care. And I would say 9 times out of 10 he's not. I mean he's 20 and I have to sometimes come behind him and smell his hair and be like, ‘did he put anything on there when he went down to the shower?’ 'Cause again, it's not the water, it's whatever that…I don't know if it's the soap feeling, if it's the lather, you know, the lather that you get, I don't know. That enjoyment that most of us would get is not enjoyable to him. So, I would say it's more.

**Interviewer:** And then again, thinking kind of broadly, what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** I would hope that he learns how to manage it better so that…to the naked eye, nobody's gonna see it. To like, when we're with relatives and friends and things like that, nobody sees that he has this, 'cause I don't think people tune into it, you know. I mean, I think we're more sensitive to it, it's probably more so me even than his dad because it's something that I just I know exists. So, then I…it's like you can't take your eyes off the car crash 'cause it is happening in front of you, that's how I feel about it sometimes, you know. And I want to help him to the best of my ability, but I don't want to create more anxiety, but I know it happens. Because these are…if it wasn't a health issue and a hygiene issue, it probably wouldn't be a big deal, but because it centers around his hygiene, which leads to his health, that is a bigger issue for me. So, I think that…gosh, I hope I answered your question.

**Interviewer:** You did. No, that was perfect. Thank you so much **[both laugh]**. No, that was wonderful. There are no wrong answers here. I could always ask clarifying questions.

**Interviewee:** Yeah, you can always tell me, ‘no, that's not what I asked.’

**Interviewer:** That was exactly what I asked you to, great. We're going to shift gears a little bit. As your son has grown up and aged, how has his and your community reacted to his sensory sensitivities, if at all?

**Interviewee:** You know, his community is so small. Like, I mean it's so…he doesn't have a lot of friends, things like that. He has a mentor that he worked with for over a year who went away to college. So, that was a huge loss for Ryan. And Ryan will text or whatever, but when he would go out with him, you know, his mentor was phenomenal. He was a young kid, just his age too. But they just got along so well that I, you know, and I tried to explain some of the things they might witness with him, just so that they're aware. Like, *“you might have to cue him, you might have to say, like, ‘hey, there's nothing there,’ or if he spills something, or if you see him with something on his hands and it becomes an issue, like this is why it's an issue.”* But then, because most of it would happen within a shower or a bathroom setting, I don't think people really…it doesn't affect in that way. I can't say what it would be like if he was in a public restroom or whatever, he might just walk out, I don't know. I mean, I couldn't tell you what he would encounter when he's in those kinds of situations. But up until the point that he had to go into the restrooms by himself, he was always with an adult that would say, ‘this is what you need to do.’ I remind him, whether he does it or not, I have no idea. So, I do think that community wise and home wise, it's probably not as big of an issue because of where it stems from.

**Interviewer:** **[00:30:41]** Yeah, totally. My next questions will then be little bit less relevant given your answer, so my apologies if they aren't super relevant.

**Interviewee:** No, you’re fine.

**Interviewer:** Would you say the community was more or less accepting of him and his sensory stuff when he was younger? Or neutral because it was **[00:31:57 inaudible].**

**Interviewee:** Well, you know, when he was younger, I don't think…like if I think about daycare, 'cause I worked all the…he always went to daycare. So, when he got into the upper grades…like well, not even upper grades, but I mean at 18 months, they knew he had sensitivity issues because all of his therapy would come into the daycare center. They were phenomenal, they would let him come in, they would do his therapy. So, I don't know how you would miss that he had sensitivity to it. Part of the thing with the pumpkin, it set me off as a parent, because *you know* he has a sensitivity to it, *don't* do that, because that just increases his anxiety, you know? So, there were times…I mean, I guess it's just how we worked with Ryan with everything, I did a lot of front-loading to people so they knew, so that there wasn't a situation that – I’m not gonna say it never happened, but that there wouldn't be a situation Ryan would be in that he was so uncomfortable. Because part of Ryan's additional problem, on top of the sensitivity was his lack of communication. You know, when you can't communicate to people, because Ryan was pretty much non-verbal till it was two 2, 2 1/2. So, when you're nonverbal and you cannot tell people what's bothering you, your only reaction is either to act out or to withdraw or cry. Well Ryan would withdraw or cry, he was was never a behavioral issue *at all, ever*, even in times when I think he should have been, like when people were mean to him or things like that, he never was. But he would withdraw, he would play by himself, things like that. But as an adult, I think I just front-loaded people *a lot* to prepare them for what they may or may not see, and then to right – or, not right, hopefully eliminate some of that anxiety and some of those problems he could have encountered.

**Interviewer:** Yeah, absolutely. And do you think because you did so much front-loading and kind of preparing people, they were more accommodating because they knew what to expect?

**Interviewee:** Oh absolutely. I mean Ryan had an IEP, the Individual Education Plan since he was six months old. So, you know, there were portions of that I probably in his school career only had a few teachers that I swear never read it. So, I would just give them the shortened version, even you know, an open house. I'd be like, *“look, I'm gonna run past you and then we're going to have a meeting.”* So, I *always* – from the time Ryan was in kindergarten till he was a senior in high school, I met with every set of teachers in a separate meeting. I never tried to overload them in an open house situation, but I set up a separate meeting to talk to them so that they understood what they were getting with Ryan. And it was, you know, not just how he reacted to his environment, but he wasn't going to communicate to you, you know. So, even thinking back, I'm like, oh yeah, glue used to bother him, like he couldn't have white glue, we had to do glue sticks. And even if it was the glue stick, that feeling was horrible. So, yeah, even some of that, or crayon, like when you color and you would get crayon on you, like ‘oh no.’

**Interviewer:** Kinda waxy?

**Interviewee:** Yeah, anything like that that would have that feeling on his hands, he did not like.

**Interviewer:** **[00:34:33]** Yeah, absolutely. And again, thinking about community, were there certain spaces or places that were more or less accommodating and accepting of him?

**Interviewee:** I mean, we went to the same…like his routine was pretty routine because of my work, you know. Luckily as well, he was in the same daycare center from the time he was 8 weeks old – well, 12 weeks old, until he was in first grade. So, he was in the same place, with the same director, with the same teachers my daughter had. And then she was also there, so I think you know, at times she was probably a very good buffer as well to maybe what he needed if we weren't there. But yeah, I just think maybe because he had the consistency of the same place, that it wasn't an issue.

**Interviewer:** Yeah. And you talked about work. Would you say that his work is also pretty accommodating and accepting of him?

**Interviewee:** Yes, they absolutely…he got hired at this new place, they wanted to hire him, just sight unseen. They were very like, *“yeah, we'll take him,”* and I was like, *“oh no, no, no, like you need to understand what you're getting.”* And when his job coach said he went to the interview and they hired him, I’m like, *“they do know he has special needs, right? Like this was not…”* And she's like, *“oh yeah, we went through it all and Ryan even explained some of his stuff, you know,”* as far as like how he communicates and stuff like that, I'm sure he did, 'cause he doesn't see the sensitivity as an issue **[chuckles]**.Just me probably. But yeah, I think they're just very accommodating to him, every place that we have put him. I think he has anxiety about that, but I probably have more than he has in those situations because it's so foreign for me to put him somewhere that I don't have any control over. But I think he's managed that very well and I think yes, but I do think yes, the community in that sense has been very accommodating and helpful.

**Interviewer:** That's wonderful, that's really great. What about family? Is family also accommodating and understanding of him and his needs?

**Interviewee:** Oh Lord, they, *“he's fine, everything's fine, there's no problem.”* So, I'm like, *“oh my God, you don't live with him.”* And my sister is a special education teacher, so for years she's like, *“he's fine, he's great,”* you know, and I'm like, *“oh, you don't live with him.”* And I'll never forget my mom coming to stay with us. I don't even know why she…I think I just needed somebody else because of my husband's work schedule or he was out of town, so she stayed. And I think it was the first time my mom was like, *“holy cow!”* I was like, *“yeah, it's a lot.”* Like you know, just managing some…like just education wise was a lot for him, but then managing some of the extra stuff, I don't think people realize it because they don't live it, you know, and there's just no way to…there’s no way for people to understand it unless you live it.

**Interviewer:** **[00:37:55]** Absolutely. And again, thinking broadly again, what hopes or worries do you have for how his community will continue to react regarding his sensory needs?

**Interviewee:** My hope is that they…that they are…because I think the transition from – and I don't know how it is in every state or every community or whatever, but our transition from school to real world was horrible, partly because Ryan I think is a unique individual, in the case that he doesn't fit your standard student that needs to go one direction or college. So, you know, and I think…and he was in a high school of like over 4000 people. So, I mean our high school is huge where he goes. His graduating class was probably close to 900 kids. So you know, we're in a very large school community, and so the variety of student is *huge*, from self-contained to general ed. But there is not a good transition for students like Ryan or individuals like Ryan, and so that, I think has been the biggest struggle. So, my hope is that now that I have to learn the adult world, that at some point it becomes a better transition. Because from our high school to community, if you are within a self-contained special education class or if you are non-diploma track, ‘cause Indiana is one of those states where you either get a core 40 diploma or you get a certificate of attendance - yay Indiana! If you do not fall within that, or you fall within one of those, that's it. There's no…so Ryan was a core 40 track, because we were not going to allow him not to come out of school without his diploma, which required him to, I'm sure, put a lot of anxiety on the backburner many days to just get through school.

But then there's nothing for him afterwards. There was not a good transition to what happens next, where students who would maybe have more special education classes, more self-contained stuff, there's a path like, ‘oh, well you can stay in high school till you’re 21,’ or ‘you can go into the transitional program – adult programming that we have, where we're going to grocery shop and we're going to teach you how to do skill-based stuff.’ Well, when you're a…or capable of fully functioning, there's nothing for you after that. So, these two years has really been an eye-opening experience, I'm sure, just you know, and for us trying to find where does he fit in the community? Because I can't send him to college, because he's definitely not ready to live on his own. I'm not going to college again, I've done that multiple times. I could do one class with him, but he would have to do it online and Ryan's not a real like self-starter.

And then you have a learning disability on top of all of that, so, you know. **[00:41:19]** But was he capable of graduating high school and going to college? Sure, I mean, he got into colleges. But even that, the support for special education students or students like him, *it's so small, it's so narrow*, that then that creates a problem with when their anxiety rises, who's there to help them? Nobody, there's not like a peer mentor kind of program set up, things like that. And then unfortunately, in our community we don't have a community college, there's not like a two-year kind of like ‘look where you can…’ you know. We have an Ivy Tech which is technically like a, I guess the closest thing to Community College, but they're not very accommodating to students with special education needs, so, you know, I guess my hope is that some of this exploration comes about and then he can continue to do the things that he really wants to. I mean, he loves history. I mean, he would be a wonderful history teacher if he could get through the schooling part of it, you know. But that's a challenge. So, I would say I would hope that he finds something he really likes. Like you know, even this job transition was a huge thing, he loves his current job. He *loves* it!

**Interviewer:** That's great!

**Interviewee:** Yeah. And this is a skill, and that's what we just keep trying to tell him, *“this is a skill, this can be a career because it's a skill that not everybody is going to ever have or get.”* So, we try to encourage him in those respects. And if he wanted to take a class, we would do it, we'd figure it out, but he's gotta have, you know, he's gotta wanna do it too. So, I hope I answered your question.

**Interviewer:** I think so. So I just want to clarify. So, you're kind of hoping that he's able to find his spot in the community. Is that kind of what I'm hearing?

**Interviewee:** Yes, yeah, I think that that's good, because we're also in a community that doesn't provide a lot of transportation services, things like that. We have one organization that does it. They run from 9:00 to 15:00 like well, if he has to be – which he does, he has to be at work at 8:00, that doesn't work. And then we have a few Uber kind of things, but I couldn't trust him to get into the right car. So, there are some limitations into what we can do. Ryan's a very trusting person. So, if the Uber driver said it was $40, he’d pay $40 even though it might have only been $10. So, you know, there are some things that we have to be cautious about when it comes to him.

**Interviewer:** **[00:44:09]** I'm sure, thank you. We’re gonna again shift, but you're giving me wonderful transitions. In the transition to adulthood, where do you see Ryan?

**Interviewee:** Ha! **[Rachel laughing]** Emerging?

**Interviewer:** That's wonderful!

**Interviewee:** Yeah, I mean I would say he's emerging. I mean, my daughter will be 23, and I try not to compare them, but the things that she is able to do as a “normal,” 23-year-old, he's nowhere near that, like nowhere near where she was at 20. Which is OK, they don't…they never have to be the same, but responsibility wise and what they can do on their own, no, he's not there, I mean, my husband and I go away, somebody comes to stay with him. Do I think he could stay a weekend by himself? Probably. 'Cause I don't…he wouldn't leave the house, but I don't know that he wouldn't answer the door. Like there's certain things that I know he would be OK doing, but then there's the safety. I guess when it comes down to the safety factors, his transition to adulthood is emerging, because he's still not able to understand the safety factor, if that makes sense? And then health wise in that, I think would be…he knows how to use the stove, he knows how to use the oven, like he can turn it on, he can put chicken nuggets in, he can do that. But the follow through, like the package says 10 minutes, that's all he's going to cook it for, but it might still be raw or frozen. So, the follow through and the ability to, oh God, how do you say that? Where you can…oh I know there's a word for it, but where you can expand, like we can expand our thinking and realize, ‘oh the package said 10 minutes, but it's not done, so I need to cook it some more.’ He cannot do that, like the inference of that, oh no, no, there is none of that. Like, I know he ate…he makes these little pizzas and I know he ate it frozen, I know he did because he was like, *“oh it said 2 minutes,”* 'cause when he made it in front of me, I was like, *“that's still frozen, put that back in.”* And he was like, *“but I ate it like this the other day.”* I was like, *“oh no, no, no no, you don't do that.”* So, it's like some of that inferencing things that we just do naturally or as you gain the knowledge into adulthood, into cooking, into expanding that, he's still very – I don't wanna say amateur, but limited, limited in it. So, it's emerging.

**Interviewer:** **[00:47:14]** Absolutely. Is he able to shop for himself? You talked about how he could cook for himself, but he would just follow the directions to a T? What about like shopping for foods he needs?

**Interviewee:** Like a variety or just the things he likes, like the oatmeal cream pies and like the ice cream?

**Interviewer:** I mean, a bit of both.

**Interviewee:** Yeah, I mean he could shop. The issue would be like he would know what to put into his cart and he could…like if he, I guess if he learned how to establish a list, I mean he sees me do a grocery list and look at recipes and things like that, but he knows what he likes and he has like…when he worked at the grocery store, he would buy things, he would get off his shift and he would go and shop. So, he can do that. The issue becomes he doesn't understand money.

**Interviewer:** That was my next question, great!

**Interviewee:** Yeah, he doesn't understand how money works. So, if the bill could be $20 and 50 cents, and he's going to give you – maybe he'll have to…it'll take him a while to figure that out, 'cause he can get the $20, but he's not going to be able to fully comprehend how to do the 50 cents. And he might give you $21, or he might give you $25, and he's going to walk away, that's it. So, like the concept of change and things like that, no. He has a debit card and we've had to take that away a couple times because you can't just keep sliding it. And it's not that he didn't have money on it, he did. We were just trying to get him to understand you can't just slide it whenever you want to, that's not how the world works. So he does have a debit card. Where he works now, they go for breakfast every morning. It's not healthy, but they go for pizza every morning and he knows like…and even when he worked at the previous place, it was right next to a Speedway gas station, so my husband would get him a Speedway gift card. But I know there was a time when he had to pay for something and there was portion on his gift card and he left cash, and *I* *know* the cashier took the rest of that money, 'cause he has to bring the bills home, he has to have a receipt. And my husband's like, *“he got taken.”* And so, we had to explain that to him, like, *“because you didn't pay attention, you lost $5 $8,”* whatever it was. And in his world, he's like, *“so what? I’ve got money,”* which he does, but you need to understand that $8 on top of $8 adds up. So, there would be the lack. Could he shop? Sure, but the follow through for managing his money is not there.

**Interviewer:** **[00:49:57]** I presume he doesn't also really understand budgeting then as well?

**Interviewee:** Oh no, no. ‘Gift card ran out, just get me a new one,’ you know. Ryan understands, like we don't hide anything from him. So, Ryan receives Social Security, which he doesn't really understand the concept of that, although I don't really understand the concept of it either, so I'm learning. So, he has certain money he gets every month that he has to spend in certain ways, and so we have…he's like, *“OK, so I can put it away and I can buy a house.”* *“No, you cannot buy a house, because you can't own property. So, you can buy a car, but you don't drive currently.”* so you know. So, just explaining those kinds of things and how the money has to be spent. And the money doesn't go to him, he had to have a representative payee because he cannot manage his money at all. So, the money comes in and then his dad and I have to manage that money for him, so there are some budgeting he does. But his paycheck was direct deposited too, so he never really saw money. His check now is actually a paper check, 'cause they’re smaller place. So, he gets a check and he'll just leave it there, and he's like, *“OK, what do I do with this?”* And we're like, *“oh my gosh, you're going to take it to the bank and they're gonna give you that amount of money in cash.” “Oh, OK”,* so like even like having to explain that kind of stuff to him he needs, and then he'll need reminders.

**Interviewer:** Absolutely. How is he with like household chores and things like that?

**Interviewee:** **[Laughs]** You're funny. I mean he can do them, like vacuuming is his number one thing. I hate to vacuum, so vacuuming is his job. And if Ryan is motivated, like *“you're going to vacuum or you don't have your iPad for a month,”* then he'll do it. But he's very motivated under a watchful eye, he's better if I'm home and doing his chores than not. But for a while, because he is in therapy, he has a therapist that we started in April, after we got the diagnosis, they thought it would be helpful, and it truly is helped all of us. But he had a checklist every day of things that he had to do because at that point he wasn't working during the day, he would work once we got home from work 'cause we could get him there when he was bagging groceries. Now that he works during the day, it's a little bit different, but he would have a checklist and he'd have to go through the checklist. But he can fold laundry. He's not great with the washing machine, he gets a little confused where the downy he goes, versus the detergent, and everything would be washed on one setting, which I guess wouldn't be the worst thing in the world. But like he can move that from place to place, he can fold everything, but he will…I'll call on my way home from work and be like, *“I'm coming home from work, is that done?” “Oh yeah.”* And then sometimes the basket is still sitting where he put it. But he's capable. I mean, he empties the dishwasher and all of that kind of stuff. It's just a lot of times that’s Ryan's own space and timeframe, usually not mine, but yeah.

**Interviewer:** **[00:53:33]** And does he ever express interest in one day wanting to live on his own?

**Interviewee:** No, he’s told us he will live with us forever and we have told him no, that's not possible. For a long time when he grew up **[chuckles]**, he told us he was going to find the cheapest free nursing home to put us in so he would have all our money, which makes me laugh now, realizing he couldn't manage that. But *I* would like to see him in an independent living situation. He absolutely would need a case manager or a house person or something, but I think he absolutely could do that. I think it would be *phenomenal* for him, I think that independence would be wonderful, it just would have to be the right setting. He would not be good with a whole group of people, I think that would be way overwhelming for him, but if it was a couple of guys…I mean, my dream is that he is in some kind of townhouse or condo with a two or three other guys and they live together and there's somebody that comes in, you know, that doesn't necessarily have to live there, but they would come in and they would do the checking every day or stuff like that, because I think he could do that very well. I think he could manage that easily on his own, but you know, he would need reminders to like…I mean, he knows how to do changing of his linens and all of that kind of stuff, but he would need a reminder like, ‘hey, it's been a week and a half, you probably need to change your linens,’ you know. And at this point, he needs reminders to still go and shower. I mean, he'll do it if he's worked, but he has no concept of why you shower if you've just gone to bed, like *not at all, not at all.* His therapist is working diligently with him on why we shower, even though all we've done is sleep. So that's just…I guess that's just part of his way he thinks about things. If he doesn't see the purpose for it, I'm not going to do it, so there's that. But yeah, I think I think he could absolutely live on his own.

**Interviewer:** For sure, that's wonderful. And you talked about friends really briefly, and that he doesn't have many friends, but he still texts that mentor?

**Interviewee:** Yes, he will reach out to his mentor. Ryan’s very good with adults, always has been. I think it's his comfort zone because it's more…I don't know how to say it, like it's just he's more comfortable with adults. He would hang out with his teachers, like all the other high school kids are worming the halls and talking and whatever, and he would go and sit in the PE office with the two gym teachers, and that was like his comfort zone. And I know that anytime I've talked to his teachers, that's where he hung out. Like he might go and use the bathroom, but then he's coming and he's hanging out in the hallway with them, and you know, he could hold these conversations with them far beyond his like age. Ryan's always had an unbelievable vocabulary. I mean he couldn't read and he didn't know sight words, but his vocabulary was outstanding even as a young kid. And now that I'm understanding autism more, that was his thing, that was…probably would have been a very good indication to me that there was something else.

So yeah, friend wise, he's…it's a varied…people like him, he just doesn't have the confidence to do it. And then I think sometimes he's just too literal, and that will prevent him from some things. But like with the way the world was yesterday, he's very…it was the first thing he told me today when I got home from work, *“you know this is going to be one of those days everybody remembers,”* you know, like it was almost too much. He was two when 911 happened, and 911 is my daughter's birthday, but we were not on…I mean she was four when that happened and so he was two. We didn't publicize the news, we didn't watch the news, I mean, not around them at all, and I've always been very cognizant of that, just because they don't need to know what's going on, you know. Well, now he's 20, so world events, things like that….and we took a trip to Washington not that long ago and we were in the capital, so he, you know, that memory, and then he's a history buff. So, all of that. But now it's going to be something he perseverates over. So, I think that sometimes the way that he thinks about things are much more adult like than they’re kid like and so then I think sometimes he doesn't feel like he fits in, 'cause I think as you become aware, I mean, and every kid does, I don't care what their disability is. At some point they become aware that they're not exactly like everybody.

And then I think for him that put kind of a hold to things. I mean, we went to the grocery store he worked out over the weekend, and everybody that he worked with was like, *“hey Ryan, how's it going? Hey Ryan.”* But he does not know how to initiate that next step of, ‘hey, I'm gonna text you, you want to hang out?’ But he *has* reached out. There was a boy he worked with at the granite place before he left and they will FaceTime each other and they have true conversations, but it's hysterical because when they go to hang up there's no goodbye, they just click ‘end.’ I'm like, *“did you say goodbye?”* And he's like, *“no, Elijah hit the button first this time.”* I was like, *“no no, it's not about hitting the button, you're supposed to say goodbye.”* But they'll do that and they'll hang up on each other, but for them it works, so.

**Interviewer:** **[00:59:46]** Whatever floats their boats, right?

**Interviewee:** Right, right.

**Interviewer:** Thank you for that, that was wonderful. Do you think your son will be able to achieve more independence in the future?

**Interviewee:** Oh yeah, I mean we work on different things all the time. I'll be honest, I think I just I have to learn how to let go more and not worry so much about what the end result will be. When he was little, I would worry he would get hurt, now that he's an adult, I guess I still worry he will get hurt, and not emotionally, you know, 'cause I think that does just happen. And with Ryan we know it happens, we just unfortunately never know for like a week or two after it's happened, and then he’ll tell us, because he's got a processing problem. So, by the time he processes what happened, then he'll tell us. It could be two days, three days, four days later, but he'll tell us. But I think *physically* is what I worry about sometimes, because I don't think he…he doesn't see the danger in anything. Like crossing a sidewalk, he'll just cross, till today, at 20. When I would drop him off at school, his last year of high school 'cause my husband's job changed, so I took him the last year of high school. I would park, I would get in the lane where I could park right by the sidewalk, so he just had to get out the car and go in. If I had to park on the outside lane to drop him off – mind you, this is where 4000 kids go to school – he would just walk across *every time.* I'm like, *“oh my God, you're gonna get run over by a car.”* He bagged groceries and I swear to God I don't know why, God must've been watching him because he never got hit by a car, but he always walked out of that store and never looked, and would pull those carts in and, you know, I'm like, *“oh my God, I just watched you walk out, you never looked.”* *“Yeah, I did.” “No, you didn't, you never even lifted up your head.”* So, there's a safety factor in it. But yeah, I definitely think he will gain independence.

**Interviewer:** This worry about like physical safety, do you think that's driven by his lack of like awareness or also the fact that he doesn't seem to sense pain?

**Interviewee:** Oh no, it's his utter lack of awareness. He's clueless when it comes to that there's somebody else. I mean, that's part of the reason he's not driving. Not that he's not aware there's other cars on the [road], it's almost like he's overly aware, 'cause he's not looking around at them, but he knows they're out there, so it makes him extremely cautious to even drive. And then, like it was a yellow light, *“well, it was yellow and you didn't tell me to slow down to stop,”* so he went through it. *“No, no,”* like you know, it's like some of the again, I think it's the inference thinking, he lacks that. I hope he drives one day, I mean that is an ultimate goal. We practice with him going the same route to work every day. So hopefully someday he'll be able to do that. His dad drives with him more, I can't do it, I just can't even do it. And he says there's days he's better and there's days he's like, *“I don't even know where he was, I don't know if he's looking at the road or if he's overthinking it,”* you know. And because he doesn't communicate well, we're not 100% sure.

**Interviewer:** **[01:03:22]** Understood. I think it's hard to learn how to drive for everyone. For *every* child, I don't think it's an easy task. What do you think will help Ryan move into adulthood?

**Interviewee:** I think his therapy is absolutely, 100% helpful. I notice a huge difference between when he's not in therapy. We had a few weeks where his work schedule got messed up and he had to miss, compared to when he is consistent with therapy. She's just phenomenal for one, but he's grown a lot in that, 'cause I think he's learned how to express himself. The other thing that I think has happened is that Ryan now has some of those, the social communication, like he's gained that. And so where before he might have been really quiet or he wouldn't argue with his sister, 'cause he really didn't know how. Well now, I have like 7- and 8-year-olds in my house instead of 20- and 23-year-olds, because he would never have had the skill, the words to communicate it. Well, now he does, so now he's able to give it back and tell her, *“I don’t like that,”* or whatever. So now, they do argue, not a ton, because they're still very good to each other, but it's more 'cause he's figured it out, you know?

**Interviewer:** So, how do you think that relates to how he'll move into adulthood? Do you think kind of gaining the skills will kind of propel him? Is that what you're saying?

**Interviewee:** Oh yeah. I think he's gaining some of that ability to see the world kind of the way we all do, in a general speaking versus him being more narrow in how he looks at things. I think partly because Ryan is learning there's a grey area, and that has been a very *slow* process, up until probably…really, I would say probably six months ago, Ryan was black and white. There absolutely *never, ever, ever* has been a grey area and we actually might have just like a hint of grey starting, so I think as that emerges more, he will absolutely be able to do more and experience life better, because you can't really be independent and not understand there's a grey area, because…well, I guess you can, we all know people that only have black and white, but they can still function. For him, it causes him not to function because then the perseveration sets in and then it's days of perseverating, instead of ‘we're gonna move on now.’

**Interviewer:** **[01:06:15]** Awesome, thank you. Now putting these two things together, his sensory sensitivities and his transition to adulthood, how do they intersect for Ryan?

**Interviewee:** I think we're at a point where they are…probably a month or two ago I would have said we're probably at a crossroads of them, like figuring out how this is going to work. But I think as he really enjoys what he's doing for work, and I think he feels…I mean, 'cause he calls his previous bagging job a… *“well it was just like a starter, it was like just a stepping-stone,”* and I'm like, *“yes, but it provided you with all of these skills.”* So, I think as he learns that this is like a true career, then those sensory things, I mean, they're going to be there, he's going to have to learn how to figure it out. But I don't think we're as stuck, where a few months ago I would have said we're stuck, and until he learns how to navigate the world, he's not going anywhere. And now I think he's learning how to be with adults and not just people his age and understand that this is career. And so I think some of that sensory stuff will…it's going to be there, I don't think it will ever go away, you just have to learn to manage your environment. So, I think that he's learning how to do that, and that will help. I just think that will help with the transition more.

**Interviewer:** So, you think because he's learning how to modify his environment, he's no longer stuck on his sensory stuff, is that it?

**Interviewee:** Oh no, I think he's still stuck on the sensory stuff. I think it's just allowing him to be to transition to different things and to grow more. That sensory stuff, unless I'm completely crazy, I don't think it's ever gonna go away. I think he'll just learn how to…and again, I think, I don't want to say we're lucky, maybe he's lucky that it's not a sensitivity to light and to sound and to motor things and…I mean, he had…I think I put it in one of the forms, but he would do this thing, I call it like the superhero thing, I don't know, with his hands and he would **[makes a sound while gesticulating]**. And I was like, *“don't do that at school, we don't do that in public. You wanna do that at home, you do that at home, but you don't do that out in public.”* So, I think again, there are those things where we created for him the social norm that he didn't have. Right or wrong, I'm not sure yet if it was right or wrong to do, I'm hoping it didn't cause damage to him, but you know, I mean, we taught him that. And I think that that was something that we were lucky and we were fortunate that he could learn it, that he didn't get stuck there either. Do you know what I mean?

**Interviewer:** **[01:09:48]** I think so.

**Interviewee:** There are times like, I mean, I just…I don't think there's anybody that's even typical, but he was not a rocker or headbanger or, you know, he doesn't become outwardly overly frustrated about things or so overwhelmed that he cannot function. It'll happen, he might walk away for a minute, or he might…for him it's more internal. So then, that's where I think then he over thinks it, and he gets stuck maybe at that moment. Like, ‘I'm just not gonna do this particular job right now, I'm just not gonna do it, I can't do it, and then I'm not going to do it for three weeks because I'm worried…’ like one of the things is the granite they move in is very expensive, obviously it's granite, or quartz, whatever they're moving in. And he is so worried about dropping it, that he just refuses to carry it. So instead of working through that with his supervisor and saying something like, ‘this is overwhelming to me,’ I don't find out till last week when the job coach calls me and they say, *“hey, he's not doing the job,”* and they used the word ‘lazy’ and then his supervisor said, *“I know it's not lazy, he just can't figure out what it is.”* Well, it's because he's overwhelmed, and he doesn't know how to tell you he's overwhelmed. So, I think he gets stuck. And that's where it comes out in certain things, so I think *that's* what holds him back in adulthood, it’s because if you can't communicate that, or you can't understand ‘I might make a mistake and it'll be OK.’ 'Cause to him if he makes a mistake, it's a done deal. And so that's like, I think it all goes back to how we all can inference and we know that what ifs exist, but they don't stop us, a what if stops him.

**Interviewer:** **[01:11:49]** Got you. Do you think his sensory stuff also sometimes makes him stuck and prohibits him from doing more adulty things?

**Interviewee:** Yes. Because if you can't handle the feeling of things, I think, about all the stuff that you have to feel on a daily basis – and I am sure that there are so many other things that bother him and we just don't know it. I mean, I truly can tell you it's soap and whatever, because those are visual things I see. He does not shave with shaving cream, he only uses an electric razor, because God forbid we would put that on him. He will not do that for himself though either, like shaving. He cannot handle having his nails clipped *at all*, fingers or toes, *at all*. And that was since he was a baby, and I thought we'd just outgrow that, 'cause maybe I like cut him too short or whatever when they’re babies. Oh no. Like I literally have to look and be like, *“oh come on, you can't look down and see?”* Well, I know he looks down and he sees but he doesn't want you to touch it. I'm like, *“well you can't walk around like that,”* I mean to the point where I…I mean there's been times where I'm like, *“there is no way your feet do not hurt,”* but like I don't think about cutting his toes every day because I'm like, oh, I'm going about my world. But then I'm like holy crap, when was the last time I did that! And my daughter jokes, but she calls it the spa day. *“Oh, is it Ryan’s spa day now?”* you know, and that's when we go through everything. He won't clean his ears. I mean, any of that kind of stuff, I think yeah, it stops him and it will stop him and things, in the world. I mean I think about…they said, *“well, what about like doing dishes as a job, like you know, being a dishwasher?”* And not that the job is not worthy, but I laughed and like, *“forget it! He can't put his hands in soap.”*

**Interviewer:** **[01:14:10]** Yeah, that would make it hard.

**Interviewee:** Which also stopped. I mean, washing dishes here, I have to go behind him and wash them again because he hasn't washed them. So yeah, I mean absolutely, it's a constant preventative thing. So, I guess where I said before, we're lucky that he can accommodate his environment, but how well he's doing that, I don't know a 100%, I guess.

**Interviewer:** Yeah. Thank you for sharing that. Would you then say that his sensitivities are an obstacle, a vehicle, or a bit of both, or neither towards independence?

**Interviewee:** I would say it's probably…I would say it's probably an obstacle. I mean, when I think about it, and maybe not so much as work, but health and hygiene wise, who would want to live with you if you can't shower and use soap? And that's great that you can put deodorant on, but you stink. And then you have your…I mean he'd be…at least like he's going to be those people with the super long nails and they'll be writing stories about him or taking pictures of his really long nails, and he laughs at me because he's like, *“that's your pet peeve.”* Well, darn right it is. But I'm sure there's so many things that it could be an obstacle more than it would be a vehicle, I think, for him.

**Interviewer:** And then, relatedly, what do you anticipate as being challenging for him as he does gain more independence in relation to his sensory needs?

**Interviewee:** I think he'll have to pick jobs, truly, that he can manipulate the sensory. I think he will have to truly manipulate that, because there's no job that you will ever have that you are not going to have the feeling of something. I know when we’ve looked at jobs with his job coach during discovery, like some of the things they talked about was working in a hospital and we both – well one, it was because of COVID I was like there's no way in God's green earth he can go to work in the hospital right now. But the other thing was the cleaning portion of that. Like how clean you have to be and how aware of your cleanliness in that kind of environment, and he does not have that. So, I think there are some limitations of places he could go and he could work, because it wouldn't be healthy for him, it would be a danger to him. And I worry about that, like I can even think of if you went to a chemical plant or if you…like Eli Lilly is really big here in Indiana, you know, or…

**Interviewer:** What's that?

**Interviewee:** Eli Lilly's like the pharmaceutical company, and they make all the pharmaceuticals. Like if he went to a company like that, I would worry that he would touch something and then touch his mouth and he wouldn't have cleaned his hands. Because water is not going to get rid of stuff or you know, working in a chemical plant or…we have like Ford stamping plants and big companies like that around us that are wonderful jobs, but if you are not cleanly and if you do not think about the warnings of your safety, it could make him sick, so those kinds of things, yeah. I think…or like just having to touch things, he's not going to touch tar and grease and oil, you know. I mean he's not doing it. And if he did, I think his anxiety would be so high, then I don't know how that would be enjoyable and…I mean, I love going to my job every day, I love my career. I actually say it's a career, it's not a job, 'cause I love it so much. That's what I want for him. And if he's in a situation where he's got to touch things that are going to increase his anxiety, how is that enjoyable as a life? And that's what I would want for him, is that he's doing something he truly enjoys, that brings him happiness and not something he has to worry about every day. 'Cause even wearing gloves during COVID was very hard for him. The mask, *horribly hard, horribly hard.* But we were like, *“there's no option, you have to wear it.”*

**Interviewer:** **[01:18:50]** Yeah, absolutely thank you. Almost done, I know it's getting a little bit long.

**Interviewee:** You’re fine!

**Interviewer:** Oh, thank you. What do you think could help your son at this intersection of like sensory and this transition?

**Interviewee:** I think there are a couple of things. I mean, I think not just him, but I think as a family, resources for us would have been helpful. That's why I say therapy right now for him is great, except it's really helped us *understand him* better, because she can shed so much light on his autism and why that prevents him from doing things and the way that he reacts to things and just all of that. So, therapy has been huge, I think that that is something that he will have to continue. She's talked about having someone come in and do some ABA stuff. Ryan is not open to that at all at this point, and I'm OK with that because he's home with us. I think if he was living on his own, that would be a really great thing, because then, I know it's not the same, but the only way I can think of it as like kind of like a homemaker, that they would come in and then in his environment, teach him those skills. So, I think that that is something that is in the back of my head that would be very useful someday, is that, if right now, because of…apparently that can be covered by our insurance, and Ryan also has Medicaid. So, some of that could be covered by the state program, the state insurance, but I think that that might be very helpful for him to have access to those resources someday to get to that independence level.

**Interviewer:** Yeah. Do you feel like there are gaps in the available services and interventions for individuals like your son?

**Interviewee:** Oh 100%. There are waitlists for everything. The only advantage that Ryan had, and we are…I don't know, by the grace of God or by I don't know who, I read his paperwork before he graduated high school that they kept giving me every year, that said, *“oh, when he graduates, Voc Rehab would be the place to fill out this paperwork,”* and blah blah blah, and it they kept saying you know, “*well you don't need to do that till senior year, you don't need to do that till…”* and we got to senior year and I was like wait they kept telling me I gotta wait and I read it and it's like, no you should fill this out by junior high school. I was like holy crap, we're six months from graduation, what are we…and I fill it out, and we had a wonderful case manager. **[01:21:38]** And here in Indiana, well, I guess it's federal, so it's federally. If you are graduating from high school, you're a priority and you used to be ranked one way, and of course, when Ryan was graduating two years ago, they changed the ranking system, and if you were graduating high school, you were like the top rank, and then it went from there based on need. So, by the grace, in December, he qualifies, and he gets in there and then just because I kept asking questions, 'cause like I said, nobody explains the adult world to you, but nobody explains school to parents either.

So it's my honest to God, my biggest complaint, is that nobody takes the time to explain any of this to us. And it's not just whether your child has autism or a cognitive delay or just a learning disability, *nobody* explains it. You have to figure it out, you've got to learn it, and then you have to learn how to advocate in the correct way so that you're not making people mad. And then you have to learn, it doesn't matter if you make somebody mad because your child needs what they need. So, I think that that's my biggest complaint, is that there's nobody that helps them or a parent. And if you aren't a parent who somewhat understands the system, your child’s screwed, because this is a federal system and the federal government doesn't want to give these kids anything. And then they make it so hard to get a service. So, he has services, like he has…he qualifies for the Waiver Program, which I don’t 100% understand, but he is $18,000 a year that is eligible to him, we *cannot* get a service. We have been out without a mentor for a year and a half because *none* of these agencies have mentors, or they send him a 35-year-old woman. He doesn't want a 35-year-old woman as his mentor. The last man they sent was probably close to 40, not that this is a big deal, he was a pastor and they had *nothing* in common. And we tried to work with Ryan to understand where you can find things in common or somebody to hang out with. And Ryan's like, *“we have nothing in common,”* and I can't argue with that, 'cause he's right, you know. And that's the other thing that I think people dismiss, is that these clients, these children, these young adults, they know what they need and they know what they want, but nobody will listen to him because they think they have a disability, so they're not capable.

I can't tell you how many people keep telling us, *“did you take guardianship?”* I'm like, *“why am I taking guardianship? I don't want to take his rights away,”* because, you know, if you take guardianship – and that's another thing nobody explains to you as a parent, you have to figure it out. If you take guardianship, they're like a prisoner. So, now I want my child to be a prisoner, but he can make some decisions for himself. And I know that everybody's case is different, but I think that's my biggest issue with this, is nobody helps us. There's *nobody* you can go to that is going to help you, unless you are willing to make the calls, anger people. I mean, I've had fights with people at Social Security, I've had fights with supervisors at Social Security because your case manager doesn't call me back. **[01:25:05]** I'm sorry, I know it's COVID, but I'm working, I don't know why the Social Security Office isn't open, I don't get that. So, I can only call you and then you never call me back. So, you know, way more than I'm sure you wanted to know, but there's no assistance for families, there's no help to navigate this world. It is not part of our school system and it absolutely should be from the time these kids get into school, somebody should be saying ‘this is what you need to do.’ You know, the pediatricians and your doctor, they don't know, everybody has their own job, but nobody collectively works together.

And we've had a couple case managers, we've been fortunate our case manager has stayed, but she has no better answers. Then, well, you can try another agency and then they give you a list, because they can't recommend one. And then I got to spend 3 days calling all these places to find out that none of them can service you anyway, because the waitlist. Like music therapy would be great for him, the waitlist is 2 years. OK, so he'll be 22 by the time he can get music therapy. OK, well that's not helpful. And when's he going to get his next mentor, when he's 25? You know, so I guess that's…and it's not unique to him, and it's unfortunate that this truly is our government. And I feel the same way about other people too, like veterans and things like that, I just feel like you know, they’re these…you're just on your own, you're an island. And it shouldn't have to be that way, it shouldn't have to be that way. I think that there should be more connectedness, there should be more of a something, a network that would help parents and their kids, because I know there's other kids like Ryan out there that are probably down the block, we just don't know it. And so how do we connect so that, one, parents can have some outlets, but also him.

And I can't stand when all these agencies keep telling you, *“well, do you have somebody in your family that wants to do it?” “No!”* Because they gotta be…then they gotta go through all your rigamarole to get paid, my family is not going to take money to do it, but that's their answer to everything, *“well, get a family member to do it.”* And the mentor he did have was somebody's child I knew, like it just so happened I was like, *“hey, does your son want to do this?”* But it took them six months to go through the process, and the last two months were because I yelled. I actually got on the phone and had to yell at the supervisors because they hadn't finished his training, and the world should not revolve like that, and I've worked in social service, so I totally get it. I'm not crazy about that, but this is nuts. **[01:27:47]** Families should not have to wait when they have a 2-year-old, six months, eight months, two years, three years. By the time they're in school, they're still on a waitlist! So, I mean, I think that's the most frustrating part. And I know it's my worry and my frustration is that I don't know enough. Though in the two years that he's been in this limbo. Everything we've done is because I finally made the right phone call or I finally asked the right person. And I mean, I have a 40-hour work week job and then this truly is another like 40 hours a week. So, if we're doing it, why does every family have to do it? There has to be a better way. And when you're unhappy with one agency, then you gotta call 5 people to not have that agency to get to somebody else. So, I don't think that that's I don't think that's good for us, but I truly do not feel that that is the system Ryan should be living in. And that *we* have to make sure that things are set up for him in case something happens to my husband and I, so he is not left alone to try and manage this world that is not very kind to adults with disabilities, you know. And then you add the sensitivities and everything else, and it's just…it's a horrible, vicious cycle, you know.

**Interviewer:** Yeah. Thank you for sharing all that, I appreciate it.

**Interviewee:** Way more than you need, I'm sure.

**Interviewer:** That's OK, this is qualitative data, that's perfectly fine **[both laugh].** We're gonna think a little more broadly again, and kind of tie back these two things together. How have your son’s sensory sensitivities impacted your goals, hopes, and expectations for him as he does navigate adulthood?

**Interviewee:** **[01:29:56]** I think we've had to think outside the box more. I think we've had to get a little more creative in…like I mean, I think we really had to think outside the box because the job he's currently doing would have never been something I would have thought, like, oh, that's even something possible, you know? So, thankfully we had the second go round, we had a better job coach, and we were with a better agency and we had a better discovery who really…the worker that he had was phenomenal that could work with Ryan’s skills and then really spent some quality time with him to see what he needed, and then matched him to a few places that he would have done very well in. And then I think that part of it is that because Ryan has had the skills that we have developed with him overtime of how to manage things when they’re overwhelming or you become anxious or because you don't like the feel of something, how to deal with that, he is able to navigate his world better. So, I think it's kind of two-fold, you have to think outside the box to something that he may enjoy, and then teach him how you enjoy that activity while you're doing something that's going to put your sensitivity over the radar. Because I think about how he has to be in that environment, and while he loves the work, when you're touching that caulk that's like glue and taping and all of this stuff that are these things that are so tactile. So, I think he has to just learn his environment, and then by luck, he's with people who are very accepting of who he is.

**Interviewer:** That's great, thank you. Last chunk of questions, the shortest one almost done.

**Interviewee:** OK, no problem.

**Interviewer:** **[01:32:08]** Thank you. So, finally, as a caregiver, as a mom, as a parent of someone with autism, but also some sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** ‘Hold on, you're on a roller coaster,’ that's kinda what it means sometimes, you know. I think that it's a whirlwind sometimes, but there's a lot of ups and there's some downs, and then you figure it out and you level off. And then you're going to have some really good highs. And then again, you know, the bottom drops out. And I think just talking to other people and the work that I do in school and I'm obviously with students that have autism and their families and whatever. And when I look at them, especially knowing like how old Ryan is, and I work K- to five, so I'm with young people, and I watch these parents come in and try to navigate this new world, and I think holy cow, we've come a long way and we're still so far. Like we're still so far. So, I think as a parent, it really is a rollercoaster of good things and you know, when you hit the top and you know, OK, and then all of a sudden the bottom drops out and you're like, ‘well alright.’ But I think you just have to prepare for that, I mean, whether you have a child with autism or not, I mean life is going to throw stuff at you, whether they're quote unquote normal or they've got issues, I think that's just life. It's a rollercoaster and sometimes you're holding on and you hope for the best. And there's other times where everybody's in it together and we're all riding along. And, you know, I try not to think about when the next time the bottom will drop out. I just try to like…I think we've learned to live in the moment with him. He has struggled for so long, so it's nice to be on the uphill.

**Interviewer:** Yeah, I'm sure. That's great. Has this perspective or has this feeling changed overtime for you?

**Interviewee:** Oh, all the time. Daily, sometimes. I mean, when they're younger, you're just hoping that they don't go to school in diapers. And then when you hit that milestone, you're like ‘oh man, now I hope you can write.’ So, I think when you're a parent of a child that has any kind of disability, and for us, I think our perspective is just so probably way different than a lot of parents because with…Ryan was tested for autism in 4th grade…yes, 4th grade going into 5th grade, and he didn't meet the qualifications on the form. And when we did that one because I was anti another label, I really was. I'll be honest I was like, *“he doesn't need another label, it's not going to change anything.”* And my husband said the same thing, he's like, *“you're right, it's not going to change anything, fill out the form.”* And I didn't like his school psych at the time either, her and I had had some difficulty figuring out how Ryan would work. And we went in separate rooms and we did our forms and we put him in the envelope, and his teachers did the forms and they all calculated and there was no indication – not even close – that he had any…so I'm like…and now I look back and I'm like OK, we all filled out these forms separately. How did this happen? But then, I think maybe there was some like – and I believe in like winks from above or however you want to say it, that somebody just was like, *“look, just let him be, let him be, get him through and do what you're doing,”* because again another label wouldn't have *changed* anything. And we had to be really careful when Ryan learned this diagnosis because this one, he was really upset about a label. And I said, *“well, it doesn't change anything. I mean, if you had had this label five years ago, it still wouldn't change anything, you know, it doesn't change who you are and you don't have to walk into a room and be like,* ‘hey, I have autism,’ *nobody's asking you that.”,* So you know, 'cause I think when you when some people hear autism, it's the ‘oh, they rock, oh they headbang, oh they over-stim, oh the lights.’ People just don't really realize that it's just so different for every person, but then I don't think they realize that it affects every family differently as well.

So, I think for us because the diagnosis was so late, it just is, you know. And so, we can't do anything different. And I don't know that we would have. I mean, it's kind of like I said, every time, whether they're autism, or you're just looking at the learning disability, there's something that is next around the corner. So, when you live your life based on an IEP per se, I mean not that that was like our life at home, but when that's your life in school and that is what is dictating in a way, first, where are you going to go, I think that's where parents need to understand that's just a piece of paper. And the limitation is not in that piece of paper, the limitation is in the view that people have, or in the view that a teacher has, or in a view that the school psych has that's written it. But if *you* put the limitation there because of something you've been told, then that's a different story. And for us we never set a limit for Ryan, so I think that that's a different mindset for how we handled him as well.

There was never a limit, there was not a ‘you're not going to go to high school and you're already not going to be on a core 40 and you're already not going to achieve,’ because that wasn't even in our real house. It was, *“you're going to go to high school, your classes might not be the same as your sister’s, but you are graduating with Core 40 – if it kills me, this is what you're going to do.”* So, could we have said, ‘yeah, you're not taking Algebra 2 and you're not going to take Geometry and you're just get…’ yeah, we could have, but why? Our saying in our house was, ‘the bar is here, and we're moving it here.’ So, every time Ryan would hit the bar, we would move it higher, every time he hit the bar, we move it higher. And we did that when he didn't talk, and we did it when he didn't walk, and we did it when he couldn't hold a pencil. And so what? And so, when we did things, I think that was probably the best thing he ever taught me, is how to advocate, because nobody was going to do it for him and he couldn't do it, so I had to do it. I had to learn it. And that's what you that's what you have to do as a parent.

**Interviewer: [01:39:28]** So I've heard. I don't know that yet **[both laugh]**. What do you see happening in your son's future?

**Interviewee:** Shoot, I see him getting wherever he needs to go, however that is. I mean, he is fortunate that he has…and we are…I mean, we have a phenomenal support system that is family and friends, and even though I say that nobody understands, 'cause truly nobody understands. He has neighbors that drive him to work, and my neighbors are 80.

**Interviewer:** Aww, that’s so nice.

**Interviewee:** Yes, I mean they're just phenomenal. He has a sister who is good to him and her friends are good to him. And so really, he's going to do…and Ryan always has done whatever the heck he wants to do. And not in a bad sense, but just in a sense if…like with this job, like until he told us he was no longer happy at Stracks, I wasn't looking to do anything else. I mean, I was like OK, this is what he's gonna do, and there's nothing wrong with being a bagger at Stracks, like I was OK with that, he was OK with that, and it was safe. And as soon as he said he didn't want to do it anymore, I was like, *“oh Lord, now what?”* But we figured it out. And my hope for him and his dependence on me more than his dad lessens, 'cause sometimes he looks to me to do the talking and all of that for him, and he needs to do that. And so that, again, everybody needs a Doctor Megan in their life, because she is just *phenomenal* with him and with us as a family of like learning how to navigate this adult piece. I give her a lot of accolades, 'cause she really has helped *me* understand what's going on, but it's been nice to – not that my husband is not involved, but when it came to the academics and the school and the IEP, it was just something I knew. But it's helped *him* kind of see, like ‘holy cow, there is stuff sometimes and this is how we deal with it in a different way,’ so we're learning to navigate that. So, I think the sky is the limit for him, there's never been a limit. So, whatever he wants to do, we'll figure it out. We may not always do it the easiest way, but we get there eventually. So yeah, I think he's good, he'll be good.

**Interviewer:** **[01:42:14]** That's awesome. You mentioned that you think he could live independently with some support? Do you see him moving out eventually?

**Interviewee:** Ohh yeah, yep, he's gonna go. I mean, I firmly believe – and maybe I'm just crazy, but I really believe that all children need to live somewhere else, I just really feel that. I mean, I don't know…I know I really felt that way with my daughter, I think it's something that women need, to live on their own and they need to understand that independence, whether it's college or whether you get an apartment and you live with your friends or whatever. But I feel like for him that if he had that independence, even if there was support, he would feel better, he would learn more, he would have…and I always tell him this, he needs his own life, he can't live always with us, he has to have his own life, whatever that looks like. And it's not going to be the same as his sisters, and it's not going to be the same as ours, but he needs to have that, you know. So however we can figure that out in the future for him, I think it would be very positive.

**Interviewer:** Do you see him ever going back to school? You mentioned that he could be a teacher one day for history.

**Interviewee:** He'd really have to be motivated. His learning disability is pretty hefty. I mean, it requires…like he needs assistance reading and stuff like that. And the math classes in college, I mean shoot, they would kill me today, they almost killed me back *way* in the past. So, I don't know how he would muster those. But again, I don't ever set a limit on him. I mean, I didn't think he'd make it through Algebra 2, and he did. And like, I think I wrote or said, it was the only D he ever got in high school, the only D was in Algebra 2, and that is because it was unsupported, completely unsupported. And the teacher he had didn't believe in him, so I think that made it even worse. So, you know, but there was never a class whether it was supported or not, that he…I don't even think he had less than a B in high school ever, except for that one D in Algebra 2. And I'll tell people this, like I’ll tell parents *“no, I may have helped him with his homework, not meaning give him the answers, but maybe I wrote it at night because he was already overwhelmed, or I typed it for him or whatever, but he always gave the answers.”* And I don't care what I did at home with him, because I never went and took the test for him. So, you can tell me all day long that homework is this and they gotta do it independently or whatever, I don't believe that. I think homework can be a joint effort, because when it turned around and he had to go take that test, he never failed a test. And homework in our high school system, our school system, is worth 10% of their grade. So, yeah, it's very minimal. And they did that so that homework didn't carry you and you actually had to work to complete. So, it was broken up, but homework was 10%. And I never took the test for him. So, you know he made those grades on his own and we make sure that he understands that everything that he did in high school, he did on his own. Yeah, there was effort at home and he was supported well, but there's nothing he can't do, you just have to teach him a different way, or give him the support that they need and they'll go far. And I think that's what he will do, no matter what it is. So, he *could* go to school, we would just have to *really* figure that out, like that would be the most advantageous for him because that's what it ends up being about now, it's not about me, it's not about the teachers, whatever, it's truly about how would that work for him?

**Interviewer:** **[01:46:18]** Absolutely. And you see him one day having a family of sorts? A partner perhaps?

**Interviewee:** He has told us ‘no,’ he has no interest in girls. I think that's a lie though, ‘cause there are some really cute girls that worked at Stracks that he would say things about and it would be like, *“would you want to go to the McDonald's on the corner and then I can take you home? All you have to do is ask.”* And as soon as he walks in there, the girls are all about him. So, I don't know. That one I really don't know. I mean, if it happened that be great for him. I think it would have to be somebody as quirky as him though, 'cause I don't know that they would get it. But I mean, if that happened, that would be fantastic, you know. But I would truly be happy with him living with some guys, being content that way, and having a life that has friends and that he's well supported. He has cousins his age and we've seen great growth in that in him being able to hold conversations. At Thanksgiving, my daughter’s friends were over the day before, and he came out and spent time in the garage with them. And he didn't sit at the table with them, he sat on a stool, but you know. So, the progress is there, it's just he's reaching some of these milestones later because he's gaining the skills later. And then I think even in those settings, he picks and chooses…trying to think [if] he ate in front of them, but he went to a different place. So, I think he picks, like they were all around the island and he chose to come and eat at the table with his dad and I. So, I mean he will…I think he learns to navigate that sensory piece to his advantage.

**Interviewer:** Yeah, that's great, though. I mean piece by piece step by step.

**Interviewee:** Yep.

**Interviewer:** **[01:48:16]** And you always see him having a job or some type of career, whatever that may mean for him?

**Interviewee:** Oh yeah, there's no option on that one, he already knows that. That I am dead set against. He’s not sitting here, I don't care what it is, he will not sit in my house…and that was a *huge* thing for me when he graduated. Graduated in May and by June he was working at Stracks as a bagger, he was not sitting here.

**Interviewer:** Good for him!

**Interviewee:** That's just a huge…he understands he has Social Security, he just got full disability because he's worked so much that he qualified. So, we've explained that to him too because he feels like that's a handout and I'm like, *“dude, you've paid into that, like that's your money coming back to you, that's how Social Security works. When they take all that money out of your check, you actually get to get it back.”* So, he just got that. But work is a good thing for him, and having a career, whatever that is, this company he's working for now has been around for 60 years. By luck, he finds himself in good company. He knows that if he loses this job I’m like, *“you're going right back to bagging at Stracks, sorry.”* I just think it's very important for his independence that he works. I think working gave him a lot more…control might not be the right word, but a more…well, maybe control is. Control over that sensory stuff, and that awareness. And it also put him in a position that he had to do something about it, like he couldn't go in and wash the bathrooms – because that was part of the responsibility – and not clean his hands. Now I really hope he did 'cause I wasn't there. But you know, he never was sick, so I'm hoping he followed through. So, I think it did, it is providing him some opportunities to work within that sensory sensation that he has.

**Interviewer:** **[01:50:28]** Absolutely, thank you. Last final question. This perspective about what it means to transition into adulthood, how, if at all, do your child’s sensory sensitivities impact that perspective you articulated? Like this rollercoaster you described?

**Interviewee:** I don't know that it was like major, you know. I mean, I think it's…if I'm really honest, it's like been in the last two years that it's like really dawned on me that it's bad. 'Cause I think there were so many other things going on in trying to navigate school and how busy we were, and we just kept going through life. Because really, I'll tell you, in the last two years, these last two years are probably the most calm our home has been. I mean, obviously, we go out at night if Ryan had to work and things like that. But *home life* has not been calm, except in the last two years, because getting him through school at night was not calm in this house.

**Interviewer:** Oh, I'm sure it wasn't.

**Interviewee:** There is homework, there was…I mean, Ryan did not work throughout high school because there was no way we would have been able to manage that, because if he had a test on a Friday, we were studying on Monday. So, you know, we were studying every night, Ryan never had a night off. Even weekends, my husband's always worked weekends, and so there was always something that we were doing. And so, the calm finally happened when he graduated and we could all like – well, me, probably more than anybody, and probably him, I really think if you ask Ryan, he'd probably be like, ‘oh my God, that was the best day of my life because I could breathe again,’ you know. There wasn't this hurry up every night, we can have dinner casually, we can…like if we wanna take a walk when it's nice, we can do those kinds of things because we don't have the anxiety and the worry. And this is for me, if he said he wanted to go to college tomorrow, I would help him do that. I know that the anxiety and the worry would go skyrocketing for me. He may have it, but we're not going to know for couple of weeks. But for me, I just know what our evenings and nights would be like to get him through that. And so, I don't take it lightly, I will never stop him from doing something, I'll figure it out and we’ll do it. But I think that the last two years have had a calming effect on all of us, especially him and I, our relationship to one another, because it's not as dependent as it was. It's still dependent. I mean, there's definitely like…his therapist sees it, 'cause if I'm in with him in session, he looks to me to answer and I'm like, *“I'm not answering.”* And obviously you can tell I can talk, so a therapy session would be great for me **[Rachel laughs]**, but I think it's had a calming effect on us as he transitions too, because there's so much more we can do, and it's not…yes, it's stressful because this adult world stinks, it really does…

**Interviewer:** For everyone also.

**Interviewee:** …when you have a child with a disability, because there's no way…yeah, I mean, absolutely adulting is not fun. Like somebody said, *“well, what do you wanna do?” “Well, I'd like to go back to preschool, 'cause that might be a little more fun.”* But even that's changed for our kids, now you gotta know how to color and everything by [the time] you’re [in] preschool. **[01:54:01]** But I think for him everything was always so ‘did he achieve this? Did he get there? Did he get that milestone?’ I mean, we bought toys and everything until he was probably 5 years old when I said enough, I'm not buying another toy that he has to push that it's gotta light up for him to achieve that it's a three. I'm not doing it. It finally dawned on me, like everything we have ever done is to get him to learn something else, I'm not doing it. Like he needs to be a kid too. So, now I think it's fun to see him be a young adult and understand why his sister and him are arguing. Well, it's because he's got the skill finally to do that. So, I kind of appreciate it a little more than annoyance that they're arguing at 20 and 23. But I'm proud of him and I'm hopeful for his future because I think he can do whatever he sets his mind to. So, I've learned to appreciate the calm, because we really have never had that. So, the hiccups we have on that roller coaster because he decides to change jobs or whatever, I'm thankful that we can do that and then he has the opportunity to do it. As crappy as I think the federal system is and services are. I also appreciate the fact that there are services, even though we might have to wait six months or two years or whatever. I mean, I can't imagine what…and I'm on some parent resources in our community, that's how I found you – that are waiting for services for so long for their kids who are so young, and that wasn't our situation, 'cause I always appreciate that there is somebody that is so much worse off than us. Like I totally understand that. So, I try not to ever wallow in the fact that this is what we have because it just is, and my husband and I would do whatever we need to do *for* *both* of our kids. So, the roller coaster is just life, and at times it's been fun, at times it's been frustrating. Now I would say we're kind of in the fun part to see what's next for him.

**Interviewer:** Yeah, but because it was so rollercoaster, was it hard for the sensory to kind of come to light?

**Interviewee:** Oh! Yeah, and then I think that's why we didn't see it. I mean, I think that's why, in all honesty, I think that's why I didn't see the autism in the true sense, you know. Because everything else was so…like, yeah. Like, you know, we're making decisions – do we print or do we hand write? Well, no, we're not going to hand write 'cause he can't print. Or do we continue to practice multiplication facts? No, because he's going to use a calculator, like let's move on. Those were the decisions we were making, and I don't make light of them, I mean, I can kind of laugh now, but in the moment, that's what we were dealing with. So, some of that other stuff, 'cause I just stuck him in the bathtub, and I washed him, and he might have been squirming around, but I didn't even think. I didn’t even think about it. And I think if anything that is the one thing, and I know I've gone back to it multiple times, that *I hope* I didn't cause undue anxiety or worry or stress for him because in…I'm working, they’re at daycare, they're going to school, my daughter is doing her activities, he was in whatever he liked to do at that time, which wasn't much, but we would always try something, that we just kept going. It was life, you know, and it was crazy and whatever. So, in the down times when we did take vacation or whatever, I mean, I don't remember there being like that super light massive sensory stuff, but again, like when you're talking about just it's the feeling of things, who knows? I mean, maybe that's why he didn't like our dog, because God, he didn't like our dog! And we had the sweetest Golden Retriever, but he hated her, and I always thought it was because she scared him. But now I'm wondering if it is because of the way she felt. No? He might not like the fur. I mean he loves dogs now, so I think he got over that, but we're not getting one. But I mean, like I look back and I'm like, well maybe that was it, who knows? So yeah, I would absolutely say I think that it was always there, but I am sure we missed it.

Oh, he wouldn't go in a…like you couldn't spray it with the hose, stuff like that, anything like that that would shock, no. But…‘it’s was just cold, he just didn't like it.’ No, that's probably not what it was. But yeah, I think it was always there, we just didn't realize the severity of it until the calm set in and then now I notice it, and I'm like, *“oh my God, stop doing that.”* **[Chuckles]** It's crazy! Or now that he's out in “the real world,” and he's in a supportive work environment for that time, they noticed it, 'cause he would have to paint too, he would have to paint at the Green Abilities place. Nope! Wiping it off, always ruining their paper towel, jeez, you know. So yeah, so I think we probably just didn't even…as he's moved into the adult world, I think it…gosh, I've probably gone both ways, I've probably said it wasn't, but now I think it's probably more, I really do.

**Interviewer:** **[01:59:53]** It’s what you said though, it’s what you said in the beginning, you’re consistent.

**Interviewee:** OK, good. OK, alright.

**Interviewer:** Thank you, that's actually it for my formal questions. Do you want to add anything else?

**Interviewee:** Oh, I've probably talked your ear off.

**Interviewer:** That's OK.

**Interviewee:** Hopefully I'm not the longest one, but I've had that effect on people.

**Interviewer:** You’re not, I promise you, you are not the longest one. The longest one was really long, you're not really, really long. You're good.

**Interviewee:** Well, and I'm sure…what time is it there? Are you ahead of me?

**Interviewer:** I am ahead of you. Yeah, I'm an hour ahead of you.

**Interviewee:** Oh, so it's bedtime there now.

**Interviewer:** Don't worry about it, this is my job. Not a problem at all.

**Interviewee:** No, I think I mean this was very interesting, so I hope your study comes up with some good data, 'cause this is definitely an area that I think is so lacking for our kids.

**Interviewer:** I think so too. I think it is, definitely finding some interesting patterns and I'm hoping that these patterns are ultimately helpful for people like you.

**Interviewee:** Awesome, but thank you. No, I don't have anything unless you do, I'm great.

**Interviewer:** No, no. Well, one small question, do you actually know anyone else who might want to participate? It's OK if you don't, I ask everyone, just in case.

**Interviewee:** I don't…I mean, in Ryan's world, there's a few parents who still are not acknowledging that their child even has needs. There's one family I think it would be very beneficial for, but they…the mom is good, the dad will not acknowledge that the son has issues. And it's interesting because I mean, I guess it's because Ryan's a boy, but I mean, a lot of the parents I talked to, it's all…it's like our sons all have something. And where I grew up, it's very interesting; if I look back at all of my neighbors and people like that, we all – and this is sad to say, we all, almost every one of us has a child with some type of disability. And I had a teacher way back in college, when I was in college, and he said, *“oh, do you live by blah blah blah?”* And I was like, *“yeah.”* He's like, *“you look back someday, and you let me know if you have children that have disabilities of some kind.”* And I was like *“what?”* Well, we lived by a garbage dump, and not close, like I would say it was probably a couple miles away, but back when I was growing up in the 70s is when they put everything in metal barrels and all of that went into the soil and then went into the water. And so, his theory was, in years to come, would our children have disabilities or looking and seeing cancer and things like that? And I was always like struck by that. But when I look back at all of my friends who now have children our ages, and I'm like wow, Ryan had a learning disability, now the autism. I have a friend that their child has Downs. I mean there's a lot of us from that area where we grew up that our children have disabilities of some kind. So, it's very interesting. And I'm not saying that's it, but I was like, wow, that teacher was kind of dead on or did he like just hate the class? **[laughs]** Was like, *“you guys are gonna have…”* you know, but just very interesting to look back and see. But if I do, I have your contact information, so I can send that out. I'll see if this one family [will], 'cause it might help the mom. I don't know that the dad agrees to it.

**Interviewer:** There's no pressure. If they don't want to, that's super OK too, you know. Whoever wants to join, they’re welcome. And if they don't, that's OK too

**Interviewee:** Awesome

**Interviewer:** Yeah. Thank you so much for taking time out of your evening, it's been such a pleasure to learn from you. I really have.

**Interviewee:** No problem, thank you.

**Interviewer:** Thank you. So, once this audio renders, I will send you a gift card as a compensation for your **[01:03:53 inaudible]** effort, so expect it tomorrow. It takes a couple hours to render, so.

**Interviewee:** Oh, no worries. Thank you so much, it's been great to do this, it really is. It's kind of cathartic on my end, I don't know if other parents say it, but it's kind of cathartic to look back and see where he's come from and where we're going.

**Interviewer:** I'm so happy to hear that. Can I do anything to help you? Would you like any copies of the reports that you did? Like, can I do anything?

**Interviewee:** I don't think so. I mean, hopefully those were helpful, and you know. I think we're…I'm good on my end, I don't need that, I mean that that's probably something that I could roll off in my head if somebody asked. But no, I'm very good. But thank you for your time.

**Interviewer:** Of course. And if you need anything, you know where to find me, please reach out.

**Interviewee:** Alright, sounds good. Thank you so much.

**Interviewer:** Bye. Have a nice evening.

**Interviewee:** Bye, you too.

**[END OF TRANSCRIPT]**