**Interviewer:** Alright, we are recording and I will be asking your perspective regarding your child’s transition to adulthood in relation to his sensory sensitivities and sensory interests and I’ll be doing something called a semi-structured interview, which means I have my planned questions and my script but I’m going to be adapting my questions to actually follow our conversation so it makes sense for us. Do you have any questions?

**Interviewee:** Nope.

**Interviewer:** Okay, awesome and if there are any questions that come up that you don’t want to answer for whatever reason, that is okay, you do not have to, I want to make this positive for you.

**Interviewee:** Okay.

**Interviewer:** And, if there are things that come up that you think about later, feel free to bring them up, it doesn’t have to be a linear conversation. Could you please start off by telling me about your child’s sensory sensitivities and sensory interests?

**Interviewee:** His sensitivities are to pretty much everything: clothing, foods, textures, sand, leaves, I always try to describe one thing that Ryan said one day that just blew my mind and it kind of gave us a little insight into his sensory issues. Jamie was giving him a shower and Ryan said*, “Dad, the water is too wet.”* So I was like, *“Alright.”* So I kind of got a little insight into how he feels.

**Interviewer:** Yeah. Go ahead.

**Interviewee:** I was going to say, everything, every little touch, every little…we have to go around wondering if it’s going to set him off a little bit.

**Interviewer:** Absolutely. So, you talk about the textures because water is a texture, sand is a texture, clothes, is it…is every sensory modality amplified or just touch?

**Interviewee:** Well sound, as long as he can control the sound, he’s okay. That was another thing that we discovered back when he was very young, he would bite, well yes again to his father, he’s pointing to himself, when he was younger and he was in preschool, he would bite crying children and we couldn’t figure out why he did that but it was the sound that they were making, the crying and he bit them, they would be removed from the room. So in his little mind, that was how he would do it. So, we’ve discovered that he can listen to really loud music on his headphones as long as he’s controlling the volume. He’s gone to concerts and we get the noise cancelling headphones and stuff like that, it’s gotten better as he’s gotten older, we didn’t have to use them and he was okay with going to places **[0:03:00]** that were a little louder. But… I’m just saying that was one of his things with sound. It’s touch, it’s sound, it’s texture. You know, he doesn’t really touch anybody else; he doesn’t run up and hug his grandmother, he’ll give someone a hug if he’s told to but not... his father and I, that he will do but not anybody else.

**Interviewer:** Got you. For the sounds, you mentioned control, does he still dislike sounds he can’t control? Like say a crowd if he’s out in public and maybe before COVID?

**Interviewee:** He could get disoriented, yes if he’s in a large crowd or if it’s too loud or if there is too much going on. If it’s something he’s interested in though, he’s fine.

**Interviewer:** Okay, got you.

**Interviewee:** Like if we were just at a mall or something that he wasn’t interested in, it could be very overwhelming for him.

**Interviewer:** What about unexpected sounds like a fire truck or some other like non-human noise that is unexpected?

**Interviewee:** [Talking to her husband] I meanhe seems to be okay with loud noises that just suddenly happen, Ryan’s reaction, he seems to be okay with them now. Before, when he was younger, no he wasn’t, not by any stretch of the imagination, he would freak out. Sorry, I’m having a sip of coffee here.

**Interviewer:** Please, drink as much coffee as you need, it’s quite early. So going back to textures and touch, it sounds like things are amplified, is it everything? Are there things he likes or is it all just kind of too much for him?

**Interviewee:** He likes soft, fluffy, anything that’s soft and cozy, he loves it but anything hard or rough, or an unpleasant texture, no way. Tags, we have to cut them out, go tagless we’ve always had to do that, we discovered that very very young.

**Interviewer:** Yeah, totally. Go ahead.

**Interviewee:** I was going to say he was actually very easy to toilet train because he couldn’t stand the feeling of a diaper.

**Interviewer:** Oh, that’s good, that’s helpful for you. What happens when he is faced with a texture that he doesn’t like, like maybe jeans because I think jeans can be kind of scratchy or something?

**Interviewee:** Yeah, he won’t go near it. He doesn’t mind the jeans but I mean if there is a tag, he would just constantly be ripping at it or he’ll rip the shirt off.

**Interviewer:** Oh, okay, he will just like avoid that completely?

**Interviewee:** Yes.

**Interviewer:** Got you. **[0:06:00]** What about taste? I think you mentioned taste.

**Interviewee:** Ryan has a very strange pallet; he loves hot and spicy. I mean the hotter and the spicier the better. He loves sour, pucker, he dislikes anything gushy, mushy, gritty, oatmeal or cream of wheat or something like that but he loves smooth and creamy, he likes yogurt or like a pudding texture, he’ll eat that. He loves chicken, he loves fried foods. I always call them…for a very long time he only ate the ‘Autistic five.’

**Interviewer:** What’s that?

**Interviewee:** Chicken nuggets, mac and cheese, chips and I can’t remember what else, there was one other thing he would eat and there was only five foods and he only ate those five foods until he was about 15.

**Interviewer:** And what happened at 15 that made him like other things, do you know?

**Interviewee:** I started cooking in a certain way and adding spice to things and then all of a sudden, his spice level just blew up. I mean he would go and get habanero chicken wings, which just the smell of them will make me cry.

**Interviewer:** Yeah, same.

**Interviewee:** He puts crushed red on everything. I mean I’m afraid what his stomach’s going to look like as he gets older because of the spice level but he will always say it has no flavor, it has no taste. So, unless it’s a pow flavor, to him it’s nothing.

**Interviewer:** Got you, interesting. What about maybe like vision or smell, other senses?

**Interviewee:** He has such bad allergies and congestion all the time, I mean so he doesn’t smell a lot of things, so he never really complains about smells. He blows his nose constantly; he’s been to the allergy doctors and he’s had the allergy tests and he’s basically allergic to everything.

**Interviewer:** Oh, poor guy, that’s not pleasant.

**Interviewee:** Yeah, so he takes a lot of antihistamines so the smell thing is not a real problem. And what was the other question?

**Interviewer:** Vision, are there any visual things that his likes, dislikes?

**Interviewee:** He loves bright colors, anything bright, fun, he loves graffiti art, anything strange and unusual, doesn’t conform to any things that are popular, very weird. He likes a lot of really bright, bright colors.

**Interviewer:** Okay. Will he…Would you consider those kind of a general preference or do you think they are beyond a preference that someone might have?

**Interviewee:** A little beyond, definitely a little beyond. **[0:09:00]**

**Interviewer:** Got you. And so how have his sensory sensitivities and sensory preferences changed over time? You kind of touched upon that.

**Interviewee:** He’s gone from not liking pretty much anything and everything being an issue to really adapting to the world. He can go out into the community without having a breakdown or a meltdown if something doesn’t go his way, where before it could be... I could be in Target and we’d end up with a complete meltdown and I’d have to put him in a cart and get him out but now he can go into stores, he can go shopping so he’s kind of adapted to the world.

**Interviewer:** Yeah, absolutely. And is this for all of the sensory modalities or is it for more particular ones?

**Interviewee:** It’s pretty much for all of them but we have learned with Ryan is as long as he has his iPod and his headphones in, he can pretty much do anything. So if it’s too much sensory around him, he just listens to his music and goes into his own little world and he’s fine.

**Interviewer:** That’s great. You talked a lot about adapting, would you say... in addition to adapting do you think his sensory sensitivities have changed in terms of severity, are they less severe than when he was younger? Are they more severe?

**Interviewee:** Less, definitely less.

**Interviewer:** For all of them?

**Interviewee:** For all of them.

**Interviewer:** Got you. And do you think any other changes that you’ve noticed over time, do you think they’re related to any independence that he’s gained?

**Interviewee:** Yeah, I do.

**Interviewer:** How so?

**Interviewee:** He has very low confidence in himself but once he gets a little bit of confidence, he’s able to adapt to the situation a little bit better because he gets a little bit of confidence, *“I can do it, I can do it.”* Those are really special moments for us when he decides, *“I can do this.”*

**Interviewer:** That’s excellent, that’s really lovely. You’re giving me great segues. So you talked about headphones and you kind of talked about exposure to spicy food through your cooking but how does Ryan or how do you help him manage and cope and handle his sensory sensitivities?

**Interviewee:** We just roll with it. I mean we don’t have any coping mechanisms that we use on a regular basis, like we’re going to use this structured thing to get him through this, we just kind of roll with whatever the situation is, we just know him so well, that we can just get him through it. I don’t really know how to answer that.

**Interviewer:** No, you just did, that was great. In one of your forms you filled out you talked about that he received OT and he had a feeding nurse, could you talk a little bit about those? **[0:12:00]**

**Interviewee:** Ryan did not eat solid food for a very long time. He went six months without eating any solid food whatsoever and he was…would have been about maybe two when that started and he just decided he wasn’t eating anything so he lived on Pedi sure and Alba 66 was one of the things we used back then. We would mix milk in with it. So we had feeding nurses come in and I wasn’t real happy with it because they basically just wanted to get the calories into him, so they’re trying to give him syrup, butter and stuff like that but that was when we did learn that he would respond to citrus, so we started doing lemon and lime yogurt and things like that and he was responding to that. We would take an electric toothbrush and try to stimulate him with that in his mouth to try to get him then to eat the foods. It was a very, very long time and then he had a French fry and he liked the French fry and then decided he’d eat French fries but the kid can’t live on French fries so we were doing the shakes and the fries. Eventually, it just kind of morphed into a few more things but then we had a good 10 years when there were only five foods he would eat.

**Interviewer:** Do you think his lack of wanting to eat solid food was kind of related to his preference to not mushy things? You talked about not liking that gushy…?

**Interviewee:** Absolutely, because even as a baby, he never ate the cereal that you give an infant, we tried and tried and tried wouldn’t eat it. Even tried putting it in his formula, wouldn’t eat it, if it wasn’t anything smooth. I make him smoothies now and I had to go buy a $600 blender, I had to go buy a Vitamix just so I could make them with zero chunks, you could take a whole orange and throw it in there and it would smooth it out. That’s just his texture thing. Lumps, bumps, nothing, no chunks of any foods left over.

**Interviewer:** Did all that feeding therapy help him do you think?

**Interviewee:** I don’t know. I’m not really sure if it helped or not because they were more interested in just trying to get calories into him. Ryan was very underweight for the first 15 years of his life and now he’s overweight, so we never had that real balance.

**Interviewer:** Got you.

**Interviewee:** He was in the one percentile till he was about 15. I’m talking skin and bones; he was so thin.

**Interviewer:** What about OT? You mentioned that on your form.

**Interviewee:** He’s still doing OT. I used to take him to the Barret Center in Southborough…was it Southborough or Westborough, I’m not sure which… **[0:15:00]** He would…outside therapy, I would take him to Children’s Hospital for outside therapy. [Talks to her husband] But I would drive him to all these places, I would drive him from Hope Dale to Wall Ham, so he could get therapy there, it was OT, PT and speech.

**Interviewer:** And were these therapies, do they focus on sensory sensitivities and sensory preferences?

**Interviewee:** They did that as well. I mean we did sandboxes, trying to do that. When he was younger it was the bubble therapy so you put him in the sandbox and then blow bubbles and try to get them and then pour sand on his legs and arms and try to get him to touch it and then of course, to him, it was like hot burning coals, so it wasn’t nice smooth sand, it was…that was bad.

**Interviewer:** Do you think the therapies helped him with his sensory sensitivities, particularly to touch?

**Interviewee:** Yeah, I do.

**Interviewer:** You do, why?

**Interviewee:** Because he seemed more tolerable afterwards. Even do the stuff with the hands where you just take and massage the hands or get him a touch board, get him to touch this is smooth, this is a sponge, this is rough, this is bumpy, so we did a lot of stuff with touch boards. I think it got him a little more accumulated to touching things in the world.

**Interviewer:** Absolutely. Were there any other therapies or interventions that he received related to sensory sensitivities and sensory preferences?

**Interviewee:** Well, he was in early intervention, he did it for three years, we started early intervention at four months because I knew at four months something was wrong.

**Interviewer:** That must have helped him so much to be doing it so early?

**Interviewee:** It did. I swear, if we didn’t have the therapies that we had from the time he was basically born, then I don’t know where he would be. He also didn’t talk till he was five. He said one word, *‘touchdown’*, that was the only word he ever spoke. He hates football. That was the only word he ever spoke in five years until he broke his arm and we went to the hospital and of course the hospital is going ask this little child*, “How did you break your arm?”* My nephew, his cousin had pushed him off the bed and I said, *“He’s Autistic, he doesn’t talk.”* So, of course at the hospital he doesn’t talk and then we go to the casting place the next day because he had a buckle fracture and of course, the doctors are asking and I say, “*He’s Autistic, he doesn’t talk.”* And then he said, *“Mathew push me bed.”* And I started crying in the doctor’s office **[0:18:00]** and they couldn’t figure out what was wrong with me and I’m like, *“That’s the first words he’s ever spoken.”*

**Interviewer:** That’s a pretty complex sentence too.

**Interviewee:** The doctor looked at me and said, *“Who’s Mathew?”* I’m like, *“He’s four.”* I think that the speech and all that, eventually really kind of helped. What also helped with him is he was diagnosed with Epilepsy, he has Electrical Status Epilepticus during sleep, so it’s called ESES, it’s actually kind of a rare form of Epilepsy where he has up to 100 seizures an hour during third and fourth stage sleep and doesn’t go into REM, so we discovered that when he was four. We decided on heavy anti-convulsants and between that and the therapy, I don’t know which one it was but all of a sudden, his language came in.

**Interviewer:** That makes sense.

**Interviewee:** It was definitely an intense time. Really glad we’re not going through that anymore.

**Interviewer:** Yeah, me too for you.

**Interviewee:** And about three years ago…[inaudible]

**Interviewer:** That’s good. Did the early intervention, did that target sensory sensitivities or was that more holistic therapy?

**Interviewee:** Oh no, we did play therapy. We did ABA and play. So they would bring in a sandbox and bubble guns and floor play and the books with all the fuzzy things. He would have this beach lady come in and he loved bubbles, so she would do the edible bubbles to bring stuff to his mouth. He had three play groups; he had a play therapist. He had an OT, a PT and a speech, so we had seven things a week. So they were constantly at our house and then we would go out into the community, they would have three different play groups a week and I made sure that he went to all of them.

**Interviewer:** Good for you. And you think all of this therapy kind of helped him adapt, like you talked about earlier?

**Interviewee:** Absolutely.

**Interviewer:** Got you, that’s excellent.

**Interviewee:** He’s been in SPED his entire life. He started in a regular school from preschool, first and second grade. After second grade he was still in regular school but that’s when our problems started. He started regressing severely and between second grade and fifth grade the depression set in, the whole world crashed. When he was in fifth grade, he tried to kill himself. He thought that if he put a fishing hook through his eye because fish die **[0:21:00]** on a fishing hook, so that’s when we had to get him started him with a therapist, he’s still with the same therapist today. We got him out of public school because it was public school that was doing it to him. The integration classes don’t work. I’m not a believer. Will never advocate for that. I’m sorry, if your kid is Autistic, put them in a special school, it’s the only thing that works because kids are cruel. I don’t care how much you say*, “They’ll help them.”* No they won’t. So he went to a special school and he’s been doing that ever since and he’s had therapy every day at school.

**Interviewer:** Good. Is it helping him?

**Interviewee:** It is.

**Interviewer:** Good.

**Interviewee:** We suffered during COVID. Right now, he’s on Zoom, Wednesday is the remote class. This is also his last year, he inches out in May and we’re really scared because I can’t tour any adult services, I can’t get him into an adult program. DDS isn’t able to get us pretty much an appointment with anybody because people are taking care of what they already have instead of adding on new clientele. Come May, he’s going to have no therapies. He’s going to have no support and he’s going to be an adult and basically the school system kicks you out and we’re kind of torn and we’re not sure what’s going to happen after that.

**Interviewer:** I can imagine that’s really hard and very scary.

**Interviewee:** I’m sorry, I’m probably not even answering your questions.

**Interviewer:** No, no, that was excellent. We’re going to talk more about this transition period in a couple questions, this is a beautiful preview and I’m excited to ask you some more questions. Thinking a little bit more about his sensory sensitivities and sensory preferences, when he is in a scenario where he is surrounded by things that are distressing to him does it cause or increase anxiety?

**Interviewee:** Yes.

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

**Interviewee:** His eyes will start darting around, he gets this look on his face, he can’t answer any questions, he goes, *‘ah, ah, ah, ah’* and starts looking around, shut down, that’s basically it, you have to just kind of lead him away.

**Interviewer:** Is this all sensory things? Is it touch mostly? Is it unexpected, uncontrollable noise?

**Interviewee:** That’s his overwhelming reaction or if he was in a crowd or in a space where he wasn’t comfortable, that would be his reaction. Touch, he just moves away. He’ll just try to get away from whatever it is that’s uncomfortable, he doesn’t usually verbally say anything unless I’m there or his dad’s there.

**Interviewer: [0:24:00]** Got you. Has this changed over time?

**Interviewee:** It’s better. When he was younger it was a complete meltdown. If he touched something he didn’t like, it was fall to the floor and it could be two hours.

**Interviewer:** And now he can just remove himself?

**Interviewee:** Yes. I couldn’t tell you how many hours I spent rocking that kid when he was having a meltdown.

**Interviewer:** Yeah, I’m sure. Thinking a little bit towards the future, what goals or hopes do you have for him in terms of his sensory sensitivities and sensory preferences?

**Interviewee:** I want him to be able to navigate the world. I don’t know how realistic it is but I’d love to have him just be able to go out in the community and have a normal experience. Be able to cross the street by himself without listening, there is a bird over there and there is a cat over there and everything pulling him in a different direction.

**Interviewer:** Right now, is something like that challenging for him because he does get distracted?

**Interviewee:** Absolutely. He can’t cross the street. He can’t... just going for a walk by himself, it’s not something that’s safe for him because he would be so distracted by everything else that’s going on. It pulls his mind away from safety.

**Interviewer:** Absolutely.

**Interviewee2:** He can’t cross the parking lot because…[inaudible]

**Interviewee:** Safety, he can’t walk in a parking lot, we have to basically lead him. He’s not able to navigate that on his own.

**Interviewee2:** He just thinks every car will stop. He doesn’t know the safety aspect of it.

**Interviewer:** Got you, absolutely.

**Interviewee:** That has to do with sensory too. We don’t know how much of that is just the noise and the environment is overwhelming him too.

**Interviewer:** For sure, absolutely, it’s all connected. We’re going to shift gears to our next chunk of questions. Again, you’ve given me nice segues. You just talked about community and that’s what we’re going to talk about. Thinking about the community, as Ryan has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities and sensory preferences?

**Interviewee:** Ryan doesn’t go out all that much. When he’s around the community he’s always with an adult, it’s not something that he ever experiences on his own, so we kind of guide him, so it’s really hard to say what’s... if we just let him loose on something **[0:27:00]** he’s dying to do it but we’re just very hesitant because we don’t know what that’s going to look like.

**Interviewer:** Yeah, absolutely. Maybe thinking about different types, school could be a community, how do they understand him? Do they accommodate? Do they accept? Do they understand his needs? Your family?

**Interviewee:** His school that he’s in right now, we’re not super happy with it but we were actually going to move him out of the Accept Program but then COVID hit, so he’s kind of stuck. They’re a little more on the holistic kinda approach and I kinda call the teachers granola crunchy where we’re not really those kinds of people, so that kind of approach doesn’t work with him. He kind of has a lot of trouble in school. He’s very quiet, very stays to himself, he doesn’t even have a friend there, he’s been there for two years, he has no friend, has no one that he communicates with. He’s had difficulty with teachers, he doesn’t understand some of their approaches. So, him, right now, it’s very difficult if you want to say the school is a community, that’s hard for him.

**Interviewer:** Yeah, so it sounds like maybe fit isn’t great there?

**Interviewee:** Yeah, he doesn’t have a good fit almost anywhere he goes.

**Interviewer:** Okay.

**Interviewee:** We haven’t found any particular place where Ryan belongs.

**Interviewer:** Got you. I was going to ask about acceptance and accommodation but it sounds like if you don’t have fit, you probably also don’t? Fit comes first.

**Interviewee:** He’s not accepted.

**Interviewer:** Has that always been the case? Was that different when he was younger?

**Interviewee:** It was a little different when he was younger because he had a lot more adult facilitation as far as playing with a friend, it was a little easier when he was younger but as he became a teenager and now a young adult, he just doesn’t fit anywhere. He has a strange sense of humor, he listens to really strange music, he doesn’t do anything mainstream. A lot of the kids at his school are really into the mainstream and so when they do these group things, he’s always like, *“Well, I don’t like that, I don’t like that.”* He doesn’t have anything in common. He has a strange sense of humor when it comes to movies, they don’t even have that in common. He’s definitely the black sheep. He just doesn’t fit in.

**Interviewer:** That must be hard?

**Interviewee:** It is.

**Interviewer: [0:30:00]** School, although it doesn’t sound like it’s a good fit for him, do they understand his sensory sensitivities? Do they accommodate him in that way?

**Interviewee:** Yes, they do.

**Interviewer:** That’s good at least.

**Interviewee:** Yeah.

**Interviewer:** Are there other types of community, like maybe your family, his family, maybe like a religious group or something like that?

**Interviewee:** No religious groups, my husband is Jewish, I’m Catholic, Ryan hates religion, he doesn’t understand it so we’ve never actually made him... he was baptized and all that but we’ve tried with church and he doesn’t understand the concept, God is not concrete, so he can’t see him, he can’t touch him, he can’t talk to him, why I am supposed to believe, he’s a very concrete person.

As far as our family goes, my family died five years ago in a house fire.

**Interviewer:** Oh god.

**Interviewee:** Today actually is the five-year anniversary of me taking my mother’s house down.

**Interviewer:** I’m sorry, are you okay?

**Interviewee:** Yeah. Sorry.

**Interviewer:** No, it’s okay. I’m so sorry. Thank you for sharing that.

**Interviewee:** So I don’t have any family. Jamie’s family is in Framingham, so they’re not close. His brother is in Framingham, so it’s not like we have family around the corner, we don’t really have anything. Jamie’s dad has passed away and his mom tries but she works full time and lives 40 minutes away.

**Interviewer:** That’s hard.

**Interviewee:** Yeah, so we don’t have a lot of family support.

**Interviewer:** Got you. When your mother-in-law is around and whatever family you do have when they are around, do they accommodate and understand his sensory sensitivities?

**Interviewee:** Yes, yes, they do.

**Interviewer:** That’s lovely then, that’s good.

**Interviewee:** They’ve been with him his whole life, so they’re pretty used to Ryan.

**Interviewer:** That’s great.

**Interviewee:** They’re good with him.

**Interviewer:** That’s really good. Thinking a bit towards the future, what are your hopes or worries for how his community will react to his sensory needs in the future?

**Interviewee:** I’m afraid of him getting hurt. I’m afraid of him freaking out about something and there is no one there that he can turn to and somebody not taking it the right way and hurting him.

**Interviewer:** Yeah, absolutely, that makes sense. Thank you for sharing that. We’re going to move on to our next chunk of questions, so hopefully it’s a little bit easier. And again, if there is anything you don’t want to talk about, we can totally skip it, we can stop at any time. I don’t want to make this sad or upsetting.

**Interviewee:** It’s okay. I’m used to it.

**Interviewer:** I’m sure. In the transition to adulthood, where do you see Ryan?

**Interviewee: [0:33:00]** I see him staying with us as long as we’re alive and then we’re hoping that his brother will step up to the plate, we don’t know if that’s going to happen or not or if his brother didn’t step up then he would end up in a group home. We don’t ever see him living independently. Neurologist told us when he was maybe two years old, that he would never live independently and pretty much everything his neurologist said back then, has come true.

**Interviewer:** In terms of what? In terms of independence?

**Interviewee:** Independence, how he would act, what he would do as far as his development would go, as far as his mental capacities would go, everything that he had put on the table for us at two years old has absolutely come true.

**Interviewer:** It must be hard.

**Interviewee:** Yeah. I think it was harder back then because that’s when you get that whole rush of *‘oh my god, this is a two-year-old child and you’re telling me this is his future’,* now we’re kind of used to it. Nothing really phases us anymore. Yeah, but I don’t see him ever living independently.

**Interviewer:** Got you. Thinking about independent skills, could you describe things that he can do by himself verses some things he needs some support on?

**Interviewee:** Okay, do by himself, he can make a bag of popcorn.

**Interviewer:** Nice.

**Interviewee:** He can put his laundry in the washer. He can put his cloths away. He can half take a shower by himself; his dad has to set it up and then help him and shave him, but he can go into the shower and wash himself and stuff by himself. He can do all his personal grooming; he can go to the bathroom by himself…he can do…I’m trying to think…

**Interviewer:** I can give you some prompts if it helps?

**Interviewee:** Yeah.

**Interviewer:** You talked about he’s good on daily hygiene, he can kind of take care of his environment like laundry and stuff. What about cooking beyond... like preparing simple meals beyond popcorn?

**Interviewee:** Nope, no skill whatsoever. We’ve tried and tried and he... if you were standing there giving him specific instructions, you measured something out and told him to pour it in the bowl, he could do that but as far as measuring it out, he would get too anxious, *“Am I doing this right? Am I putting it in right? Is this supposed to be there?”*

**Interviewer:** Could he use the microwave to heat up leftovers by himself?

**Interviewee:** He can. He can heat up pizza, simple things, mac and cheese, something like that, yeah, he can use the microwave.

**Interviewer:** That’s great. Does he help you with shopping at all? Helping you go to the store, maybe before COVID? **[0:36:00]**

**Interviewee:** He goes to the store; he doesn’t particularly help but he can go down to an aisle that he knows and pick out stuff that he wants.

**Interviewer:** Okay, that’s great.

**Interviewee:** And we have done with him, giving him the shopping list and having him go to the aisles, they also do it at school, well pre-COVID, they would go do the shopping lists and each student would have to go to a certain thing and pick out certain items, he also has a mentor who will take him out and have him do the same thing, if they go to the comedies or something and have him try to do that.

**Interviewer:** That’s great. What about... you said you don’t think he’ll live independently; does he ever express interest in his own way that he would like something like that?

**Interviewee:** He doesn’t want to live alone. I think he’s very used to having some support, so I don’t think that he actually wants to live alone.

**Interviewer:** Yeah, totally. And then through school, have they helped him learn some vocational skills for jobs, things like that?

**Interviewee:** That’s where he goes... he’s in HEP so that’s pretty much what they do.

**Interviewer:** Oh, okay.

**Interviewee:** It’s all independent living skills, it’s job skills, it’s navigating the train system, the supermarket, it’s daily living, how to make a doctor’s appointment, how to call utility companies, just everything that we take for granted, that we already know. When I see some of the things that school does and I go through his email because everything comes on an email now, and I look at the life skills that they touch on every single day, I realize just how little he knows. So if I said to him, *“Okay, you have to call Dr. Lee and make your doctor’s appointment.”* Wouldn’t have any idea how to do that. Tell him something very simple that we take for granted, he just doesn’t know but school tries, he just doesn’t really remember.

**Interviewer:** Could you give another example, that was a very helpful one?

**Interviewee:** I wish I had the emails in front of me because my mind’s going totally blank.

**Interviewer:** That’s okay, that’s totally fine, don’t worry about it.

**Interviewee:** Okay, this was one of the things that they just did the other day. You going to plan to have a friend over. You’re going to serve them food. So it was taking the steps of inviting your friend over, picking a time, figuring out the menu, then going to the store to buy it and then preparing it. They had the whole thing set out completely, couldn’t even start. We walked through the whole thing together **[0:39:00]** and it was... I think it gave him less confidence in himself because he was like, *“I’m stupid, I’m stupid, I’m stupid.”* I’m like, *“You’re not stupid.”* He just doesn’t... there’s too many steps. You give him one step or two steps, he’s fine but you can’t tell him, *“I want you to go get dressed, go brush your teeth, go eat”* all at the same time. You can do it individually, after he’s done one tell him to do the next but if you told him all three at the same time, he’s not going to do any.

**Interviewer:** Yeah, totally, absolutely. And then also through his school program, have they helped him with money management, understanding money?

**Interviewee:** They’ve tried. Money is a big thing again with him. He doesn’t understand money. He doesn’t understand the concept of money. This past weekend we actually had his mentor, who takes him out once a week but he also has a little shop at the flea market which sells t-shirts, so I had Nathan put Ryan to work, we gave him some money to pay Ryan with. And so he went, Nathan’s not that much older than Ryan, so I said I want him to see what it is that people do for money. Ryan worked like three hours at the t-shirt stand, he wasn’t able to do a lot but he was able to organize some things and talk a little bit with the customers. He did a nice job and he got paid $20. He wants to see a virtual concert, well that virtual concert costs $15. So with his 20, I said, *“Well, you’ve got to buy your own ticket now. You’ve got money if you want to see it.”* We’re trying to show him what money does and what it doesn’t do but he still doesn’t understand it. He thinks that the house magically appears and food shows up. It’s also hard teaching special needs kids because everything is done on a card these days, so we try to do a lot with cash to try to show him what paper money is but everything is done with a card. You don’t see the pay check. We use to see our parents cashing the pay check, counting everything out, putting the bill money in different envelopes or whatever, the kids today just don’t see it. Understanding the concept of it is hard to teach them what to do with it.

**Interviewer:** Absolutely, it’s not as tangible.

**Interviewee:** Right, exactly.

**Interviewer:** No, that totally makes sense, whole different modality, it’s invisible. Thank you, that was really really helpful, interesting. Do you think he’ll be able to achieve more independence moving forward?

**Interviewee:** I hope so. I’m hoping with some maturity that maybe he can. I’m hoping he can build more confidence and say, *“I can do these things. I can figure this out.”* **[0:42:00]** It’s just his brain doesn’t work that way, it just stops, it doesn’t... he doesn’t have the thought process where he can think things through, it has to be immediate, not the aftermath. So it’s what’s right in front of me, this is what’s happening now, it’s not what’s going to happen three steps from now.

**Interviewer:** Absolutely, that makes sense.

**Interviewee:** In my mind I’m 27 steps ahead. I’ve already thought out every scenario, I look at it and I’ve got every scenario going through my head. But for him, I just don’t know.

**Interviewer:** Yeah, absolutely. What do you think, besides maturity and confidence, what do you think will move him into adulthood? What do you think will give him that maturity and confidence that will help him move into adulthood?

**Interviewee:** I don’t know. You got me on that one. No clue.

**Interviewer:** In an ideal world, could you imagine particular services or interventions that could help?

**Interviewee:** In an ideal world?

**Interviewer:** Yeah or in a real world, whichever?

**Interviewee:** If we had the money, I would hire someone to be with him and walk him through everything, I mean basically almost 24/7. I mean he goes out with my niece, who she just graduated with a double bachelor’s in special needs and she’s just got a job as an ABA therapist but he goes out with her and just the way that she knows how to do things with him, he’s independent, they went to a haunted house, he was fine.

**Interviewer:** That’s great. Good for her.

**Interviewee:** All the stuff, all the jumping, he was fine. It was just the way her approach and the way she’s able to just guide him into doing things. In a perfect world, if I could have someone like my niece to just be with him and constantly just showing him things, I think he could definitely get better. But, don’t have the money for that.

**Interviewer:** Yeah, those are expensive things, for sure. Putting these two things together, his sensory sensitivities, his sensory preferences and his transition to adulthood, how do they intersect?

**Interviewee:** I don’t know.

**Interviewer:** You talked about safety for instance right, so maybe you could talk a little bit more about that or something else?

**Interviewee:** His safety, he doesn’t have any. He has no sense of safety. We lived through a humongous fire **[0:45:00]** that killed his family members, my mother, my brother, he suffered this loss but we’ll say to him in the house*, “What would you do if there was a fire?”* And he says, *“But there won’t be.”* I said, *“You know that there could be.” “Yeah, but there won’t be.”* That’s his answer to it. If we are in a parking lot or trying to cross something, he doesn’t look for cars. We’ll tell him to look for cars and he’ll do the [makes sound] but doesn’t actually look for the cars because the cars are going to stop in his mind, they’re going to stop. He was bullied at school and he just allowed these kids to just keep... and these are special need kids, when you get bullied by special need kids in a special needs school, you know that your kid is not going to be able to stick up for himself or safely navigate people. So that happened to him and he wasn’t able to stick up for himself or even tell somebody until he came home and told me what was going and then they had to launch an investigation and it was found that yeah, he was being bullied. He has no sense of what could happen. If I jumped off of something, could I break a leg? Even though he’s afraid of everything, he’s afraid of heights, he doesn’t jump but I mean if he did, he would have no sense of what could happen if he did.

**Interviewer:** Yeah. You’re talking about the lack of planning kind of and like lack of understanding of what will happen next. In regards to safety, do you think that it’s more like a planning issue or do you think it’s also related to sensory sensitivities like being overwhelmed by like say his environment in a parking lot?

**Interviewee:** I think it’s both…both things, absolutely.

**Interviewer:** Got you. And would you consider his sensory sensitivities an obstacle, a vehicle, neither, or a bit of both towards his independence?

**Interviewee:** Obstacle.

**Interviewer:** Yeah, in what way?

**Interviewee:** He keeps trying to navigate all these different textures and different things and he just can’t seem to navigate around them, they are obstacles in his way.

**Interviewer:** They are what sorry?

**Interviewee:** They are obstacles in his way and he keeps ploughing straight into them.

**Interviewer:** Even though he has learned to adapt, you still see them as being obstacles?

**Interviewee:** I do, I do because I don’t know, I mean he has adapted but, in his mind, I don’t know if he’s truly, it’s hard to say. Such a different kid. **[0:48:00]** I mean he’s so... he doesn’t fit any mold, he doesn’t fit in the Autistic molds, he’s never fit the mold. He was severe and then he was not so severe and then he was in the middle, I don’t know.

**Interviewer:** Yeah, absolutely. It’s hard.

**Interviewee:** It is.

**Interviewer:** It’s hard because things are meant for molds and it’s hard when you don’t fit in the mold.

**Interviewee:** He definitely doesn’t.

**Interviewer:** What do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities?

**Interviewee:** I think it’s going to be very hard for him to get a job, even if he went to a supermarket, he would not be able to even bag groceries because if one person yelled at him, it would be the whole sensory overload or if he had to put something in the bag and it was wet or if he had to put something in the bag and it was hard or it was meat, something like that and something that touched his hand that was gushy, it would end up being all over the place, the bag would go on the floor and he would just walk into the corner and go *“Ah, ah, ah.*” So, that’s going to be a big problem for him, even just finding a job because of his sensory issues.

**Interviewer:** Absolutely, thank you. What do you think will help him in this intersection of sensory sensitivities in this transition?

**Interviewee:** I don’t know. I wish someone would tell me.

**Interviewer:** Yeah, that’s really fair. That’s really, really fair.

**Interviewee:** Cause I’m fresh out of ideas. We’ve tried everything.

**Interviewer:** Sounds like you have.

**Interviewee:** And I just don’t know that there is anything that will work for him. It just may just be him and this is just his life and we just have to adapt to him verses him adapting to us.

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

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

**Interviewer:** Can you talk a little bit more about that?

**Interviewee:** Well, there’s no groups for him. I’ve been trying to find a social group for him in our area for years, there’s no social groups. There’s no place for him to go to meet people other than the services that we do have, there is just nothing around here, it’s mostly our area because there are services available if I want to drive an hour. Well, I work full time, my husband works full time, we just don’t have that kind of time to be taking him every day for an hour and then wait the two hours that he’s there and then driving another hour home **[0:51:00]** it just doesn’t work. Just trying to find different things for him where we are, it’s been impossible. So there is a huge gap in services because there are none. I used to drive him to the Barrett Center, I used to drive him to Children’s Hospital, we used to take him to different play groups and all that stuff but you just can’t do it anymore and there is nothing around here.

**Interviewer:** Remind me where you are again?

**Interviewee:** We’re in Bellingham.

**Interviewer:** Bellingham, okay. I will think. Maybe I can think of something.

**Interviewee:** You come up with something, I am so willing to listen. I actually still belong to the Autism Alliance but it’s Metro West and we are actually in the wrong county for it but when we used to live in Watertown…

**Interviewer:** I live there.

**Interviewee:** You live in Watertown?

**Interviewer:** Yeah, right now.

**Interviewee:** I lived there for over 20 years. Gilbert Street, right next to the church.

**Interviewer:** I’m on Irving Street.

**Interviewee:** Yeah, you’re right near where we used to live.

**Interviewer:** Yeah.

**Interviewee:** You know the church down the street on Main Street?

**Interviewer:** Oh, okay, yeah, real close.

**Interviewee:** Lived there for 20 years. Then we moved out here to the middle of nowhere. I forgot where I was going with this.

**Interviewer:** We were talking about services, how there aren’t any in your geographical area.

AL Watertown was awesome, I had the best services when we were in Watertown, we were at the community center all the time, we could walk there from our house, he had all the groups, early intervention, different play groups and then as time went on and as he got older, there was nothing. Now that he is a young adult, the services I can find for him are... a lot of them are MR and he doesn’t fit in with that. So I’m trying to find a high functioning Autistic group with kids that are like him, that aren’t more on the mentally challenged scale, it’s been impossible. We’ve found dances in Menden, we went to the dance and it was mostly Down’s kids, he doesn’t fit in with the Down’s kids. We’ve gone to different places in Ashland, which is again 40 minutes away from us and again we get in there and it’s very low functioning or Down’s. I don’t know where to put him. I don’t know where he’s going to fit.

**Interviewer:** Yeah fit, that’s the thing. Absolutely. I will try to think of things and I’ll send them to you if I can find anything.

**Interviewee:** Awesome.

**Interviewer: [0:54:00**] Thinking a little bit more broadly, how have Ryan’s sensory sensitivities and sensory preferences impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** Our goal for him is just for him to survive. We don’t have a lot of really high expectations or a lot of really high goals for him. I don’t know. I don’t even know how to answer that.

**Interviewer:** That’s okay. That’s okay. Is this uncertainty and kind of that baseline of survival, is that because of his sensory sensitivities or because of every part of him?

**Interviewee:** Every part of him, the sensory issues are part of him and they are a huge part of him. If he was able to navigate centers, I think that other things would fall into place for him. If he was able to touch things and he was able to... I don’t have high expectations for a job for him but say it was assembly, if it’s hard, if it’s cold, how’s he going to put that stuff together if he can’t physically touch it? So it’s going to…that touch is going to affect his ability to get a job. His ability to get a job is going to affect the next aspect of his life. He needs to earn money, if he can’t earn money, he can’t be independent, so yeah, it’s a chain reaction.

**Interviewer:** Absolutely, thank you for sharing that. We’re going to move on to our last chunk of questions and it’s the shortest, so we’re almost done. As a mom, as a parent, as a caregiver of someone with Autism but also some sensory sensitivities and sensory interests, what does transitioning to adulthood mean to you?

**Interviewee:** It means that he’s not going to have the protection of school. He’s not going to have that transport piece, the IEP protection. It’s basically sink or swim. It’s throwing him out now to the world that he’s not ready for.

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

**Interviewee:** His perspective?

**Interviewer:** Your perspective.

**Interviewee:** My perspective. Yeah, I had high hopes for a long time, I don’t have them anymore.

**Interviewer:** What caused that shift, if you don’t mind me asking?

**Interviewee:** Reality.

**Interviewer:** Yeah, yeah, absolutely. Thank you. What do you see happening in his future?

**Interviewee:** It’s not good.

**Interviewer:** Yeah, yeah.

**Interviewee:** I don’t see a really good one. I don’t see him thriving at a job, getting married, having children. I see him pretty lonely.

**Interviewer:** Yeah. Thank you for sharing that. I know it’s hard. I have one final question and if you don’t want to answer that, that is okay too. Don’t want to upset.

**Interviewee:** You might want to wait, he’s coming out. Come here for one second.

**Ryan:** No.

**Interviewee:** Come here, just come say ‘hi.’

**Ryan:** I was just coming out to pee.

**Interviewee:** I know but just come say hi. Come wave.

**Ryan:** Okay.

**Interviewee:** Just come wave. Just say hi.

**Ryan:** Hey.

**Interviewer:** Hi, nice to meet you.

**Ryan:** What is this?

**Interviewer:** Hello, hi, I’m Rachel.

**Interviewee:** We’re talking about you.

**Ryan:** Who is this?

**Interviewee:** This is Rachel.

**Ryan:** Hi Rachel. What is this?

**Interviewee:** We’re talking about you.

**Ryan:** Ah, is this for something?

**Interviewee:** Yes.

**Ryan:** It is?

**Interviewee:** It’s for a study.

**Ryan:** I’m interested.

**Interviewee:** I know.

**Ryan:** I know.

**Interviewee:** I’m talking about you.

**Ryan:** Okay.

**Interviewee:** Alright, go and do your thing and get back to class.

**Ryan:** I just came out to pee.

**Interviewee:** Alright, I love you.

**Ryan:** I love you more.

**Interviewee:** Not possible.

**Ryan:** Pretty sure it’s possible. Why is this hanger flesh color?

**Interviewee:** I don’t know why the hanger is flesh color.

**Ryan:** It’s weird.

**Interviewer:** It’s kind of like me.

**Ryan:** Yeah, it’s white as me. It’s weird.

**Interviewee:** It’s the color that came from the manufacturer.

**Ryan:** I know but it’s weird.

**Interviewee:** It just needs to go back in the closet. So, that’s Ryan.

**Interviewer:** He seems like a very nice person.

**Interviewee:** To me, he’s adorable.

**Interviewer:** And inquisitive which is always a great characteristic too.

**Interviewee:** That’s the type of thing, like if he was meeting somebody it would be so hard because he would walk up and say, *“Why is this hanger colored?”* and they’d be like, *“Okay, why are you asking me that?”*

**Interviewer:** Absolutely, I can imagine that being a challenging first interaction.

**Interviewee:** Yes. I mean he saw you on Zoom for like three seconds and that’s his first question to you but that’s normal.

**Interviewer:** That’s who he is.

**Interviewee:** Alright, so your question was?

**Interviewer:** Yes, my question was, how did his sensory sensitivities impact this perspective that you articulated in terms of how transitioning was kind of a sink or swim situation that seems kind of scary and overwhelming, if I were to interpret what you’ve been saying?

**Interviewee:** How his sensory?

**Interviewer:** I’m just asking your perspective of what transitioning means is sink or swim, lack of protection from the services, how much of his sensory sensitivities impacted this perspective? What’s that connection?

**Interviewee:** Again, I’d have to go back to that chain, that’s what sensory, which moves into the next thing because **[1:00:00]** it disallows him from being able to do the next thing. I think a lot of sensory stuff... a lot of stuff he can’t do it has to start from the sensory, the sounds, the touch, I’m not going to say smell but…tasting, he can’t cook because he can’t taste the food and he can’t pour the things because he can’t touch the things.

**Interviewer:** Yeah, it’s all connected.

**Interviewee:** It is, it all connects back to sensory.

**Interviewer:** Absolutely. That’s actually all I have for my formal questions; would you like to add anything?

**Interviewee:** No, I hope it helps.

**Interviewer:** This is so helpful. Truly, from my perspective at least, there isn’t research on this intersection and so learning about how these things do interact and do impact each other, for me, research is the first to anything and so this is so helpful because no one has done a first step yet.

**Interviewee:** Ryan loves to do any of the surveys, he loves to go to Children’s and be part of the surveys, he’s like, *“If I can help somebody, I’m going to.”* He knows he’s not like everybody else. To help somebody who’s like him, he’s willing to do it.

**Interviewer:** We so appreciate that. Did you learn about this through the Crush Study at Children’s?

**Interviewee:** I did.

**Interviewer:** I actually used to work at that lab.

**Interviewee:** Oh, you did. We went there a bunch of times.

**Interviewer:** Yeah, it’s a great lab and actually funny enough, the person who runs that lab, used to work for my current boss way back when, so it’s all connected.

**Interviewee:** It was Project Crush who sent me this.

**Interviewer:** Excellent. Well thank you, I’m glad you were interested and I really do appreciate your time and your effort and your venerability, we couldn’t do this without you and we so, so appreciate it.

**Interviewee:** Thank you.

**Interviewer:** Do you know of anyone else who might want to participate in this study by any chance?

**Interviewee:** I don’t. I’m not like the mom friend with all the Autistic kids, I really don’t have any friends that have Autistic kids.

**Interviewer:** That’s okay.

**Interviewee:** I have acquaintances but not somebody I would be able to approach.

**Interviewer:** Nope, got it, that is no problem. We always ask because you don’t know who knows anyone. Thank you. Again, this has been wonderful, thank you. As soon as this audio renders, I will send you a thank you gift card as compensation for all of your time and your effort, so stay tuned for that. And if there is anything I can do to help you, please reach out, we want to do whatever we can to support you.

**Interviewee:** Hey, you find any groups or anything, send me an email.

**Interviewer:** I will, I will 100 percent do that for sure.

**Interviewee:** Right, well thank you very much Rachel, I appreciate everything.

**Interviewer:** Thank you, enjoy the rest of your day off.

**Interviewee:** You too. Bye.

**Interviewer:** Bye

**[End of transcript]**